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**The Citizenship Status of People Who Use  
Mental Health Services**

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**Thesis submitted for the degree of Ph.D  
in Mental Health,  
University of Kent, Canterbury.**

**May 2005**

## **Abstract**

The aim of the study was to examine whether people who use mental health services occupy the status of citizens in contemporary English society or whether they occupy the status of a socially excluded group. A discussion group with three mental health service users was followed by a series of in-depth interviews conducted with 15 individuals who had used mental health services. Participants were asked to define citizenship and were asked to discuss their experiences in response to the question of whether people who use mental health services enjoy the same opportunities to participate in society as other citizens.

The findings were analysed in accordance with the three areas of citizenship conceptualised by Marshall in 1950, namely civil, political and social citizenship. Participants defined citizenship in terms of the opportunities that are available to other citizens but exclusion of mental health service users from such opportunities. Participants described exclusion from citizenship through broad denial of valued social roles (e.g. employee, property owner, consumer, friend, partner, parent) and refuted Marshall's (1981) claim that state welfare enables mitigation of social inequality caused by a capitalist economic system in their descriptions of mental health services as undermining their status as citizens.

In conclusion, participants related instances of blatant discrimination and described a disadvantaged position in society. However, participants were not passive victims of discrimination but formulated their own forms of inclusion in meaningful activity as an alternative to the patienthood role. The study provides comprehensive confirmation of previous research which suggests the marginalised status of mental health service users in English society but also reveals a complexity of experience that perhaps has not been explored in previous research.

## **Acknowledgements**

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# Contents

Title Page

Abstract

Acknowledgements

Table of Contents

List of Appendices

**Introduction** .....p.1-5

## **Chapter One: Theories of Citizenship**

Definitions of Citizenship .....p.6-8

A Critique of Marshall's Analysis .....p.8-12

Alternative Models of Citizenship .....p.12-16

## **Chapter Two: Civil Citizenship**

The Mental Health Act 1983 .....p.17-20

Consent, Insight and Compliance .....p.20-23

Mental Health Review Tribunals .....p.23-24

Compulsion in the Community .....p.24-27

Public Attitudes .....p.28

Labelling Theory .....p.28-30

Significant Empirical Studies .....p.30-32

Public Attitudes in an Era of Community Care .....p.32-35

Media Representations .....p.35-38

Dangerousness .....p.38-41

Discriminatory Use of Compulsion .....p.42-45

Summary.....p.45-46

### **Chapter Three: Political Citizenship**

The Third Way.....p.47-48

Social Exclusion .....p.49-51

New Labour's Communitarianism .....p.51-55

Proposals for the Reform of the Mental Health Act 1983.....p.55-59

'Modernising Mental Health Services' .....p.59-62

The National Service Framework for Mental Health .....p.62-63

Summary .....p.63-64

### **Chapter Four: Social Citizenship**

Social Exclusion .....p.65-70

Employment .....p.70-71

Poverty .....p.72-76

Housing .....p.76-79

Social Networks .....p.80-81

Parenting .....p.82-84

Mental Health Services .....p.84-93

User Involvement .....p.93-98

### **Chapter Five: Methodology**

Qualitative Methodology .....p.99-105

Grounded Theory.....p.106-108

Small Group Discussion.....p.108-109

|   |           |
|---|-----------|
| Topic Guide .....                               | p.110-111 |
| Sampling .....                                  | p.112-113 |
| Demographic Characteristics of the Sample ..... | p.113-114 |
| Interviews .....                                | p.114-116 |
| Data Analysis .....                             | p.116-119 |
| Reliability and Validity .....                  | p.119-122 |
| Ethical Considerations .....                    | p.122-124 |
| Methodological Considerations .....             | p.124-126 |

## **Chapter Six: Findings**

|                        |           |
|------------------------|-----------|
| Introduction.....      | p.127     |
| Social Exclusion ..... | p.128-135 |
| Citizenship .....      | p.136-141 |

## **Part One: Social Citizenship**

|                              |           |
|------------------------------|-----------|
| Employment .....             | p.142-158 |
| Income .....                 | p.159-165 |
| Housing .....                | p.166-171 |
| Education .....              | p.172-176 |
| Social Networks .....        | p.177-190 |
| Public Attitudes .....       | p.191-200 |
| Mental Health Services ..... | p.201-216 |
| Inpatient Services .....     | p.217-232 |
| Medication .....             | p.233-240 |
| Parenting .....              | p.241-248 |

**Part Two: Civil Citizenship**

Civil Citizenship .....p.249-254

**Part Three: Political Citizenship**

Mental Health Policy .....p.255-265

User Involvement .....p.266-275

**Feedback from Participants .....p.276**

**Chapter Seven: Discussion .....p.277-298**

**Chapter Eight: Implications for Research, Policy and Practice**

..p.299-304

**Chapter Nine: Summary and Conclusions .....p.305-308**

**References .....p.309-338**

**Appendices .....p.339-357**

## **List of Appendices**

Appendix 1: Written introduction to research

Appendix 2: Poster presentation

Appendix 3: Verbal introduction to research

Appendix 4: Topic guide

Appendix 5: Consent form

Appendix 6: Receipt

Appendix 7: Letter requesting feedback

## **Introduction**

The aim of the research described in the following thesis is to explore the question of whether people who use mental health services occupy the status of full citizens in contemporary British society or whether they occupy the status of a socially excluded group. In addition, the research aims to obtain service users' definitions and conceptualisations of citizenship and to examine their thoughts on how they compare on measures of citizenship with other citizens.

The thesis begins with a definition of citizenship as involving membership of the community (Marshall, 1992: first published in 1950) and participation in normative activities, including the rights and duties expected of community members (Rees, 1995a). However, a critical stance towards the concept of citizenship is adopted, given the contentious nature of citizenship, community and membership.

Citizenship is relevant to people who use mental health services because there is a growing body of literature which suggests that mental health service users continue to be excluded from valued social roles. For example, Barham and Hayward (1995) identified the status of the 'community mental health patient' as the only role occupied by mental health service users in the absence of alternative social roles, caused by extensive discrimination and social exclusion. They identified high levels of unemployment, poverty due to receipt of welfare benefits and poor housing conditions among users of mental health services.

Similarly, Read and Baker (1996) identified high levels of discrimination against mental health service users in employment, harassment from members of the public, unreasonable questioning of parenting ability and rejection by family and friends. Sayce (2000) indicated that mental health service users experience high levels of disadvantage in the labour market, poverty, physical ill health, homelessness, imprisonment and blame for violence in society. Sayce indicated the prevalence of negative public attitudes towards service users in her comment, "we have not successfully made the case to the public for full citizenship" (p.78).

At the time of writing, the citizenship status of mental health service users appears to be threatened further by the probable increased rapidity of the proposals to reform the Mental Health Act 1983 following the ordering of an inquiry into the killing of Denis Finnegan in September 2004 by a 'paranoid schizophrenic' John Barrett, given that such inquiries tend to be followed by introduction of new mental health policy and legislation (Muijen, 1995). Moreover, on the same day that John Barrett pleaded guilty to the manslaughter of Denis Finnegan, a young woman was made the subject of an Anti-Social Behaviour Order (ASBO) prohibiting her from jumping into rivers or canals or onto railway lines following three suicide attempt using these methods. Therefore, users of mental health services look likely to be subject to increasingly coercive and condemnatory forms of control by the State.

Furthermore, until recently, mental health service users were the only group in society to be subject to preventative detention. However, the Government's Terrorism Act of 2001 enabled the preventative detention of terrorism suspects whereby the Government is, at the time of writing, hoping to introduce even greater controls over civil liberties in the form of house arrest of terrorism suspects (The Observer, 27<sup>th</sup> February 2005). Therefore, at present, the only citizens to be subject to preventative detention are mental health service users and people suspected of terrorism; both represent discrimination and an affront to basic civil liberties whereas the latter has provoked an outcry from lawyers and civil liberties groups but the former remains a minority interest (see Lister, 2001).

In addition, the emergence of a user movement and demands for greater user involvement in mental health services indicates a dissatisfaction with welfare services that refutes Marshall's (1992) assertion that state welfare serves to realise equal citizenship within the context of inequality linked to 20<sup>th</sup> century capitalism. Moreover, the potential for increased power of service users in services must be examined within the broader context of power within society, given the indication that service users experience significant discrimination and exclusion in British society (Barham and Hayward, 1995; Read and Baker, 1996; Dunn, 1999; Sayce, 2000).

Ultimately, however, the citizenship of people who use mental health services is of paramount importance because citizenship implies equality with other citizens

(Marshall, 1950; Parshad Griffin, 2003) whereby it is important to examine whether service users have achieved equality since deinstitutionalisation, given that they are more likely to be located amongst other citizens than was the case during the institutional era.

The research described in this thesis is significant because it is the first to examine a broad range of areas of citizenship in relation to mental health service users and which employs a wholly qualitative methodology. Barham and Hayward's research was seminal in this respect whereby my research seeks to extend their research, given that they examined a relatively narrow range of areas with a relatively homogeneous sample of participants. My research is also the first to apply Marshall's (1992) tripartite model of citizenship as a conceptual framework for the analysis of the citizenship status of people who use mental health services.

Citizenship was examined by conducting interviews with 18 people who have used mental health services in order to examine their experiences in a broad range of areas. The research topics were organised in accordance with Marshall's tripartite model of civil, political and social citizenship by exploring experiences and views in relation to employment, income, housing, education, social networks, public attitudes, community mental health services, psychiatric inpatient treatment, medication, parenting, the Mental Health Act 1983, mental health policy and user involvement.

The overall paradigm adopted in the current research is congruent with the 'discrimination paradigm' described by Corrigan and Penn (1997) who contrast the discrimination paradigm with the 'disease paradigm'. The latter is descriptive of conventional psychiatry in depicting 'mental illness' as an objective medical phenomenon that attributes causality to biological factors and assumes the effectiveness of biological treatments. The discrimination paradigm, on the other hand, argues that social participation is not inherently limited by mental illness but is impeded by social categorisation, stigma and assumptions concerning the impairments suffered by people with mental health problems. In examining the citizenship status of people who use mental health services, I intend to avoid the implication that service users are passive victims of discrimination but I assert that assumptions concerning the incapacity, dangerousness or otherness of people with mental health problems



determine their position within society. Within this framework, power is central to an examination of citizenship.

Chapter One provides a brief introduction to theoretical approaches to citizenship, using T.H.Marshall's (1992) model as a starting point. Marshall asserted that citizenship rights had been realised by the majority of citizens by the 20<sup>th</sup> century in Britain. The chapter will provide an overview of the most common criticisms of Marshall's analysis and will describe more recent developments in citizenship theory.

Chapter Two examines the concept of civil citizenship and how this relates to the experiences of community participation of mental health service users. The increasing emphasis on coercion and control in mental health legislation and policy is examined in relation to public attitudes and perceptions of dangerousness, the discriminatory use of compulsion and the influence of notions of consent, compliance and insight on the operation of mental health legislation.

Chapter Three examines the political citizenship of mental health service users within the context of New Labour discourse on community membership and social inclusion. I will argue that current mental health policy is incongruent with New Labour discourse on social inclusion.

Chapter Four reviews the literature that describes the social location of people who use mental health services. The chapter is organised in accordance with the concept of social exclusion and examines literature relating to employment, poverty, housing, social networks, parenting, mental health services and user involvement in mental health services.

Chapter Five describes the qualitative methodology adopted in the study in order to examine the experiences of citizenship described by users of mental health services. Chapter Six presents the findings obtained from interviews with service users, presented in accordance with the tripartite model proposed by Marshall (1992). Chapter Seven discusses the findings in relation to the research questions and Chapter Eight examines the implications of the findings for mental health policy, practice and research.

## **A Note on Language**

The use of language in relation to people who use mental health services is contentious due to the implications of language for beliefs concerning mental health issues. I have used the terms 'mental illness' and 'the mentally ill' when referring to literature that uses such terms. In addition, the participants in the research described in this thesis used terms such as 'mental illness'. However, I have attempted to avoid the use of terms such as 'mental illness' and 'mental disorder' because such terms imply a medical view of mental health issues. I have preferred to use terms such as 'mental health problems', 'people with mental health problems', 'psychiatric service users', 'people with a psychiatric diagnosis' and 'mental health service users' in an attempt to distance myself from the medical view of mental health issues and I have included terms such as 'mental illness' only when such terms reflect the language used in the literature described or by research participants.

# Chapter One: Theories of Citizenship

Citizenship is an ambiguous concept that requires explication through reference to theories of citizenship, followed by an examination of the problems associated with such theories. Because citizenship is a relatively ambiguous concept, it is appropriate to seek clarification on the characteristics of citizens and definitions of citizenship.

## Definitions of Citizenship

Marshall (in Marshall and Bottomore, 1992) states:

Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed (p.18).

Barbalet (1988) claims that citizenship:

Defines those who are and who are not, members of a common society (p.1).

Rees (1995a) argues:

Citizenship is a matter of rights and duties attendant upon membership of a specified community (p.313).

Therefore, definitions stated in accordance with Marshall's typology emphasise that citizenship is a status to which rights are attached (Lister, 1997) but also comprises duties demanded of citizens. However, the simultaneous emphasis on citizenship as a status that involves membership and one that involves duties indicates the nebulous nature of the concept in that liberal and communitarian conceptions of citizenship often overlap.

T.H.Marshall (1992)<sup>1</sup> is the typical starting point for discussions of contemporary conceptions of citizenship because he provided the seminal exposition of the social liberal model of citizenship in 1950 (Faulks, 1998). He discussed the role of the welfare state in the development of citizenship rights and espoused a tripartite model of citizenship whereby civil, political and social citizenship rights were suggested to

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<sup>1</sup> Marshall's original exposition of citizenship appeared in 1950 but this edition is now out of print, therefore the more recent print in Marshall and Bottomore (1992) will be referred to throughout this thesis.

have been realised by all citizens by the mid-20<sup>th</sup> century with the advent of the welfare state. Marshall (1981) argued that state welfare distributed risk more equitably in British society. Therefore, Marshall (1992) identified three dimensions of citizenship, namely civil, political and social.

**Civil citizenship** refers to the equality of all citizens before the law and particularly relates to the enjoyment of individual freedoms and the right to due process<sup>2</sup> (Marshall, 1992). Individual freedoms pertain to the freedom of speech and thought, ownership of property, the right to justice and the freedom to engage in contractual relations (Heater, 1999). Marshall (1992) argued that civil citizenship rights were realised by the 18<sup>th</sup> century whereby reform targeted individual rights, defended through a formal system of courts (Turner, 1990). Therefore, the development of civil citizenship rights is related to the development of legal institutions such as the civil and criminal courts. Emphasis on individual freedoms is a significant defining characteristic of the liberal approach to citizenship (Oliver and Heater, 1994).

**Political citizenship** refers to political participation and influence over political decision-making (Marshall, 1992). Marshall described the growth of political citizenship by the 19<sup>th</sup> century as being associated with the development of formal political institutions and as the outcome of working class struggle for enfranchisement. It is particularly associated with the emergence of new political parties, the expansion of franchise and with the emergence of Parliament as the seat of political decision-making (Turner, 1990). However, the liberal conception of political citizenship has been criticised as being restricted to voting rather than broad political participation (Prior, Stewart and Walsh, 1995).

**Social citizenship** refers to economic welfare and social participation (Rees, 1996) or, as Marshall stated, to the “right to a modicum of economic welfare and security to the right to share in the full social heritage...and according to the standards prevailing in society”(Marshall, 1992, p.8). He argued that social citizenship rights were realised by the majority of the population by the 20<sup>th</sup> century with the

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<sup>2</sup> Due process has been defined as the way in which liberty should only be denied following legal procedures that safeguard the rights of the individual (Cavadino, 1989) or a general right to a hearing before a court of law in order to examine the justification for deprivation of liberty (Gostin, 1985).

emergence of the welfare state that was thought to offer protection from the risks of unemployment, sickness and poverty. Such risks were argued to have been distributed more equitably rather than being eliminated altogether. In other words, Marshall asserted that welfare renders inequality more tolerable rather than achieving an aim of equality of outcome. Social citizenship appears to refer to a general conception of quality of life in that minimum conditions should be met to provide opportunities for a standard of living within a specific society and encompasses health, education, housing, income, employment and consumption (Roche, 1992). Roche, like Marshall, argued that the welfare state is the primary provider of social rights. However, Heater (1999) asserts that social rights are ill defined and impossible to legislate for.

Heater (1999) highlights the distinction that civil citizenship involves rights against the state whereas social citizenship establishes rights provided by the state via taxation. Marshall focused on substantive citizenship in describing the rights that citizens can expect rather than formal citizenship, which examines who should enjoy such rights (Heater, 1999).

### **A Critique of Marshall's Analysis**

Marshall's analysis has been accused of being Anglocentric. For example, Turner (1990) argued that Marshall's analysis is restricted to the growth of citizenship rights in England. England is an atypical case because its citizens are subjects of the Crown rather than citizens of the state (Wilson, 1998a; Pattie, Seyd and Whitely, 2004). Citizenship in the US, for instance, has followed an entirely different course and assumes a different character to English citizenship due to America's absence of a monarch, pervasive individualism and the absence of a welfare state in a highly fragmented society (Turner, 1990). Turner argues that American citizenship has developed from the bottom-up: from grass-roots pressure for the extension for citizenship rights to marginalised groups, as exemplified by the Black civil rights movement of the 1960s. Moreover, Turner asserts that, while American citizenship has followed an 'active' course, the development of citizenship in England has

developed 'passively' whereby citizens have passively acquired rights from the top downwards (i.e. from the state) (see also Wilson, 1998a).

Marshall's analysis assumes that the state is neutral in relation to citizens (Heater, 1999) whereas Marx challenged the liberal view of rights in claiming that rights fail to guarantee true equality in society (Wolff, 2003). Marxist analysis argues that the state exists to manage capitalism and, in doing so, promotes the interests of the powerful in society (Finlayson, 2003). In addition, Marxists argue that civil and political rights are meaningless without full realisation of social rights (Heater, 1999) and that liberal notions of rights represent an individualistic bourgeois hegemony constructed to obscure class divisions in society (Lister, 1997).

A fundamental question in relation to rights is whether rights are absolute or conditional (Waldron, 1984). Currently, rights are depicted as conditional on the fulfilment of certain obligations that risk reinforcing the exclusive nature of citizenship. T.H. Marshall (1992) depicted rights as absolute. However, rights are not absolute in the sense that the rights of different groups may conflict and thus groups are either treated preferentially or detrimentally. For instance, the right to liberty of people who use mental health services is subordinated to the right of people without such diagnoses to be free from the perceived dangerousness associated with psychiatric patients (Laurance, 2003). This argument will be further explicated in the chapter concerning political citizenship, particularly in a discussion of the nature of current mental health policy.

Social rights are also conditional on resources. T.H. Marshall (1992) argued that rights are absolute but service users are finding that resources impact on the availability of services. For instance, a number of elderly service users challenged the decision of Gloucester County Council to withdraw services on the grounds of resource constraints. The High Court, in a decision upheld by the Appeal Court, ruled that service users do not enjoy an absolute entitlement to services and that resources can be taken into consideration when assessing individual need under the NHS and Community Care Act 1990 (Drewett, 1999). This ruling highlights the problematic relationship between formal and substantive citizenship rights in that formal rights may not necessarily be realised in practice. Formal citizenship

guarantees individual rights whereas substantive citizenship involves a status that provides opportunities to enjoy rights but cannot guarantee rights (Prior, Stewart and Walsh, 1995). Prior, Stewart and Walsh indicate that substantive rights require the provision of sufficient resources to guarantee entitlement to rights. Therefore, the ability of welfare services to facilitate social citizenship depends, in part, on adequate funding of such provision.

In addition, rights do not necessarily bestow equality (Waldron, 1984; Young, 1989). For instance, the US has a well developed constitutionally based rights system, including the most comprehensive disability discrimination legislation in the western world, yet also features the most extreme economic and social polarisation (Sayce, 2000).

Marshall's original analysis appears to have been optimistic in claiming that there had been a dramatic reduction of inequality. He later discussed the role of 'welfare capitalism' in mitigating the effects of capitalism in that the role of welfare was no longer considered to ensure rights and equality but to mitigate the effects of capitalism on the individual (Marshall, 1981). He also acknowledged that increasing emphasis on means testing in welfare meant that absolute rights are fallacious (Marshall, 1981). Therefore, the welfare state has not led to greater social equality, the 1970s witnessing increasing levels of unemployment and poverty (Dahrendorf, 1988; Walker, 1997) and the 1980s onwards witnessing an increase in workless households from 9% in 1979 to 20% in 1995-6 (Callinicos, 2000). Marshall (1981) diverged from a discussion of rights to a discussion of 'legitimate expectations' in which citizens can expect minimal standards of welfare provision rather than enjoying absolute rights of citizenship. Therefore, T.H. Marshall's later work was pragmatically liberal rather than egalitarian, as is commonly assumed (Rees, 1995b).

Marshall has also been accused of producing a gender-blind analysis of citizenship. Lister (1990a, 1990b, 1997, 1998a) argued that citizenship is not a gender-neutral concept, claiming that Marshall essentially wrote the history of men's citizenship. She asserts that women continue to be excluded from certain citizenship rights and advocated 'differentiated universalism' which recognises the impact of social inequalities on public participation (Lister, 1997). Lister (1990b) argued that

women's participation is undermined by the artificial division of public and private in orthodox citizenship theory, which fails to recognise that women's oppression in the private sphere impedes their participation in the public sphere. Lister argues that state welfare undermines public participation by treating families as homogeneous units rather than individuals requiring individual economic rights. Therefore, she argues, state welfare reinforces women's economic dependency on men and fails to facilitate a balance between paid work and family responsibilities, primarily because the state welfare system is based on male employment patterns and on the assumption that women fulfil a primarily reproductive role in the family (Lister, 1990b).

Citizenship has been described as a potentially exclusive category (Lister, 1997; 1998a). The way Marshall excluded certain categories of people from his analysis (e.g. ethnic minorities, women and disabled people) partly reflects the era in which he was writing (Heater, 1999), but also reflects the way citizenship can be employed as an exclusive category (Lister, 1997, 1998a). Rees (1995b) states:

...citizenship, like another favourite, community, shuts people out as much as it welcomes them in (p.367)

Those not conforming to the ideals of citizenship can be excluded from rights attendant on fulfilment of certain citizenship obligations (Rees, 1995b).

Marshall's (1992) analysis combined classical and liberal notions of citizenship (Lister, 1997). In Ancient Greek polity, citizenship was based on political participation and excluded women, children and adult slaves (Aristotle, Book III, 'The Politics'. Trans. Ellis, 1986). In fact, only propertied wealthy males were considered to possess the education and time to engage in public duties required of citizens of the polity. In more recent years, citizenship analysis has emphasised plurality in society and the diverse groups of people who remain excluded from certain citizenship rights (e.g. Young, 1989, 1995). Citizenship can also be a useful tool in highlighting the way certain groups lack full citizenship status (Lister, 1997). It is a useful concept because it has intuitive appeal and thus its value is difficult to refute, in the same way that human rights and democracy are generally agreed to be valid aims.



The reputed validity of citizenship has meant that it is employed to satisfy a broad range of political agendas (Kymlicka, 2002) and is a hegemonic concept (Faulks, 1998). For example, the neoliberals of the 1980s used the notion of 'active' citizenship to denote a property-owning consumer (Held, 1991; Ignatieff, 1991) in order to advance its ethos of individualism and philanthropic welfare to detract from citizens' rights to state welfare. New Labour has used the concept to invoke authoritarian demands for adherence to community norms (Levitas, 1998).

It is also unclear whether Marshall (1992) was presenting a historical analysis or was positing an ideal type of society (Bulmer and Rees 1996), although his thesis is usually interpreted as a historical analysis. Furthermore, Faulks (1998) claims that Marshall's analysis is 'elitist' in producing an asocial theory that negates continuing social inequalities; is 'exclusive' in producing a weak analysis of power differences in society and 'abstract' in allowing dominant liberal political discourse to direct his analysis of citizenship.

### **Alternative Models of Citizenship**

The 1980s witnessed a renewal of interest in the concept of citizenship within the context of consumerism and individual autonomy in order to detract from state welfare provision (Mulgan, 1991). However, citizenship has also been employed to demand responsibility from citizens in return for citizenship rights. This approach is posited as a response to social problems ascribed by the New Right and New Labour to diminishment of citizens' sense of obligation to the community (Rees, 1995b).

Marshall's (1992) analysis was somewhat atomistic in examining the development of individual rights. However, New Labour has responded to the narrow consumerist interpretation of citizenship adopted by neoliberals by advocating 'governmental communitarianism' (Delanty, 2003) which emphasises participation in public decision-making and fulfilment of obligations to the community (Prior, Stewart and Walsh, 1995). Social welfare is no longer regarded as providing protection against market mechanisms whereby the role of the state is to support individuals to help

themselves (Lund, 1999; Tonge, 1999). Governmental communitarianism emphasises redistribution of opportunities rather than redistribution of wealth, as the original social liberal conception of citizenship described.

Communitarianism is informed by the notion of civic virtue which dates back to classical Greco-Roman societies in which a 'good citizen' is one who participates in legal and political decision-making (see Aristotle, 'The Politics'; Oliver and Heater, 1994). Nevertheless, communitarianism is argued to be a modification of liberalism, except that it eschews moral individualism in favour of emphasising public participation for the common good of the community (Delanty, 2003).

However, classical citizenship was exclusive (only adult, indigenous males were included in decision-making) and citizenship was based on small tightly knit communities (Oliver and Heater, 1994), thus the notion of civic virtue draws on archaic, idealistic notions of community and political participation. Civic republicanism also demands homogeneity of citizens in fulfilling obligations defined by the powerful, thus negating group differences and power inequalities (Young, 1989).

In summary, the renewal of interest in citizenship in the late 20<sup>th</sup> century has witnessed a transformation of emphasis from the rights and entitlements of Marshall's approach to a greater emphasis by neoliberals and New Labour on rights in return for fulfilment of obligations. Oliver and Heater (1994) failed to predict the increasing similarity between right wing and left-wing conceptions of citizenship. Both emphasise obligations rather than placing exclusive emphasis on rights. Therefore, a crude distinction involves the liberal model of citizenship in which individual rights are emphasised and the civic republican model that emphasises individuals' obligations to the community (Lister, 1998a).

Citizenship theory has also been influenced by the emergence of postmodernist thinking that places an emphasis on plurality in society (Lister, 1998b). Therefore, recent conceptions of citizenship examine the claims to citizenship of a broader range of social groups than included in T.H. Marshall's analysis. Marshall has been accused of over-emphasising class at the expense of other social divisions (Heater,

1999). Iris Marion Young (1995) referred to 'differential citizenship' to emphasise group differences and to eschew the universality of Marshall's conception of citizenship. She argued that equality in modern citizenship theory is problematically equated with homogeneity, thus failing to encompass plurality in modern society. T.H. Marshall regarded citizenship as a shared identity that integrates disparate groups (Kymlicka and Norman, 1995) but this notion has been referred to as 'false universalism' in its failure to recognise the needs of specific marginalised groups and conflicting social rights (Lister, 1998a).

Hall and Held (1989) indicate the tension between the universal status of citizenship and meeting diverse needs within this status and Young (1995) argues that, because citizenship was thought to transcend group differences, people not thought able to exercise citizenship rights have typically been excluded from traditional analyses of citizenship. Postmodernism also demonstrates how Marshall's emphasis on class struggle is archaic in the light of the struggle by diverse social groups for citizenship rights (Rees, 1996). The 'modern social conflict' described by Dahrendorf (1988) involves a struggle for membership by marginalised social groups who are increasingly challenging the social inequalities that serve to undermine their community membership by laying claim to entitlements which enable realisation of a more complete citizenship status.

Therefore, the role of contemporary citizenship theory has increasingly involved examining the citizenship status of marginalised groups. People with mental health problems have been described as "incomplete citizens" (Bulmer and Rees, 1996). The relevance of citizenship to people who use mental health services lies in their greater risk of experiencing exclusion from citizenship than other members of society. For example, Barham and Hayward (1995) described people with mental health problems as occupying a 'community mental patient' role whereby alternative social roles were difficult to attain due to discrimination. Similarly, Sayce (2000) identified discrimination against people with mental health problems as underlying social rejection, denial of housing, unemployment, violent victimisation, increased mortality and denial of the role of parent. Sayce stated:

People with a diagnosis of mental illness experience exclusion across every sphere of social and economic life, from holidays to work, driving cars to raising children (Sayce, 2000: 60).

Read and Baker (1996) found that discrimination impedes participation in a broad range of institutions, particularly employment, housing, parenting and financial services. Dunn (1999) identified exclusion from a similar range of institutions, including education and training and Rogers and Pilgrim (2003) summarised a comprehensive range of research which suggests that mental health service users are significantly more likely to experience social inequality than other social groups, for instance, in terms of high unemployment, poverty and homelessness.

As mentioned previously, Turner (1990) drew a distinction between active and passive citizenship whereby active citizenship involves a struggle for rights by those denied full citizenship status. The struggle by new social (welfare) movements, such as the disability movement, for further development of citizenship rights represents the emergence of more active forms of citizenship (Lister, 1998a, 1998b). Such movements critique the paternalism of state welfare services (e.g. Ignatieff, 1991) and the failure of state welfare to achieve equality for welfare service users (Croft and Beresford, 1989, 1992).

Runciman (1996) argues that citizenship is problematic in that the middle class tends to define valued rights. This analysis can be extended to argue that dominant social groups define valued rights and that the value of new social movements ('new' because their interests extend beyond traditional class interests: Merlucci, 1995; Young, 1995) lies in marginalised groups gaining a greater stake in the definition of crucial rights. This point also indicates the importance of examining mental health service users' views on valued rights.

A final criticism of Marshall's analysis involves a refutation of his assumption that state welfare is a positive ascriber of social citizenship rights. Oliver (1994) refers to 'welfare paternalism' as indicating the destructive nature of state welfare services in undermining, rather than enhancing, disabled service users' citizenship.

The following chapters will examine citizenship as a status in relation to people who use mental health services. The analysis will follow Marshall's (1992) tripartite model of citizenship as a conceptual framework, in accordance with Lister's (1997)

suggestion that citizenship can be employed to highlight the social position of marginalised groups. Marshall (1992) argued that citizenship rights enable more equitable distribution of risk but I will examine the claims that risk is not equally distributed because people who use mental health services bear a disproportionate amount of risk in relation to broad social inequalities (Barham and Hayward, 1995; Read and Baker, 1996; Sayce, 2000; Rogers and Pilgrim, 2003).

Kymlicka and Norman (1995) argue that confusion often occurs between citizenship as a legal status bestowing rights and citizenship as an activity, implying public participation in citizens' duties. Moreover, Faulks (1998) draws a distinction between legal definitions of citizenship, encompassing the rights and duties of citizens in relation to the state; philosophical definitions which examine normative issues such as the most useful model of citizenship; and socio-political approaches which argue that citizenship is a status denoting social membership.

The analysis in the current thesis adopts the socio-political approach in its examination of the community membership and social participation of people who use mental health services. Faulks (1998) argues that socio-political analyses are the most appropriate in relation to citizenship due to their examination of the power relationships that serve to define citizenship.

In summary, citizenship is an ambiguous concept in that it carries a number of meanings and has been utilised by differing political approaches. Therefore, citizenship can be a highly contentious, problematic concept when used uncritically. The thesis will examine the citizenship status of people who use mental health services in relation to Marshall's (1992) tripartite model whilst noting the inherent contradictions in the concept of citizenship.

## **Chapter Two: Civil Citizenship**

Civil citizenship refers to equal access and representation in relation to legal institutions, including the right to due process, to engage in contractual relations and the right to enjoy individual freedoms such as freedom of speech, thought and ownership of property (Marshall, 1992).

This chapter will examine the role of mental health legislation in England and Wales in defining the legal status of people with a psychiatric diagnosis in hospital and in the community. It will be argued that increasing use of coercive measures has occurred in the community and that this level of compulsion is related to negative public attitudes, in particular, the postulated association between mental illness and dangerousness. The chapter will also trace the development of compulsion in mental health legislation within the context of community care. The relationship between notions of rationality, compliance and consent will be examined as corollaries of the treatment of people who use mental health services.

### **The Mental Health Act 1983**

The Mental Health Act 1983 primarily governs the admission of individuals to psychiatric hospital or forensic units. Mental health legislation provides the framework for compulsory treatment and detention of mental health service users (Pilgrim and Rogers, 1994). The compulsory admission of individuals to hospital ('sectioning') involves the denial of autonomy in treatment decision-making and involves the state, via doctors and approved social workers, exerting control over the individual (Barnes, Bowl and Fisher, 1990). Essentially, sectioning is based on a fundamental distinction between physically and mentally ill patients in that the latter are deemed to lack competence in decision-making due directly to the presence of mental illness and thus psychiatric patients relinquish the power to make treatment-related decisions to medical professionals (Pols, 1989). The legal perspective is intended to protect the individual from over-zealous medical decision-making and to ensure that deprivation of liberty is in accordance with the principles of natural law and due process (Barnes, Bowl and Fisher, 1990). However, Bean (1986) and

Pilgrim and Rogers (1994) argue that the Mental Health Act is discriminatory because the principles of protectionism and paternalism enshrined in the Act are selectively applied to people who use psychiatric services and not to other members of the community who represent a danger to themselves or others.

Hotopf et al. (2000) conducted a Department of Health commissioned analysis of the patterns of use of the Mental Health Act 1983 between 1984 and 1996. They discovered an overall increase in the number of formal admissions, especially in relation to Sections 2 and 3 in Part II of the Act. The use of section 47 (transfer from hospital to prison) more than doubled in the study period and use of section 48 (transfer from prison to hospital) increased from 77 in 1987 to 481 in 1996.

The trends observed in this study occur within the context of a huge reduction in the number of in-patient beds available, thus suggesting that the increase in the number of formal admissions predominantly impacts on the most severely ill patients who are likely to be subject to repeated periods of relatively brief hospitalisations (SCMH, 1998; Hotopf et al., 2000). The authors concluded that the steady increase in the use of formal admissions indicates increasing public concern over risk posed by mentally ill people in the community, thus demonstrating an emphasis in psychiatry on risk management and indicating a steady increase in the use of compulsion over psychiatric service users.

The overall picture is that formal admissions now comprise 12% of all psychiatric admissions, compared with 7% in 1986 (Barnes, Bowl and Fisher, 1990). The results of a survey by Wall et al. (1999) suggest that the average urban resident with a psychotic illness will experience at least one formal admission in the course of their illness and that formal admissions are most likely to involve young males from an ethnic minority with a psychotic illness. The authors argue that this group demonstrates poor compliance with medication, greater denial of mental illness and greater delays in seeking help, indicating the authors' uncritical acceptance of medical explanations of mental distress and negation of racist assumptions in psychiatry (see Browne, 1997).

The Mental Health Act 1983 is intended to be based on the 'least restrictive alternative' principle in which informal admission or diversion into community services is preferred to compulsory hospital admission (Barnes, Bowl and Fisher, 1990; Hoggett, 1996).

However, the aim of the 1983 Mental Health Act to provide a social perspective on mental disorder and to pursue the 'least restrictive alternative' has not been achieved in practice due to the ineffectiveness of approved social workers in tempering medical dominance of decision-making in compulsory detention (Barnes, Bowl and Fisher, 1990; Hatfield, Mohamad and Huxley, 1992).

In addition, the least restrictive alternative principle has itself been subject to criticism. Munetz and Geller (1993) argue that the least restrictive alternative is typically interpreted as referring to location thus any service located outside the hospital is regarded as less restrictive than hospital-based care. However, the authors argue that this assumption fails to consider that community-based services may be at least as restrictive as hospital-based intervention. They also argue that there is great variability in the restrictiveness of facilities with restrictiveness mediated by staff, activities and rationale rather than location per se. The least restrictive alternative also ignores the impact of the development of inpatient-type facilities in the community, such as 24-hour staffed beds or secure facilities (see DoH, 1998a).

There are a number of differences between the Mental Health Act 1983 and its predecessor, the Mental Health Act 1959. Cavadino (1989) argues that the 1959 Mental Health Act was heavily committed to the medical model whereby medicalism dominated legalism in the Act. The 1983 Mental Health Act, however, represents an attempt to revert to the legalism, which predominated prior to the 1959 Act. The increased emphasis on legalism is demonstrated by the introduction of numerous additional legal safeguards to protect patients from unjustified medical intervention. For instance, the 1983 Mental Health Act narrowed and clarified admission criteria, clarified the law on compulsory treatment and increased access to the appeals system (mental health review tribunals). However, despite the introduction of such safeguards, Cavadino (1989) argues that the medical perspective continues to dominate. This is exemplified in the broad definitions employed by the 1983 Act that



enable considerable scope for professional discretion in interpretation (Hoggett, 1996). For example, the Mental Health Act 1983 fails to provide a precise definition of 'mental illness'. It is also unclear what 'harm' (e.g. 'harm to self or others') refers to but is typically interpreted as dangerousness (Hoggett, 1996). In addition, it is clear that the way most types of patients can be compelled to accept treatment without consent confirms the dominance of the medical profession over any safeguards offered by mental health law (Pilgrim and Rogers, 1994) and treatment is defined under the Mental Health Act in narrow terms to refer to medical treatment (Bean, 1986).

### **Consent, Insight and Compliance**

Bean (1986) argues that the concept of insight lies at the root of compulsory hospital detention given the range of assumptions held about the capacity of people with mental health problems to engage in rational treatment-related decision-making. As mentioned previously, a fundamental distinction in the treatment of physical and mental disorders lies in the way psychiatric patients are typically excluded from decision-making on treatment.

Under common law, medical intervention performed without consent constitutes the tort of trespass to the person whereby:

It has been held that an adult of sound mind and full understanding should be able to refuse treatment, even if the treatment is necessary to save his or her life...Only where there is doubt as to the patient's free will and capacity will no trespass take place. (Giliker and Beckwith, 2001: 267)

However, under the Mental Health Act 1983, treatment can be administered without consent (with the exception of psychosurgery) on the grounds of being in the patient's best interests, expressed in the common law principle of necessity which states that a person can be treated against their will in their best interests due to the doctor's duty of care to the patient (Hoggett, 1996).

The common law doctrine of necessity was central to the Bournemouth case (House of Lords: *Re L (By His Next Friend GE)* (DoH, 1998b)). The Lord's ruling on the

case argued that the patient was detained as an informal patient, despite lack of consent, in his best interests. The ruling indicated that patients can be held in hospitals informally without the patient providing explicit consent as long as they do not make a deliberate attempt to leave. The ruling recognised a distinction between voluntary patients who have the capacity to consent to admission and do so and informal patients who lack the capacity to consent but do not demonstrably object to admission. The subject of the Bournemouth case was a man with severe learning difficulties who fell into the latter category. Therefore, lack of dissent is inferred when a patient does not attempt to leave hospital. However, some patients may be fairly heavily sedated whilst in hospital and thus may be unlikely to attempt to physically leave the premises, suggesting that the interpretation of consent as lack of dissent is ultimately flawed. It is inherently problematic to interpret lack of dissent as compliance. The Lord's ruling is also problematic because it failed to examine whether hospitalisation and medical intervention *is* in the best interests of patients.

Furthermore, the Law Commission (1991) report on the decision-making of mentally incapacitated adults argues that medical tests of incompetence bias decisions towards the administration of treatment and typically involve a presumption of incompetence. Those refusing treatment are more likely to be deemed incompetent decision-makers and people whose explanation of their mental illness differs from professionals' views are deemed to lack insight (Beck-Sander, 1998).

Pols (1989) argues people with a psychiatric diagnosis are commonly assumed to have lost their capacity for rational decision-making and are likely to engage in irresponsible behaviour due to poor resistance to impulses. Involuntary medical intervention in psychiatric services is predicated on notions of irresponsibility deriving from lack of rational thought (Pols, 1989). The Mental Health Act 1983 allows admission on the grounds of irresponsible behaviour: that the individual is a threat to his or her own health or safety or the safety of others and treatment can be imposed in the patient's 'best interests' (Pols, 1989).

Psychiatric ideology draws an association between lack of insight and treatment non-compliance. For example, Altamura and Malhi (2000) claim that the patient's awareness and acceptance of illness is crucial to compliance but they attribute high

rates of non-compliance to lack of insight typically associated with schizophrenia and major mood disorders. Non-compliance is cited as being at 40-50% for anti-psychotic medication (Altamura and Malhi, 2000; Hughes, Hill and Budd, 1997; Bebbington, 1995) and has been associated with high rates of relapse (Hogarty, 1993), rehospitalisation (Bene-Kociemba et al., 1979), suicide (Hogan and Awad, 1983) and homicide (Appleby, 2000).

However, the concept of insight has been criticised for being applied globally (Beck-Sander, 1998; Hughes, Hill and Budd, 1997) and thus as being poorly defined and explicated. In addition, non-compliance in general medicine is also high, approximating levels associated with neuroleptic medication (around 50%) and yet this fact is rarely acknowledged (Hughes, Hill and Budd, 1997) and unlikely to be attributed to irrationality in general medicine (Perkins and Repper, 1999). Furthermore, the association between non-compliance and lack of insight has been disputed in claims that the side effects of drugs and their questionable efficacy render non-compliance a rational decision (Perkins and Repper, 1999; Hughes, Hill and Budd, 1997). Smith, Hughes and Budd (1999) found that non-compliance in a sample of depot clinic patients was associated with reporting of unpleasant side-effects, fewer reported benefits of medication and a perception of no longer being ill as reasons for cessation of medication. Equal proportions of compliant and non-compliant patients expressed dissatisfaction with the physical and psychological circumstances surrounding depot administration (e.g. pain and embarrassment) and equal numbers agreed cessation had improved their condition. The researchers concluded that non-compliance involved a rational cost-benefit analysis that examined the pros and cons of medication.

Similarly, Perkins and Repper (1999) claim that most people regard medication used in general medicine as suitable for short-term use but not to maintain health, as is expected in relation to psychiatric medication. Therefore, they argue, patients' cessation of medication once they feel well is rational when compared with orthodox beliefs concerning medication administration.

In summary, Pols (1989) claims that psychiatric patients are assumed to have lost their capacity for rational thinking and that they are at the mercy of irresistible

impulses preventing responsible behaviour. However, notions of rationality are normative and historically and culturally relative and defined by the socially powerful (e.g. psychiatrists) without an objective standard by which to judge rationality (Pols, 1989). Therefore, Pols concludes that involuntary control predicated on notions of irrationality is not justified and involves a dehumanisation of the mentally unwell on the grounds that they lack the fundamental human attribute of rationality (see Moore, 1984).

## **Mental Health Review Tribunals**

Civil citizenship includes the right to due process (Marshall, 1992). The mental health review tribunal (MHRT) is one example of the opportunity for due process in mental health legislation. Due process is defined as involving a general right to a hearing before a court of law when deprivation of liberty is threatened (Gostin, 1985). The 1983 Mental Health Act purportedly introduced greater safeguards into the use of mental health law, for example, by introducing the right to appeal to a tribunal under Section 2 and by the establishment of the Mental Health Act Commission (MHAC) (Crimlisk and Phelan, 1996).

However, Wood (1993) found excessive delays in the arrangement of hearings. Peay (1989) claimed that reviews tended to endorse professionals' recommendations in that 86% of decisions concurred with the Responsible Medical Officer's (RMO) view, although this research primarily examined tribunals in special hospitals where decision-making may err particularly on the side of caution. However, all of the MHRTs observed by Richardson and Machin (2000) (50 in total) concurred with the RMO's view. Similarly, Wood (1993) identified a tendency towards paternalism rather than deprivation of civil liberties in tribunals. For example, in research conducted by Crimlisk and Phelan (1996), 44% of the doctors interviewed argued that the tribunal was untherapeutic in establishing an adversarial relationship between doctor and patient, thus demonstrating a failure to recognise the importance of due process in the compulsory detention of psychiatric patients.

Spencer (1989) found the average rate of discharge is low at 15% (or as low as 10%: MHAC, 2005) and particularly low rates of discharge for Asian patients have been observed (Neville and O'Dwyer, 1991). In addition, the discharge rate has remained approximately the same as under the 1959 Mental Health Act (Webster, Dean and Kessel, 1987). Therefore, it is questionable whether the Mental Health Act 1983 increased protection against unwarranted detention through mental health review tribunals.

Bradley, Marshall and Gath (1995) examined why there is such a low number of appeals under Section 2, an average of 25%, by conducting interviews with patients the day before the lapse of their right to appeal under Section 2 whereby an appeal must be made in writing within 14 days of admission. It was concluded that patients' appeals were impeded by the requirement to make a request in writing either due to cognitive impairment, literacy problems or difficulty obtaining writing materials in hospital. Indeed, 97.5% of the patients questioned argued that an automatic right to appeal ought to be established.

Therefore, research on the use of mental health review tribunals suggests that they fail to realise the right of the patient to due process primarily due to a tendency towards paternalism and the failure of legalism to adequately challenge medicalism. However, there is no reason to believe that legalism would be any more effective in protecting civil rights than medicalism (Gostin, 1985; Pilgrim and Rogers, 1994) since medical decision-making is merely transferred to decision-making by legal professionals, therefore continuing to exclude service users from decision-making.

### **Compulsion in the Community**

This section will examine the growth of compulsion over mental health service users in the community.

Until 1986, psychiatrists coerced compliance in the community from discharged patients by invoking an extended leave of absence under which the patient remained liable to detention at the direction of the RMO without the need for a new admission

application. In other words, a discharged patient could be recalled to hospital if they failed to comply with the conditions of discharge, for instance, for non-compliance with a medication regime (Fennell, 1992). Psychiatrists admitted patients for a nominal period (possibly only overnight) in order to grant a leave of absence to ensure compliance with treatment in the community. However, the practice was ruled unlawful in 1986 in the cases of *R v Hallstrom, ex parte W (No.2) [1986]* and *V. Gardner and another, ex parte L [1986]* on the grounds that admission to hospital is justified only if the patient requires *detention* for treatment to be administered (Ritchie, Dick and Lingham, 1994). Therefore, compulsory treatment was restricted to compulsory inpatient admission. Thus, the Hallstrom case denied psychiatrists a means of ensuring compliance from patients in the community.

A number of high profile cases involving homicide and self-harm have generated demands from the public, politicians, mental health professionals and campaign groups for greater control over the mentally ill in the community (Laurance, 2003). Muijen (1995) claimed that the killing of social worker Isabel Schwarz in 1984 by an ex-client, Sharon Campbell, seminally shaped public attitudes towards community care. Subsequent cases such as those involving Andrew Robinson, Michael Buchanan, Christopher Clunis and Ben Silcock (the latter three all occurring in 1992 and involving young black men) reaffirm, in the mind of the public, the need for greater control over mental health service users. These cases led to demands for a reversion back to an era of institutionalisation because the publicity surrounding such cases emphasised the random danger posed to the public by such people (Muijen, 1995).

The inquiry into the case of Sharon Campbell recommended the implementation of the Care Programme Approach (CPA). The Care Programme Approach was subsequently introduced in April 1991 and involves the joint co-ordination by the district health authority and the local authority of a systematic assessment of the health and social care needs of the individual, construction of an individual care plan, allocation of a care coordinator, and the conduct of regular multi-disciplinary reviews of client progress (Bird and Davies, 1996).

In December 1993, supervision registers were introduced in which the local health authority is responsible for placing high-risk clients on a register. Harrison and Bartlett (1994) have argued that the introduction of supervision registers contravenes the important civil right of the patient to terminate the doctor-patient relationship. In addition, supervision registers are no more than an administrative tool and fail to ensure compliance with psychiatric regimes in the community (Bird and Davies, 1996). Their purpose is to ensure follow-up of high-risk patients but the National Inquiry into Suicides and Homicides by Persons with Mental Illness (Appleby et al., 1999) found that a significant proportion of those committing suicide or homicide were either on a supervision register or were subject to supervised discharge, indicating failure of supervision registers to reduce harm attributed to mental ill health.

In 1993, the Royal College of Psychiatrists proposed the introduction of community supervision orders enabling supervision, but not compulsory treatment, in the community. The Conservative government subsequently rejected the proposal. Prior to this, the Royal College of Psychiatrists, the British Medical Association and the National Schizophrenia Fellowship proposed community treatment orders (CTOs) due to perceptions of problems posed by non-compliance with medication in the 'revolving door' phenomenon and the risk posed to the public by supposed unmedicated psychotics (Fulop, 1995).

The proposals represented an indication of the large numbers of individuals reputed to require medication but not hospital admission (Cavadino, 1991), representing an explicit disassociation between compulsory treatment and hospital admission that was so prevalent in the 1959 Mental Health Act.

The Mental Health (Patients in the Community) Act 1995 introduced supervised discharge as a corollary of the Royal College of Psychiatrist's proposals for powers of community supervision. Section 25A (supervised discharge) is applicable to patients aged over 16 years and subject to detention under the 1983 Mental Health Act. The requirements imposed by the supervisor are the same as under guardianship, except that it is operated by the health authority rather than the local authority (Hoggett, 1996). However, there is no power to impose treatment under

supervised discharge and no sanctions for patient non-cooperation (Bird and Davies, 1996).

Therefore, dissatisfaction with the limited powers of supervised discharge has led the current Labour government to renew consideration of community treatment orders in their proposals for the reform of the Mental Health Act 1983 (see Chapter Three). However, the criticisms of community treatment orders (which will be explored in Chapter Three) are the same as the responses to the proposals for CTOs in the early 1990s: that they would deter help-seeking, be problematic to implement, would represent an unacceptable violation of civil liberties (Burns, Goddard and Bale, 1995) and are based on an erroneous assumption of the efficacy of anti-psychotic medication (Cavadino, 1991).

It is also questionable whether CTOs are congruent with the least restrictive alternative principle in probably equalling the restrictiveness of hospital sections (Cavadino, 1991). Cavadino concludes that CTOs would represent increased coercion and surveillance in the community and is justified by reference to a utilitarian philosophy in which the ends are purported to justify the means (Barnes, Bowl and Fisher, 1990; Cavadino, 1989). In other words, deprivation of liberty is justified by the protection of public safety.

Therefore, since the introduction of the Mental Health Act 1983, there has been an increasing emphasis on legislative reform enabling greater control of psychiatric service users in the community. The question remains, however, why such people are regarded as such a threat in the community?

In order to answer this question, the following sections will examine the nature of public attitudes towards mental illness, whether evidence is available to support public perceptions of a link between mental illness and violence (since dangerousness is typically equated with violence) and how such perceptions recreate broader discrimination in the community.



## **Public Attitudes**

Rabkin (1974: 10) states:

Mental patients have for years been regarded with more distaste and less sympathy than virtually any other disabled group in our society, and in fact their handicaps are partly attributable to public attitudes of rejection and avoidance.

Research has found that public attitudes towards mental illness are characterised by a lack of accurate knowledge, exaggeration of disturbance, distrust, dislike and fear (Star, 1955; Nunnally, 1961; Cumming and Cumming, 1957) and epitomised by a desire for social distance from the psychiatric patient (Phillips, 1966).

Research on public attitudes has addressed possible difficulties ex-patients experience finding employment (e.g. Farina and Felner, 1973; Olshansky, Grob and Malamud, 1958) and housing (Page, 1977), problems encompassing social isolation and social support (Link et al., 1989), and government failure to protect the civil rights of psychiatric patients (Wahl, 1995). Negative public attitudes may also impede the re-establishment of family, work and social relationships (Schwartz, Myers and Astrachan, 1974). Negative public attitudes may also determine public policy in that perceptions of the dangerousness of the mentally ill enable justification of a regression to more institutionalised forms of care (Laurance, 2003).

Therefore, public attitudes are likely to exert a significant impact on the ability of mental health service users to achieve adequate community participation. A direct relationship is therefore postulated between public attitudes and the citizenship of mental health service users.

The following sections compare empirical data on public attitudes towards people with psychiatric diagnoses obtained prior to and following the introduction of community care and the role of the media in generating damaging negative stereotypes that serve to influence public policy on community care.

## **Labelling Theory**

Scheff (1966) examined how mental patienthood becomes a stable social role and argued that symptoms of mental illness are defined as residual rule-breaking in the violation of behavioural social norms, thus the individual is labelled as deviant and internalises the label to assume the role of the chronic psychiatric patient.

The critical claim made by Scheff is that social reaction determines labelling (who gets labelled and which label is attached), is informed by popular stereotypes and is manifested in discrimination that prevents resumption of ordinary social roles. Therefore, Scheff's thesis is that labelling produces residual rule breaking and assumes aetiological significance by causing further entry into the mental patient role. The implication of his argument is that mental illness does not occupy an objective existence independent of labelling.

A predominant critique of Scheff's theory derives from Gove (1970; 1975) and Gove and Fain (1973). Gove (1970) criticised the lack of empirical validation of labelling theory. The central argument adopted by critics of labelling theory is that aberrant behaviour, rather than public labelling, is the significant variable in the identification of mental illness (Cumming and Cumming, 1957; Phillips, 1963). Such studies also assert that psychiatric intervention is only initiated in response to 'severe behavioural disturbance' rather than due to adverse public reaction per se (Mishler and Wexler, 1963; Mendel and Rapport, 1969; Bittner, 1967). However, this assertion fails to consider discriminatory interpretations of behaviour. For instance, data on the greater use of Section 136 in relation to ethnic minorities (e.g. Rogers and Faulkner, 1987) represents a possible refutation of such findings by suggesting that Section 136 intervention is likely to reflect dominant racist stereotypes rather than being a reaction to greater aberrance of behaviour among ethnic minorities.

Gove (1970) argues:

The evidence suggests that stigma is not a serious problem for most ex-mental patients and that when stigma is a problem, it is more directly related to a person's current psychiatric status, or general ineffectiveness, than it is to having been in a mental hospital.

However, other researchers indicate that stigma *is* a serious problem and that public attitudes *are* critical in generating a general context of rejection of psychiatric patients (Wahl, 1999; Sayce, 2000).

### **Significant Empirical Studies**

The typical research paradigm of early public attitude studies involved the presentation of social distance questionnaires as measures of social rejection (based on Bogardus, 1925, who produced the first systematic measurement of social distance) (Brockman, D'Arcy and Edmonds, 1979).

Star (1955) developed the case descriptions ('Star vignettes') that were employed in a large number of studies until the early 1970s. She presented five case descriptions, four of which involved mental illness and a normal control, to 3,500 respondents and found that only the most disturbed behaviour was identified as mental illness. The results possibly indicate that people's conceptions of mental illness are stereotypical in implicating only highly disturbed behaviour as representative of mental illness.

Whatley (1959) produced a study considered important because it introduced the social distance scale as a measure of public attitudes towards mental illness (Rabkin, 1974). Whatley administered a social distance scale to 2001 people in 1956 and found that 68% of respondents claimed a willingness to live near an ex-psychiatric patient, 57% indicated a willingness to employ such a person and 36% would approve a daughter's marriage to an ex-patient. Whatley identified 'ego involvement' as the significant variable in determining social distance whereby tolerance was most likely to be found in relatively impersonal situations. Whatley identified social rejection as presenting a significant risk of social isolation to ex-psychiatric patients. He also found that young, well-educated, married white respondents in relatively well-paid occupations demonstrated the least avoidance.

Phillips (1963, 1964) found rejection to be a function of contact with psychiatric services and of specific behaviour exhibited by the target individual in case descriptions (see also Schroder and Ehrlich, 1968; Bord, 1971). Phillips' study

relates to the fundamental conceptual question addressed by labelling theory of whether a mental illness label elicits negative reactions independent of behaviour (Nieradzik and Cochrane, 1985). Phillips' findings suggest that negative reactions are a direct consequence of behaviour that deviates from behavioural norms. Kirk (1975) supports Phillips' findings in that only a behavioural description, and not a label, influenced attitudes of respondents. However, Kirk used college students as respondents whereas a differently educated general public may find labels more salient in determining attitudes (Nieradzik and Cochrane, 1985).

Nieradzik and Cochrane (1985) found that diagnostic labelling was strongly predictive of reaction to the target in a case description in comparison with the impact of a role label. Social distance ratings were higher (indicating a greater desire for social distance) for the schizophrenic than the neurotic or normal target and rejection increased with increasing severity of behavioural disturbance.

However, Nieradzik and Cochrane's conclusion that a role not associated with mental illness can reduce rejection by diverting attention away from the mental illness is problematic due to their observation that the ex-mental patient may experience difficulty obtaining alternative roles in the community precisely because of stigma. They comment:

It may be the case that real-life situations, where the illness is debilitating, the person will be unable to fulfil any role besides that of the mental patient (Nieradzik and Cochrane, 1985: 31).

This comment might reflect the low expectations of social participation held by members of the public in relation to people with mental health problems.

However, Bord (1971) interpreted his findings as refuting Becker's (1963) notion of the 'master status' bestowed by a psychiatric diagnosis because reactions of respondents differed between classificatory groups in the case descriptions. Perceived unpredictability and threat were most predictive of rejection. Therefore, Bord's results are interpreted as a refutation of the assertion by labelling theorists that a label is more predictive of rejection than the labelled person's behaviour per se.

Link et al. (1987) found that behaviour exerted a significant impact on social distance whereas labelling had no such impact. However, they also found an interaction between perceived dangerousness and labelling whereby the label elicited beliefs concerning the target's dangerousness. Link et al. (1989) proposed a 'modified labelling theory' in which patients' expectations of negative labelling are more significant to rejection than the aetiological consequences of labelling. For example, 75% of a community sample of ex-patients agreed that employers will discriminate against former psychiatric patients; 80% and 66% expected rejection in dating relationships and close relationships respectively; 71% thought former patients would be regarded as lacking trustworthiness; 62% expected perceptions of lower intelligence and 70% believed their opinions would be devalued. Therefore, former psychiatric patients recognised the negative impact a mental illness label can have on social acceptance, thus appearing to support labelling theory.

In a summary of the literature on labelling theory, Weinstein (1983) claimed that labelling theory receives some support in patients' acceptance of mental illness stereotypes and that ex-patients feel stigmatised by mental hospitalisation *but* most studies suggest an absence of problems relating to shame, embarrassment and problems of community integration. However, Weinstein conceded that most of the studies in his review did not directly test the core propositions of labelling theory and he ignored suggestions that community integration is impeded by negative attitudes in the areas of housing, employment and social relationships (See Farina and Felner, 1973; Olshansky, Grob and Malamud, 1958; Page, 1977; Link et al., 1989).

### **Public Attitudes in an Era of Community Care**

Most of the studies cited so far were conducted in an era of mass institutionalisation, when people with mental health problems were possibly less visible in the community and were possibly perceived as less of a threat. The critical question now becomes whether community care has served to diminish negative attitudes towards mental health service users or has exacerbated negative attitudes. Bhugra (1989) argues that public attitudes towards mental illness are crucial in determining the success or failure of community care.

Crocetti, Spiro and Siassi (1971) suggested that public attitudes indicate increased acceptance of people with mental health problems by claiming their sample demonstrated lower levels of social distance than in previous studies. For example, only 2% of the sample was unwilling to work with ex-psychiatric patients, 13% would not consider a romantic relationship with an ex-patient and 15% would not share a room with an ex-patient. However, the fact that responses related to ex-patients might have decreased social distance and whether or not respondents would be willing to have contact with currently ill persons was not examined in this study. In addition, the 'halo effect' might have predominated in producing socially desirable responses (see Judd, Smith and Kidder, 1991). This is a fundamental flaw in public attitudes research.

Aviram and Segal (1973) claimed that deinstitutionalisation has led to a desire to create greater social distance from mental health service users in order to compensate for the disappearance of the physical distance enabled by institutionalisation. More recent studies of community attitudes confirm this assertion.

Wolff et al. (1996) examined public attitudes towards psychiatric facilities in the community. They administered the Community Attitudes to the Mentally Ill Scale to 305 people residing close to two new group homes following closure of a large mental hospital in the locality. They found higher rates of fear and exclusion than in previous studies (e.g. Taylor and Dear, 1981), possibly due to the salience of the proximity of community facilities, therefore inducing greater anxiety concerning the threat posed by the new community residents. The researchers found that fear and exclusionary attitudes were particularly associated with having children under the age of 18 years, higher age and lower occupational status. Attitudes pertaining to social control were particularly associated with higher age, lower social class, African-Caribbean and Asian ethnic origin, lower educational level, children in the household, longer duration of local residence, being divorced, widowed or separated and, possibly surprisingly, knowing someone with a mental illness. The finding of attitudes demanding social control in ethnic minority respondents is of concern due to the experience of greater coercion used against African-Caribbean mental health service users (Wilson, 1998b; Keating et al, 2002; Keating and Robertson, 2004).

However, the study suffered from a number of methodological weaknesses, including its use of a relatively small sample (N=350: a relatively small proportion of the local community) and respondents who were self-selected, thus possibly including people with greater motivation to object to psychiatric facilities in the community. Therefore, the study might have over-estimated the prevalence of attitudes pertaining to fear and exclusion.

Brockington et al. (1993) compared public attitudes towards mental illness in an area served by a traditional mental hospital with attitudes in an area served by community psychiatric facilities. They presented 2000 respondents with vignettes and a community attitudes questionnaire and found 85% of responses indicated an absence of fear and a significant degree of benevolence expressed towards mental health service users. There were no significant differences in attitudes between the two study sites.

Those exhibiting the least fear had the highest level of education and personal or professional contact with people with mental health problems. Those exhibiting the greatest fear had no previous contact with mental health service users, were of lower socio-economic class and were most likely to be aged over 65 years. However, greater age was also associated with higher levels of benevolence felt towards people with psychiatric diagnoses.

However, tolerant attitudes expressed on the questionnaire were contrasted with intolerance demonstrated in response to vignettes. Only 59% said they would be willing to work with a mentally ill person and only 51% said they would live next door to such a person. The place of residence exerted a minimal impact on attitudes in that residing near to a community-based facility did not increase tolerance. This finding was attributed to a lack of knowledge of community psychiatry. Knowledge of mental illness was associated with lower levels of fear and a higher level of benevolence. However, benevolence is not necessarily desirable because it may produce institutionalised attitudes on the assumption that people with mental health problems are unable to care for themselves. The outcome, for instance in demanding

the exclusion of mental health service users, might be the same as when fear is elicited in response to people with psychiatric diagnoses.

The results from the Brockington et al. (1993) study suggest that absence of contact with people with mental health problems leads to fear and exclusionary attitudes. The question remains of where attitudes derive from when there is lack of contact with the attitudinal targets. Numerous researchers have suggested that negative public attitudes derive from media misrepresentations of mental illness.

### **Media Representations**

A growing body of research indicates that the media misrepresent mental health issues in accordance with popular stereotypes of mental health service users. For example, Philo, McClaughlin and Henderson (1996) found that 66% of television coverage of mental illness, in one month in 1993, related to violence towards others; 18% involved sympathetic coverage; 13% featured self-harm; 2% involved comic images and 1% critiqued accepted definitions of mental illness. Items referring to violence towards others occupied a higher profile than sympathetic or self-harm items.

Moreover, a sample of the audience of these programmes (N=70) was able to accurately relate a storyline of a soap opera involving threat posed by a psychologically disturbed individual and were able to faithfully reproduce tabloid-style reporting of mental illness with great accuracy (Philo, 1996a). Almost two-thirds believed that mental illness begets violence and familiarity with mental disorder failed to prevent absorption of negative stereotypes. Two-thirds of the sample cited the media as the source of their beliefs. Therefore, the authors concluded, the media has a significant influence over the formation of public attitudes towards mental illness and has a huge potential to generate misinformation on the subject of mental ill health.

Scheff (1966) claimed that children are socialised into negative attitudes towards mental illness at an early age and that these attitudes form the basis of adult



attitudinal orientations. Therefore, the content of media directed towards children can exert a significant influence over the formation of children's attitudes towards mental illness.

Wilson et al. (2000) examined the content of children's television programmes in New Zealand and found frequent references to mental illness which involved stereotypical depictions based on the use of derogatory names ('wacko', 'cuckoo', 'loony' and 'freak') and stereotypical physical characteristics, especially physical abnormalities. Moreover, characters depicted as insane were either comic or villainous.

Similarly, Wahl (1995) found a high frequency of offensive depictions of the mentally ill in the media. He argued that media representations emphasise a fundamental distinction between the mentally ill and the general public, involving references to odd physical appearance, bizarre behaviour and a dehumanisation inherent in the link postulated between mental illness and violence. Wahl claims:

When one sees or reads about a person with a mental illness in the media, it is more likely that the person will be shown as a criminal and dangerous than in any other way. (Wahl, 1995: 65).

Wahl claims that the media present mental illness in this way because such representations produce the fear, suspense and excitement that the audience demand, thus increasing consumption of media products. Similarly, Henderson (1996) found that television producers expressed greater concern to entertain audiences than to educate them.

The misrepresentation of mental illness lays in the way the postulated link between violence and mental illness is not supported empirically. Wahl (1995) estimates that 72% of media depictions of mental illness make an explicit link with violence compared with an average rate of 12% of violent incidents involving mentally ill people. The danger of such misrepresentation is that the public tend to believe that media representations are an accurate reflection of reality. For instance, Wahl (1987) found that 62% of lay respondents thought multiple personality is a primary symptom of schizophrenia, as is suggested in fictional and non-fictional accounts of schizophrenia.

The consequences of media misrepresentations are serious for users of mental health services. Wahl (1995) claims that the fear induced by media misrepresentations causes a desire for social distance by the public and leads to demands for the exclusion of the mentally ill on the grounds of their dangerousness, thus undermining the integrationist aims of community care.

The Schizophrenia Media Agency (no date) claims that media representations imply that violence is a core symptom of schizophrenia and emphasise the random nature of attacks schizophrenics commit on strangers, thus leading to demands for greater institutionalisation in the name of public protection.

Negative stereotypes also encourage non-disclosure of mental health problems for fear of being labelled dangerous or incompetent, thus leading to delays in help-seeking, social isolation and loss of social support (Wahl, 1995). Negative public attitudes also serve to prevent people with mental health problems returning to normal social roles, thus impeding full social participation (Hannigan, 1999).

The importance of research into public attitudes lies in its demonstration that negative public attitudes have far-reaching consequences for social participation (e.g. in relation to housing, employment and social relationships) and that tolerance of people with psychiatric diagnoses does not appear to have increased since the introduction of community care. The issue relating to whether public attitudes are stereotypical reactions or are elicited by actual behaviour has not been clarified due to the methodological weaknesses of early studies. Nevertheless, the consequences (e.g. prevention of community integration) may be the same regardless of motivational attributions.

In summary, it is open to question whether the media influences public attitudes or whether the media satisfies demand for sensationalist reporting of mental health issues. Henderson (1996) reported that television producers claimed to be merely satisfying public demand for melodramatic representation of mental health issues. However, numerous other researchers claim that public attitudes are influenced directly by the media. Wahl (1987) argues that the public believe that media

representations of mental health problems are accurate, citing the commonly held view that is propounded by the media that schizophrenia is characterised by a 'split personality'. However, Wahl (1995) also argued that the media reinforces existing stereotypes, especially in relation to the stereotypical association made between violence and mental ill health. Furthermore, Philo (1996a) suggests that public attitudes *are* influenced by the media but indicates that the public actively choose which media to access and thus existing beliefs influence responses to media representations. However, the relationship between public attitudes and the media is stated to be complex because the media does not create the social environment but is simply an important part of the social context and may simply reinforce existing stereotypes adopted through the process of socialisation. (Philo, 1996a)

### **Dangerousness**

The previous section referred to the predominance of public perceptions of the dangerousness of the mentally ill. A link is also postulated between mental illness and violence in empirical literature (Monahan, 1992; Mulvey, 1994), especially when combined with the use of illicit drugs or misuse of alcohol (Swanson et al., 1990; Swanson, 1994).

Active symptoms such as delusions are thought to be the most likely factor influencing violence in the mentally unwell rather than a specific diagnosis (Marzuk, 1996). Haffner and Boker (1982) claimed that delusional content involving jealousy, injury or persecution is particularly associated with violence, especially delusions of persecution. Link, Andrews and Cullen (1992) argued that symptoms of psychosis are most predictive of violence because their study found a link between psychotic symptoms and violence even in a sample of untreated community residents, thus suggesting violence is associated with symptoms rather than due to a medicalisation of deviance, contact with services or labelling.

Link, Andrews and Cullen (1992) concluded that the mentally ill *are* more dangerous than members of the public due to the presence of certain symptoms. However, they also indicated that the risk of violence is not particularly high and that mental illness

is less significant in predicting violence than age, gender or educational attainment. The authors argue that if risk is a sufficient justification for containment, exclusion should extend to young males with poor educational attainment.

However, research on violence in the mentally ill is beset by numerous methodological problems. For example, data reliant on arrest rates may underestimate levels of violence since mentally disordered offenders may be more likely to be hospitalised than arrested (Monahan, 1988). The inquiry into the care of Christopher Clunis noted that police officers failed to arrest Clunis following repeated involvement in violent incidents, including threatening others with a knife and one incident of an actual stabbing (Ritchie, Dick and Lingham, 1994).

Moreover, research tends to employ ill-defined terms, relies on retrospective analyses and fails to standardise methods employed (Marzuk, 1996). In addition, the location selected for individual studies is likely to influence data in that hospital studies may underestimate violence due to higher levels of surveillance and medication than in the community. Therefore, research that suggests an association between mental illness and violence may not be reliable due to basic methodological flaws.

Furthermore, the clinical prediction of violence in psychiatric patients is flawed, despite inaccurate prediction of risk by psychiatrists involving high-cost error because it is likely to result in the denial of the individual's civil liberties (Steadman, 1983). Psychiatrists tend to over-predict violence (Cavadino, 1989) and errors in predictions have been attributed to psychiatric assessments occurring in institutional settings rather than in the individual's social context, thus casting doubt on the ecological validity of risk assessments (Levinson and Ramsay, 1979). Psychiatrists are also aware of the consequences of producing a false negative prediction of violence in which a discharged patient is subsequently involved in a violent incident (Levinson and Ramsay, 1979; Steadman, 1983). Psychiatrists also encounter problems predicting behaviour due to social and cultural distance from patients (Levinson and Ramsay, 1979) and appear better at predicting general violence than in specifying the conditions under which violence is likely to occur (Mulvey and Lidz, 1995).

Although empirical studies of violence and mental illness appear flawed, national statistics on homicide may be more reliable (although methods of recording are likely to influence overall figures). Szmukler (2000) indicates that there are approximately 500 homicides in England and Wales each year and approximately 50 of those are committed by people accepted under Section 2 of the Homicide Act 1957 as suffering from a mental disorder. Therefore, 90% of homicides are committed by people not suffering from a mental disorder.

The National Inquiry into Suicide and Homicide by People with Mental Illness found 8% of the homicides in the study involved people in contact with mental health services in the year prior to the incident and 14% had previous contact with services at some time (Appleby et al., 1999). It was also found that 39% of all people convicted of homicide had a history of alcohol misuse and 35% had a history of illicit drug use. A significant proportion of mentally disordered people involved in homicides had a diagnosis of personality disorder and perpetrators of homicide tended to have had less contact with services than those committing suicide.

Risk factors for homicide were identified as encompassing a previous history of violence, alcohol and drug abuse, deliberate self-harm, previous formal detention and secondary diagnoses. Refusal of medication was implicated in at least 25% of suicides and homicides and disengagement from services in at least 71% of homicide cases. Disengagement was associated with broad social exclusion: living alone, being unmarried, unemployed or homeless.

However, Appleby (2000) concluded that homicides by the mentally ill are rare, that family members are most likely to be victims and that homicide can be reduced by services addressing non-compliance and disengagement from services. Unfortunately, non-compliance with medication has been used to justify compulsion in service provision and disengagement from services is currently being addressed by the potentially oppressive assertive outreach approach (Coleman, 1998).

Furthermore, as Szmukler (2000) argues, the majority of people who represent a danger to themselves or others are not subject to the compulsion that confronts

people with a psychiatric diagnosis. He indicates that, in the UK in 1994, there were approximately 5000 suicides, 4000 deaths from accidental falls and 4000 deaths from road accidents and none of these were subject to official inquiries, unlike the relatively small number of deaths caused by mentally unwell individuals.

Despite the fact that the chances of being killed by a stranger with psychosis is approximately 1 in 10 million (the equivalent chance as being killed by lightning) (Szmukler, 2000), there is broad public concern of the random danger posed by the mentally ill in the community. Such concern led to the establishment in 1994 of an obligation on local authorities to establish formal inquiries into all killings involving people known to psychiatric services (Muijen, 1995).

Such inquiries are problematic because they emphasise the failings of community care and exaggerate the dangers involved in failing to exert adequate control over the mental health service users in the community (Munro and Rungay, 2000). Muijen (1995) questions whether mental health policies are determined by the government or by formal inquiries. For instance, the Care Programme Approach derived from recommendations made by the inquiry into the case of Sharon Campbell and the introduction of supervision registers was influenced by the cases of Sharon Campbell, Andrew Robinson and Christopher Clunis (Bird and Davies, 1996; Ritchie, Dick and Lingham, 1994). Supervision registers were recommended on the grounds that Section 117 of the Mental Health Act 1983 was not being implemented properly and was thus allowing people like Christopher Clunis to become disengaged from services (Ritchie, Dick and Lingham, 1994).

Munro and Rungay (2000) claim that inquiries into the care of psychiatric service users who have committed homicide emphasise the unpredictability of violence: 27.5% of inquiries in their study concluded that violence could have been predicted, thus implying that 72.5% of homicides could not have been predicted. Therefore, such inquiries emphasise public safety concerns. Munro and Rungay argue that the emphasis of inquiries generates public demand for an avoidance of false negatives (failure to predict violence) and therefore produce an over-prediction of risk and a consequential erosion of patients' civil liberties.

## **Discriminatory Use of Compulsion**

Perceptions of dangerousness disproportionately influence the use of compulsion in relation to black mental health service users. Moreover, the racist treatment of black people in the psychiatric system reflects broader societal racial discrimination (Wilson, 1998b) and indicates that the state does not intervene in a neutral way with its citizens.

McGovern and Cope (1987) examined the case notes of all male patients aged 16-65 years admitted under the 1959 Mental Health Act between 1975 and 1982. In terms of Part IV (civil) admissions, the youngest group of West Indian 'immigrants' had compulsory admission rates 17 times the white admission rate. Differences between white people and British-born West Indians were also highly significant but there were no significant differences between British-born and 'immigrant' West Indian patients. In relation to Part V (forensic) admissions, the youngest age group of West Indians had admission rates 25 times the rate for white patients.

Schizophrenia was found to be the most common diagnosis amongst West Indian patients and 'drug induced psychosis' was a diagnosis reserved exclusively for West Indian patients. However, McGovern and Cope attribute higher West Indian admission rates to higher actual levels of schizophrenia in the West Indian population, unlike Littlewood and Lipsedge (1981) who found an excess of compulsory admissions amongst a West Indian population to be independent of diagnosis. The McGovern and Cope study is particularly problematic in that it relied on case note diagnosis that may reflect racial bias in diagnostic practices.

Davies et al. (1996) found the mean number of compulsory admissions was significantly higher for ethnic minority patients: 42.5% of white patients and 70.4% of black Caribbean patients and 69% of black African patients had been detained under the Mental Health Act 1983. Black people were particularly likely to be detained under Sections 136, 2 and 3, and had greater contact with forensic services. These findings were independent of diagnosis, total number of admissions in a year and age, sex and marital status. The study is pertinent in demonstrating different

pathways into services experienced by black people. For instance, black patients were more socially isolated, had greater prior contact with the police and forensic services and were more likely to be compulsorily detained.

Pipe et al. (1991) found the greatest preponderance of Section 136 referrals involved young black males aged under 30 years who were more likely than young white males to be regarded by the police and public as 'threatening, incoherent and disturbed', and yet were less clearly defined as being mentally ill and were more likely to be living in stable accommodation.

Rogers and Faulkner (1987) conducted a three-year study of Section 136 referrals in London across three referral sites: a police station, an emergency and assessment unit and a hospital. Black people were over-represented in referrals in comparison with their numbers in the general population and male African-Caribbeans were particularly more likely to receive a diagnosis of drug-induced or unspecified psychosis. However, the researchers were unable to specify whether diagnostic differences were due to actual behaviour, differences in symptoms or to observer bias. Nevertheless, the results reiterated the racism inherent in the postulated exclusive use of 'drug-induced' psychosis for ethnic minorities (see Fernando, 1991).

Rogers and Faulkner argue that perceptions of dangerousness are central to Section 136 referrals whereby higher rates of Section 136 use for young African-Caribbean individuals suggest police and public perceptions of dangerousness are particularly likely to be applied to this group. Moreover, Section 136 referrals in the Rogers and Faulkner study were associated with excessive coercion in that all detained cases were held on a locked ward until expiry of the 72-hour detention period and 70% of detainees were administered with medication during this period.

In relation to the administration of medication, Littlewood and Cross (1980) found that the average black outpatient was more likely to receive major tranquillisers than the average white outpatient (84% vs. 67%), was more likely to receive depot medication (71% vs. 49%) and the average dose was higher for black patients (35mg. vs. 23mg.). The differences were largely due to a small number of black patients receiving excessively large doses of medication. Nevertheless, these findings imply



perceptions of a greater need to control the symptoms and behaviour of black patients and are likely to reflect perceptions of the dangerousness of black mental health service users.

Fernando (1998) argued that diagnosis depends on interpersonal interactions between doctor and patient that allow the doctor's cultural stereotypes to influence assessment of the patient. Fernando (1991) also argued that the existence of 'cannabis-induced psychosis' diagnosis demonstrates the impact of cultural stereotypes on diagnosis. The stereotype of the black mental health service user as 'Big, Black and Dangerous' (Wilson, 1998b) appears prevalent in the greater use of medication and greater police involvement due to the implied greater need to control the behaviour of black service users.

Racist stereotypes and institutionalised racism were prevalent in a study conducted by Browne (1997) who examined black people's experiences of sectioning and the influence of cultural assumptions on professional decision-making. Browne conducted interviews with police officers, approved social workers, GPs and voluntary service workers. The police were found to hold explicitly racist stereotypes whereby discussions of dangerousness and control were almost exclusively focused on black people. The police officers cited 'gut feeling' as directing their responses to people with mental health problems, thus allowing subjective and racist decisions to affect their behaviour. Racist stereotyping is epitomised in the following statement made by a police officer:

Violence is more of a factor because persuasion can't be used: one race that tends to get excited are Nigerians. It's the same with people from Arab countries. I mean they really know how to demonstrate don't they? (Browne, 1997: 15).

Over 75% of the professionals questioned concurred that black clients were more likely to be perceived as dangerous than white clients, although agreeing that others hold particular attitudes is not equivalent to admitting such tendencies in one's own attitudes. Browne concluded that the racist attitudes expressed by professionals in his study must have been strongly held because they were expressed to a black interviewer (Browne himself). However, the respondents' willingness to express

racist views to a black interviewer might also suggest a belief that such views are acceptable and legitimately held.

However, research on perceptions of the dangerousness of black mental health service users should be considered in relation to Wilson's (1998b) assertion that the psychiatric treatment of black mental health service users reflects racism in wider society (see also Keating et al, 2002; Keating and Robertson, 2004). Therefore, the treatment of black mental health service users should not be attributed solely to the actions of individual professionals but should be considered within the context of the discrimination, prejudice and social exclusion of ethnic 'minorities' generally.

## **Summary**

Increasing rates of formal admissions demonstrate the dominance of the medical perspective in the use of mental health legislation. Service users' decision-making is undermined by predominant notions of lack of insight and postulated irrationality in relation to medication refusal, by the way in which medical professionals are permitted to act in the patient's best interests and by the way mental health legislation is predicated on principles of protectionism and paternalism.

The civil citizenship rights of psychiatric service users appear to be increasingly undermined by the progressive extension of compulsion in the community, as exemplified by the proposed introduction of community treatment orders (DoH, 1999, 2004). Tolerance does not appear to have increased since the emergence of community care and the low status of people with mental health problems in the community is epitomised by the explicit stereotyping and misinformation contained in media representations of mental illness.

The following chapter will examine current mental health policy in relation to New Labour discourse on social inclusion in an attempt to determine the relative influence of service users, the public and the media on policy. An investigation of the relative influence of each group will elucidate on the political citizenship of people who use

mental health services, since I have interpreted political citizenship as involving influence over political decision-making.

## **Chapter Three: Political Citizenship**

Political citizenship refers to political participation and influence (Marshall, 1992). I will argue in this chapter that New Labour's preoccupation with the language of 'citizenship' and 'social inclusion' is incongruent with their increasingly exclusionary mental health policies.<sup>3</sup>

### **The Third Way**

Tony Blair's aim is to create a centre-left consensus for the 21<sup>st</sup> century (Giddens, 1998) by advocating the 'third way' as an alternative to the neo-liberal individualism of the 1980s and the post-war liberal collectivism that dominated left-wing politics until the mid-1970s. The third way is New Labour's political ideology that aims to transcend the divide between social democracy and neoliberalism, encompassing neoliberalism, communitarianism and Christian ethics (Finlayson, 2003). However, White (2001) claims that the third way is not a coherent philosophy because it straddles such differing ideological approaches.

The third way was developed by Anthony Giddens (purportedly Blair's favourite intellectual: Hutton, cited in Giddens, 1998), who is quoted as saying "no rights without responsibilities" (the 'new social contract': Giddens, 1998: 65). Giddens claims that post-war social democrats, such as T.H.Marshall, over-emphasised rights at the expense of responsibility. The third way ethos states that rights must be attendant on fulfilling certain obligations.

Equality is defined by Giddens (1998) as inclusion in civil society with citizenship as the guiding principle. Participation in civil society is interpreted as involving the assumption of responsibility within the community to behave in ways that fulfil collective obligations. The third way demonstrates the moral ethos underlying New Labour policy whereby obligations to the community should predominate individual

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<sup>3</sup> Although user involvement is regarded as a form of political citizenship (Lister, 1997), an examination of user involvement is included in Chapter 4 rather than this chapter because it is examined within the context of participation in services rather than in relation to broader political participation.

rights. The neo-liberals of the 1980s accused the welfare state of propagating welfare dependency and as representing an inefficient distribution of public expenditure. They advocated the 'active citizen' as responsible for their own welfare (Ignatieff, 1991).

Some commentators have argued that New Labour discourse is remarkably similar to the ethos advocated by the Conservative government of 1979-1997. Fairclough (2000) claims that both the Conservatives and New Labour emphasise national renewal, individual responsibility, competition, the limitations of government and the role of government in initiating cultural change among the populace. Such cultural change is particularly directed at people thought to be implicated in urban decay (the poor, the unemployed, single parents and young offenders). Barratt Brown and Coates (1996) claim:

The alternative [to the Conservatives] has to be discerned through a mist of vacuous aspiration and moralising sentiment and does not seem to amount to anything real (p.1).

In other words, the differences between New Labour and the Conservatives may be more apparent than real. Indeed, New Labour has been described as "Mrs Thatcher without the handbag" (Giddens, 2000). However, Fairclough (2000) argues that Thatcher and Blair are distinct in that Thatcherite discourse was polemical and divisive whereas New Labour discourse aspires to be inclusive and consensual.

However, like the Conservatives, New Labour places an emphasis on attacking welfare dependency due to the 'moral hazard' of such dependency (Giddens, 1998). Lister (1998a) argues that New Labour has diluted its political aims by transmuting from a pursuit of equality to emphasising equality of opportunity, implying individual responsibility for exploiting opportunities provided by the Government's 'welfare-to-work' programme. Lister also claims that New Labour has transformed its discourse from one involving poverty to a social inclusion discourse whereby inclusion is defined narrowly as participation in paid work. Lister (2004) argues that the concept of social exclusion complements the concept of poverty but is not its replacement. Therefore, she argues, analyses of poverty should remain central to an examination of social inequalities.

## Social Exclusion

Ruth Levitas (1998) produced a comprehensive critique of the moral underpinnings of New Labour rhetoric. She deconstructed the popular language of 'inclusion', 'stakeholding' and 'community' by examining such concepts in relation to three categories of discourse:

1. **RED:** A 'redistributionist discourse' places an emphasis on the redistribution of economic resources as a route to social inclusion. It is informed by T.H.Marshall's analysis of citizenship and produces a broad analysis of inequality.
2. **MUD:** Refers to the 'moral underclass debate' and involves an attack on the morals of certain social groups, such as social security benefit claimants and single mothers, on the basis of their hypothesised moral and behavioural deficits (see Mead, 1986; Murray, 1989).
3. **SID:** Refers to 'social integrationist discourse' which is influenced by European discourse on social exclusion (see Chapter Four) but which places a narrow emphasis on inclusion through paid work (cf. Lister, 1998a).

Levitas states:

To oversimplify, in RED they have no money, in SID they have no work, in MUD they have no morals (Levitas, 1998: 27).

Levitas argues that the Government's Social Exclusion Unit (SEU) demonstrates strong MUD influences but that Labour has generally shifted from the redistributionist discourse of the Commission of Social Justice, to SID, with an emphasis on equality of opportunity rather than equality of outcome and using the language of fairness rather than the language of equality.

The Social Exclusion Unit (1998) defined social exclusion as:

...a shorthand label for what can happen when individuals or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown.

Therefore, New Labour adopts European and Anglo-American approaches to social inequality that emphasise the multi-dimensional nature of disadvantage in which numerous factors interact to produce broad social exclusion (Silver, 1994; de Haan, 1998). The stated aim of the SEU is to improve comprehension of specified problems, to promote co-operation between government departments and to produce recommendations for more effective solutions to social exclusion (SEU, 1998). The Social Exclusion Unit does not have access to a separate budget with which to address social exclusion but merely directs the expenditure of existing budgets in various Government departments (SEU, 2004).

In 2003, the Social Exclusion Unit launched an investigation into the social exclusion of people with mental health problems with the aims of examining how to increase employment rates in this population, how to promote greater social participation and how to improve access to services. Following consultation with a range of 'stakeholders', the SEU launched a report into social exclusion and mental health in September 2004. Predictably, the main route to social inclusion was deemed to be through paid work (see Levitas, 1998; Lister, 1998a) whereby a large proportion of the report concentrated on policies to enable people with mental health problems to engage in paid work. However, the report did identify a broad range of risk factors associated with social exclusion, including stigma and discrimination, low expectations by professionals, and barriers to housing, transport and leisure facilities. Nevertheless, the report adopts a discernible individualistic approach in locating the causes of social exclusion in individuals, specifically the attitudes of professionals, employers and the public. The report even identifies a (postulated) link between dangerousness and mental ill health as a 'myth'. This is inconsistent with the Government's proclamations on the 'failure of community care' and the need for legislation to address the purportedly dangerous mentally unwell (see DoH, 1998a).

Blair's vision of a modern, socially inclusive Britain is conveyed in a speech delivered on 8<sup>th</sup> December 1997, entitled 'Bringing Britain Together':

At the heart of our work, however, is one central theme: national renewal. Britain rebuilt as one nation, in which each citizen is valued and has a stake; in which no one is excluded from opportunity and the chance to develop their potential, in which we make it, once more, our national purpose to tackle social division and inequality (cited in Fairclough, 2000).

In summary, Tony Blair and the third way considers the relationship between the individual and the community as central to civic renewal and views a modernised Britain as a nation in which no one is socially excluded. However, despite New Labour proclaiming a pursuit of a more inclusive society, the third way represents a morally authoritarian ethos that emphasises individual responsibility and obligations rather than rights (Stepney, Lynch and Jordan, 1999; Tonge, 1999). This point is exemplified in New Labour's conception of community that underlies their interpretation of communitarianism.

### **New Labour's Communitarianism**

Barratt Brown and Coates (1996) argue that New Labour's conception of community is ambiguous and can encompass a hypothetical national community or can be interpreted as common fellowship or common identity. Similarly, Levitas (1998) indicates that 'community' could refer to neighbourhoods, regional or national communities, the community of Europe or the global community. Nevertheless, one of the prime exponents of 'responsive communitarianism', Henry Tam (1998) asserts that:

At its most basic level, a community is no more than a group of people who have something in common which brings them (and keeps them) together (p.220)

Etzioni (1997), another prominent exponent of responsive communitarianism, claims that the "community is a set of attributes, not a concrete place" (p.6).

Such definitions exemplify the nebulous nature of the concept of community, yet communicate the sense of belonging, social solidarity and membership inherent in conceptions of community (Delanty, 2003). Driver and Martell (1997) describe communitarianism as being based on assumptions that individuals are determined by their communities, that communities facilitate social cohesion and that normative assertions can be made concerning the characteristics of beneficial communities.

Communitarians espouse the ideal of the inclusive community which includes all members in decision-making and in which each member accepts responsibility for the



welfare of other community members (Tam, 1998). Responsive communitarianism claims to be influenced by classical civic republicanism in which participation in democratic decision-making and subordination of personal needs to the needs of the community are the fundamental attributes of the citizen (Etzioni, 1997).

Etzioni advocates the 'new golden rule', which espouses that a good society nurtures both social values and individual rights, thus achieving a balance between social order and individual autonomy. He states:

The new golden rule requires that the tension between one's preferences and one's social commitments be reduced by increasing the realm of duties one affirms as moral responsibilities-not the realm of duties that are forcibly imposed but the realm of responsibilities one believes one should discharge and that one believes is fairly called upon to assume (p.12-13).

In other words, social order is dependent on voluntary adherence to the norms of the community which are determined by moral dialogues (Etzioni, 1997) or 'co-operative inquiry' (Tam, 1998) on the assumption that discussions between community members can achieve a consensus on core values while enabling relative individual autonomy on more peripheral concerns. The latter point indicates the importance placed by responsive communitarians on achieving a balance between social cohesion and individual autonomy.

The communitarianism of Tam and Etzioni claims to encompass diverse groups by only seeking consensus on core values. However, it is questionable whether responsive communitarianism is able to avoid the influence of unequal power relations in the determination of community norms. Hughes (1996) argues that the moral authoritarianism of responsive communitarianism is not inevitable by advocating 'radical egalitarian communitarianism' which argues that a moral consensus can only be achieved when all citizens are equally able to participate in society as a result of economic redistribution. Otherwise, economic inequality undermines each individual's capacity to influence group decision-making, especially in the case of women (Lister, 1997). Responsive communitarianism assumes that each individual is equally able to exercise autonomy, thus it fails to address the relationship between resources and power relations within the community (Bauman, 1997).

Heater (1999) describes communitarianism as the intellectual foundation of the third way. Communitarianism emphasises a moral consensus achieved through persuasion rather than coercion. Indeed, Etzioni (1997) argues that coerciveness in ensuring adherence to community norms demonstrates a weak society in which there is a minimal commitment to shared values. Similarly, New Labour emphasise the need for cultural change in society in order to appraise common values (see Blair, 1998). However, New Labour has also emphasised coercive means of pursuing social cohesion, particularly in their assault on youth offending, welfare benefit receipt and community treatment of mental health service users (Stepney, Lynch and Jordan, 1999; Lister, 2001; Laurance, 2003).

Both communitarianism and New Labour emphasise accountability and transparency of government in encouraging citizens' participation in political decision-making. The problem for both communitarianism and New Labour is that neither has managed to escape from the conservative, authoritarian connotations of demanding consensus in highly pluralistic societies that are beset by countless conflicting interests.

Driver and Martell (1997) argue that New Labour's brand of communitarianism is conservative, for example, in adopting moral views on ideal family structure and by asserting that poor parenting causes youth crime. They also argue that it is conformist in emphasising strict adherence to community norms; is conditional in demanding fulfilment of obligations in return for rights; and is atomistic in placing an emphasis on individual responsibility in human relationships.

New Labour's communitarianism advocates morally prescriptive notions of community which, although espousing social cohesion, can have a seriously detrimental effect on people not conforming to the expectations of an ideal citizen. Communitarianism potentially disadvantages people who use mental health services in that they are either regarded as being incapable of fulfilling their obligations as citizens or by not being considered legitimate members of the community.

New Labour's communitarianism also fails to encompass plurality in society and fails to deal adequately with the resolution of conflicting interests in the determination of community norms. Levitas (1998) refers to the 'new Durkheimian hegemony' in New

Labour discourse in its reiteration of Durkheim's emphasis on social inclusion and social solidarity in small communities based on shared social values. Like Durkheim, New Labour fails to question whose interests are served by a moral consensus (Levitas, 1998).

Herein lies the crux of the problem. Communitarianism would enable the most powerful members of society to define community norms and to determine who has the power to demand the exclusion of people not conforming to such normative standards. Communitarianism holds the potential for even greater 'nimbyism' on the grounds that the presence of people with mental health problems offends community norms. Sayce (2000) argues that 'nimbyism' against psychiatric facilities in the community implies that the public regard people with mental health problems as not legitimate members of the community. Repper et al. (1997) found that two-thirds of mental health service providers surveyed had experienced 'nimby' opposition: 63% of Mind associations were forced to delay a community development and 30% had withdrawn plans altogether. Therefore, 'nimby' opposition is both common and effective in its exclusionary aims.

Furthermore, communitarianism is paternalistic towards people it considers incapable of fulfilling citizenship obligations. For instance, Tam (1998) states:

...some people have severe psychological problems which render them incapable of controlling their behaviour, and they should be treated as victims who deserve the wider community's help to resist behavioural patterns they struggle to reject. (p.122)

Tam (1998) also refers to "irreversible mental problems" which may leave people with "little chance of being able to look after themselves in the future"(p.134). This exclusive notion of citizenship echoes Aristotle's notion that only the propertied elite possess the skills to perform the duties of a citizen. Therefore, although communitarians espouse equal participation in society, they qualify this by adopting a highly pessimistic and paternalistic approach to people deemed incapable of fulfilling their obligations to the community. This pessimism is also detectable in New Labour discourse. This is how Peter Mandelson described some sections of the socially excluded in a speech delivered on 14<sup>th</sup> August 1997 to the Fabian Society:

Groups such as poor pensioners as well as the chronically sick and disabled *who are little able to help themselves [my emphasis]* and for whom the message of opportunity must seem hollow should be stakeholders in Britain's economic success and share its rewards (cited in Fairclough, 2000).

Therefore, although the Labour government advocates the social inclusion of all, it argues that some people may be excluded from their obligations due to the implied inherent incapacities associated with sickness and disability. Therefore, since rights are supposedly attendant on fulfilling obligations, enjoyment of rights might be compromised for those not considered capable of meeting such obligations. Furthermore, since citizenship is defined according to meeting certain obligations, those deemed incapable of fulfilling such obligations would seem to be excluded from occupying the status of citizens. Therefore, one must question the Government's conception of citizenship of marginalised groups, such as users of mental health services.

Furthermore, in relation to the problem of the dominant voices in the community determining legitimate membership of the community, the influence of public attitudes on current mental health policy demonstrates the power of discriminatory public opinion on the formulation of national policies (Muijen, 1995; Wahl, 1999).

At the time of the research described in this thesis, the Government's mental health policy comprised three foremost strands:

- Proposals for the reform of the Mental Health Act 1983 (DoH, 1999b)
- 'Modernising Mental Health Services' (DoH, 1998a)
- The National Service Framework for mental health [sic] (DoH, 1999a)

I will argue that the content of current mental health policy is incongruent with New Labour's rhetoric on creating inclusive communities and tackling social exclusion.

### **The Proposals for the Reform of the Mental Health Act 1983**

Laurance (2003) claims that the draft Mental Health Bill (DoH, 2002) exposes the authoritarian style of New Labour, citing Paul Boeteng's statement that the Labour government "...will not tolerate a culture of non-compliance". Boeteng's statement

and the draft Mental Health Bill is based on the proposition that relapse in mental illness is caused by non-compliance with medication (Laurance, 2003) and demonstrates the Government's commitment to the medical model (see Beresford and Croft, 2001). Therefore, the explicit aim of the Green Paper on the reform of the current Mental Health Act is to examine how legislation can be updated to enable the extension of compulsory treatment beyond the hospital into the community. This reflects the Government's concern that the current Mental Health Act only enables compulsory treatment within inpatient settings and thus is regarded as inappropriate in an era of community care.

The proposals argue that people with mental health problems are equivalent to patients with physical illness. However, this rationale fails to recognise that general medical patients have the power to refuse treatment (Giliker and Beckwith, 2001) and generally do not suffer the same degree of stigma typically associated with mental health problems (Wahl, 1999). The proposals support the medical view of mental health problems by equating mental and physical ill health, thus continuing to invest significant power in medically oriented psychiatric professionals.

The main aim of the proposals to secure compulsory treatment in the community appears to be a knee-jerk reaction to public concerns over the dangerousness of mental health service users (Laurance, 2003). Therefore, proposals for legislative reform represent populist concern to satisfy public demands for control or containment of the 'dangerous' mentally ill. One of the key underlying principles of the proposals is the prioritisation of public safety over the civil rights of psychiatric service users.

An additional principle underlying the proposals is that treatment should, whenever possible, be conducted on an informal basis. However, Cavadino (1989) refers to the 'myth' of voluntary patient status, indicating that coercion of patients to comply with treatment regimes is enforced through the explicit or implicit threat of coercion. For example, the patient might comply with medical directives in fear of compulsion being imposed as a response to perceived non-compliance. Cavadino found that voluntary patients had been subjected to physical force, locked in seclusion rooms,

had clothes withheld and had been forcibly administered treatment, thus casting doubt on the voluntariness of the voluntary patient status.

One of the key features of the Green Paper is the proposal for the introduction of community treatment orders on the grounds that the Mental Health (Patients in the Community) Act 1995 failed to address the problem of non-compliance with medication. Therefore, it is proposed that a new Mental Health Act would permit compulsory treatment in the community, using the same criteria as compulsory treatment in hospital (DoH, 1999b).

The Green Paper (DoH, 1999b) proposed the introduction of the community treatment order which would be able to stipulate a place of residence; define a proposed care and treatment plan; place an obligation on health and local authorities to comply with the care plan and non-compliance with their care plan by patients would be met with the power to enter premises and to convey the patient either to hospital or to a community treatment centre to receive treatment.

Mind (2000) and Pedler (1999) raised a number of concerns in relation to the proposed community treatment orders (CTOs). They argued that CTOs would discourage people from seeking help from services; they would undermine the trust essential to user-professional relationships and they have the potential to be used in a discriminatory way, especially in relation to black service users given the currently high rate of compulsion directed at this group (McGovern and Cope, 1987; Davies et al., 1996; Pipe et al., 1991; Rogers and Faulkner, 1987).

Community treatment orders also emphasise medication at the expense of other forms of treatment and assume that medication is effective (Pedler, 1999), yet 10-20% of psychiatric inpatients diagnosed with schizophrenia do not respond to medication (Davis et al., 1980). The emphasis on medication in the Green Paper demonstrates the Labour government's commitment to the biomedical approach to mental health. Moreover, side effects of medication mean that non-compliance may constitute rational decision-making (Hughes, Hill and Budd, 1997; Perkins and Repper, 1999). Mind (2000) asserted that the imposition of medication on people with a mental health problem and not on other groups who pose a risk to themselves is discriminatory.

They also argued that it is erroneous to claim that mental illness is a predictor of violence (as suggested by the Government). Mental illness is only a predictor of violence when combined with other risk factors such as substance misuse (Appleby, 2000). Mind also argued that community treatment orders would be associated with greater stigma because it involves the public labelling of incompetence in treatment-related decision-making and would lead to an even greater defensiveness in medicine with increased emphasis on risk management.

The Green Paper was followed in 2002 by further consultation and in 2004 by the draft Mental Health Bill. The consultation (DoH, 2002) introduced the Mental Health Act Order which includes the notion of compulsory care plans in which individuals can be ordered to reside at a specified location, to attend a day centre, to be assessed by an authorised mental health professional and to accept medical treatment specified in a care plan. Failure to comply with the care plan would be met with the power of mental health professionals or the police to transfer individuals to a 'place of safety', including hospital. The proposals emphatically indicate that the Mental Health Act Order would not allow compulsory treatment in the individual's own home. However, the draft Mental Health Bill (DoH, 2004) introduces the concept of the 'non-resident patient' who must allow access to professionals to conduct an assessment and, if necessary, to order treatment in the community. Refusing to make oneself available for assessment or failure to attend a specified place as part of a care plan could result in the individual being conveyed to hospital or to a 'clinical setting' in order to receive treatment. Moreover, treatment is broadly defined in the Bill and seems to include attendance at a day centre or even living in a specified place. The wording contained in the Bill conveys the construction of the patient in mental health policy. For example, it describes how a Justice of the Peace could issue a warrant for removal of an individual to a place of safety if a person is believed to be suffering from a mental disorder and "has been or is being ill-treated, neglected or kept otherwise than *under proper control [my emphasis]...*" Such language appears more appropriate to describe a stray dog than a human being with fundamental human rights.

Although the Bill proposes a statutory right to access an independent mental health advocate to ensure that the individual's rights are observed, the Bill extends compulsion beyond the originally-proposed community treatment orders to

compulsory care plans that even remove the individual's right to determine where they live, whether to attend a day centre or whether to accept or decline a mental health service in the first place. However, the Mental Health Act Order appears to replicate the powers of Supervised Discharge in that the supervisor can stipulate a place of residence, attendance for medical treatment or rehabilitation and a supervisor can gain access to a supervisee's residence. Nevertheless, the Mental Health Act Order introduces the status of a 'non-resident patient' and it is this development that distinguishes the proposals in the Mental Health Bill from previous mental health legislation.

Since the completion of the research described in this thesis, a Parliamentary Joint Scrutiny Committee (2005) has commented on the draft Mental Health Bill, recording a number of objections to the Bill. Most notably, the Committee expressed concern in relation to the potential of Mental Health Act Orders to be used as a form of mental health ASBO (Anti-Social Behaviour Order) in being applied to control the behaviour of people with mental health issues. The Government (DoH, 2005) responded by denying that the Orders would be used as a form of social control and rejected the Committee's recommendation to limit the use of the Orders to a small minority of people who pose a significant risk to themselves or others. Therefore, proposals for the reform of mental health legislation remains unchanged since the completion of the research.

In relation to citizenship, the proposals for Mental Health Act Orders constitute even further erosion of civil citizenship rights of mental health service users and indicate an even greater emphasis on surveillance and control (Moncrieff, 2003), thus producing greater tenuousness of community membership. This theme is reiterated in the Government proposals for the development of community services as described in the document 'Modernising Mental Health Services' (DoH, 1998a).

### **'Modernising Mental Health Services'**

On December 8<sup>th</sup> 1998, the then Secretary of State for Health Frank Dobson announced an 'extra' £700 million for mental health services. The way this money is



to be spent is described in 'Modernising Mental Health Services'. The stated aims of reform of community mental health service provision are to improve mental health care and to increase public confidence in services. The second aim reflects the Government's response to public pressure for containment of mental health service users. The executive summary of the document contains the statement:

There is a relation between active mental illness and violence (DoH, 1998a: 2).

This assertion is erroneous. Research conducted by Taylor and Gunn (1999) indicates that there has been a 3% annual decrease in instances of violence involving people with mental health problems between 1957 and 1995. However, such evidence is ignored in the following statement delivered by Frank Dobson in the foreword to the document:

Care in the community has failed because, while it improved the treatment of many people who were mentally ill, it left far too many walking the streets, often at risk to themselves and a nuisance to others. A small but *significant [my emphasis]* minority have been a threat to others or themselves (DoH, 1998a: 60).

The 'failure' of community care is attributed to the emergence of a group of seriously-ill, difficult-to-engage people in need of long-term care (schizophrenics are cited as an example); over-burdened families; under-funding; problems of staff recruitment and retention; treatments not reaching those who need them; an archaic legislative framework unsuited to the demands of community care; mental health legislation unable to deal with anti-social personality disorder and inadequate provision of community services.

However, Barham states:

Those who appear determined to show that community care policies have failed are frequently those who find the challenges of a more egalitarian mental health culture distasteful and threatening (Barham, 1997: 151).

Furthermore, Leff (2001) argued that the 'community care has failed' discourse is erroneous because deinstitutionalisation has not caused homelessness nor increased violence by deinstitutionalised patients. Moreover, Thornicroft and Goldberg (1998) argue that community care cannot be deemed to have failed because it has not been fully implemented due to the narrow range of services available in the community.

They also assert that society seeks to minimise risk by incarcerating those thought to pose a risk to society. They attempt to counter such tendencies by reiterating the low level of risk posed to the public by mental health service users. However, they recommend reform of mental health legislation and the targeting of services at the most severely mentally unwell, therefore reflecting reforms advocated by the Government that have been criticised for increasing stigma and reducing civil liberties of mental health service users (Szmukler and Holloway, 2000; Moncrieff, 2003).

The criticism of inadequate community provision is the focus of 'Modernising Mental Health Services' which directs that the extra £700 million be spent on an increased number of inpatient beds, 24-hour staffed beds, assertive outreach, extended secure and forensic provision and increased availability of atypical neuroleptics.

Although Pilgrim, Rogers and Lacey (1993) found that service users express a preference for a broader range of more accessible services, the Government's plans for service development appear to be influenced by the more coercive emphasis of American-style services, especially in relation to compulsory treatment in the community and assertive outreach. Assertive outreach in Britain is based on the assertive community treatment model in America on the basis that the American model has succeeded in reducing inpatient admissions (Wright et al., 2003). The American assertive community treatment model involves intensive community ('in vivo') support for people with 'severe and enduring mental health problems', out-of-hours support and small caseloads shared within a multi-disciplinary team (Fiander et al., 2003). Laurance (2003) describes the American model of assertive outreach as authoritarian and involved in social policing. Moreover, British assertive outreach can either be viewed positively as supporting users in their home environment or negatively as enforcing unwanted intervention (Laurance, 2003). Laurance warns that assertive outreach could emulate the American model in its authoritarianism if it attempts to enforce compliance with medication. Moreover, Coleman (1998) cites the example of an assertive outreach team in Madison, US, who control the social security benefits of clients to ensure compliance with medication; non-compliance leads to the withholding of benefits. A worker at PACT, an assertive outreach team in New Jersey is quoted as stating:

Letting services lapse because of oversight or letting clients be lost because they are tired of being involved is quite unacceptable to the program (quoted in Mosher and Burti, 1989).

In other words, the clients of such services are not allowed to escape their mental patienthood status and become permanent community mental health patients (cf. Barham and Hayward, 1995).

Modernising Mental Health Services is guided by the rubric of “safe”, “sound” and “supportive” services. I would argue that “safe” refers to public safety, “sound” refers to services that are increasingly institutionalised in nature and “supportive” in “building healthier communities” is undermined by the other two descriptors and informed by the atomistic moral authoritarianism of communitarian discourse.

### **The National Service Framework for Mental Health**

One of the main aims of the National Service Framework (DoH, 1999a) is to reduce regional variations in mental health service provision. It places emphasis on national standards and assessments of local needs and in meeting those needs. Local authorities are required to identify gaps in service provision whereby services for people with ‘serious and enduring mental illness’ must be prioritised and only when these needs are met can local authorities begin to meet the needs of people with more common mental health problems. Therefore, there is an implicit distinction made between ‘serious mental illness’ which must be met by provision that emphasises public safety and common mental health problems that occupy much lower priority. Therefore, the Government is prioritising populist concerns for the containment of people with severe mental health problems over the provision of comprehensive and preventative mental health services (Beresford and Croft, 2001).

However, Standard One in the National Service Framework refers to ‘mental health promotion’ and ‘tackling discrimination and social exclusion’. It states that action should be taken to:

Combat discrimination against people with mental health problems and to promote positive images of mental illness (p.8).

This statement is paradoxical given New Labour's emphasis on containment in other policies. Nevertheless, it places an onus on health and local authorities to "promote health and reduce the discrimination and social exclusion associated with mental health problems". The document suggests intervention by agencies in relation to strengthening social networks and communities, introducing holistic forms of treatment such as exercise and stress management and services to support people experiencing stress at work or due to unemployment or parenting responsibilities. It also suggests public education to reduce stigma and support for the mental health needs of homeless populations. However, the emphasis of intervention appears to be individualistic in failing to recognise the structural causes of inequality, although one concession made is in recommending greater use of the Disability Discrimination Act 1995 by employers to reduce discrimination in the workplace. This recommendation fails to acknowledge the low rates of employment amongst disabled people (see Barnes, 1992a).

Standard Five of the National Service Framework describes 'effective services for people with severe mental illness' but presents a convoluted approach to mental health services by claiming the 'proven effectiveness' of neuroleptic medications and blaming relapse on non-compliance with medication, yet also advocates user involvement in care planning and support to access a broad range of services to reduce the impact of social exclusion.

## **Summary**

Pilgrim and Rogers (1997) argue that mental health policy in the late 1990s could either impose a narrow focus on containment *or* initiate a wider debate on the social influences that impact on mental health. The three strands of mental health policy that have been examined demonstrate the adoption of a narrow emphasis on containment and commitment to the biomedical approach to mental health.

Therefore, despite the rhetoric on social inclusion, New Labour's mental health policy serves to exacerbate the existing exclusion of people who use mental health services

and demonstrates that service users exert minimal influence over political decision-making and thus lack full access to political citizenship.

## **Chapter Four: Social Citizenship**

Social citizenship refers to economic welfare and social participation (Marshall, 1992). This is the area in which the interaction between citizenship and social exclusion research is most obvious, social exclusion being the obverse of social participation and membership.

Barham and Hayward (1995) examined the meaning of social participation for mental health service users and found notable commonality of experience of disconnection from mainstream society, marginalisation and social isolation, as exemplified in high levels of unemployment, poverty and little choice in housing (referring to choice of geographical location or who to live with). Barham and Hayward describe the plight of the 'community mental patient' as involving a search for 'personhood' in which the individual attempts to create a meaningful social identity within the context of structural impediments to participation.

I will examine the evidence in this chapter which suggests that within the general context of increasing social exclusion in Britain (Walker, 1997), mental health service users comprise one of the most socially excluded groups in British society. The following chapter is intended to provide only a brief overview of the public institutions from which mental health service users might be excluded. The research described in this thesis aims to elicit indicators of citizenship and social inclusion from interviews with people who use mental health services in order to enable an operationalisation of citizenship as defined by people with mental health problems themselves.

### **Social Exclusion**

It is argued that social exclusion discourse in the 1990s has superseded the poverty discourse prevalent in the 1970s (Evans, 1998) due to the perceived inadequacies of individualistic approaches to poverty in dealing with new conditions associated with economic restructuring and welfare reform since the mid-1970s (Silver, 1994; Room, 1995). The 'new' discourse of social exclusion is thought to reflect the unequal

burden of risk falling on certain social groups as a result of deindustrialisation, globalisation and the resultant restructuring of the labour market (Kennett, 1995).

Social exclusion is deemed a new buzz word(s) in Britain since the ascendancy of New Labour (de Haan, 1998) and is described as "...currently the most fashionable term for describing the form of social division in European advanced capitalist countries" (Byrne, 1997: 27). However, despite being currently fashionable, the seminal use of the concept of social exclusion is attributed to Lenoir (1974) who employed the term to refer to exclusion from the employment-based social security systems of France (Silver, 1994).

The literature concerning the historical development of the concept draws a distinction between Anglo-American definitions of deprivation and European concepts of exclusion. Silver (1994) argues that the definitional distinctions are influenced by conceptualisations of social integration and reflect distinct theoretical perspectives, political ideologies and national discourses that define integration in distinctive ways. Silver suggests the existence of three 'paradigms' directing notions of exclusion.

Firstly, Silver (1994) refers to the 'solidarity' paradigm which is derived from French republican thought and which defines social exclusion as the fracturing of the bond between the individual and society. The approach is influenced by the philosophies of Durkheim and Rousseau, and in particular Durkheim's emphasis on the normative basis of social order founded on a collective consensus whereas exclusion is thought to threaten the consensus by isolating people from the dominant culture (Silver, 1994). Therefore, the republican-based approach to exclusion emphasises the moral and normative aspects of inclusion and the primary responsibility of the State to facilitate inclusion. Interestingly, the solidarity paradigm is presented as a 'third way' between liberalism and socialism and is prominent primarily in France but also across Europe.

Secondly, Silver refers to the 'specialisation' paradigm which exemplifies Anglo-American approaches to exclusion and which argues that exclusion derives from social differentiation and discrimination. Silver defined discrimination within this

paradigm as “the inappropriate exercise of personal tastes or the enforcement of group boundaries that individuals are not free to cross” (Silver, 1994: 556). Therefore, the definition presents an individualistic view of exclusion that contrasts with the institutional definition of discrimination presented by Sayce (1998). Nevertheless, the specialisation paradigm argues that inclusion implies a contractual exchange of rights and obligations, especially the obligation of the able-bodied to engage in paid work (Lister, 1998a). The specialisation paradigm is argued to encompass the apparently disparate philosophies of neoliberalism and social communitarianism.

Finally, Silver refers to the ‘monopoly’ paradigm in which exclusion is thought to derive from powerful group monopolies that exclude certain groups through a process of social closure. Therefore, society is regarded in the monopoly paradigm as comprising hierarchical power relations, following from the Weberian view of power and society. It is not clear where, geographically, this paradigm predominates and appears to be the weak link in Silver’s analysis.

However, Silver’s (1994) discrete differentiation between the paradigms appears erroneous since national discourse is currently influenced by conceptions from each paradigm (de Haan, 1998). For example, although Silver claims that the specialisation paradigm is representative of Anglo-American thought, elements of the solidarity paradigm appear in Tony Blair’s emphasis on adherence to community norms, the necessity of a moral consensus underlying those community norms and the establishment of a national consensus, as exemplified in his ‘one nation’ discourse. The influence of the solidarity paradigm is also witnessed in the emphasis on a ‘third way’ between Conservative neo-liberalism and old-style socialism in British political rhetoric (e.g. Giddens, 1998, 2000).

To reiterate, the definition of social exclusion provided by the Government’s Social Exclusion Unit is as follows:

Social exclusion is a shorthand label for what can happen when individuals or areas suffer a combination of problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown (SEU, 1998).



Therefore, the Government defines social exclusion as involving numerous inter-related problems, linking it to conditions of low socio-economic status. However, writers such as Hutton (1996) and Giddens (1998, 2000) emphasise that studies of social exclusion should recognise the voluntary nature of social exclusion of people in the highest income brackets as they opt out of social participation (e.g. by using private education and private health care). Therefore, the Government's definition of social exclusion pertains to involuntary exclusion at the bottom of the social hierarchy, thus exposing itself to accusations of blaming the poor for their exclusion.

Levitas (1998) indicates the hegemonic nature of discourse that employs terms such as 'social cohesion' and 'solidarity' due to moral judgements made concerning the alleged behavioural and moral deficits of an excluded 'underclass' (Evans, 1998). New Labour's conceptualisation of exclusion obscures inequalities in the labour market, over-emphasises inclusion through paid work (despite claims of the multi-dimensional nature of exclusion) and fails to address the fundamental inequalities of the capitalist system (Levitas, 1998). Indeed, New Labour's 'third way' argues for a modernisation of socialism that not only accepts capitalism as inevitable, but also appraises it as beneficial in encouraging national competitiveness in the global marketplace (Giddens, 2000).

Levitas (1998) questions whether inclusion which is interpreted as inclusion into the capitalist system would be beneficial, therefore questioning the assumption of much social exclusion theorising that inclusion is beneficial and a legitimate aim for governments. Indeed, Byrne (1997) argues that exclusion is beneficial to a capitalist system in preserving a reserve army of labour, thus being reminiscent of Warner's (1987) analysis of the labour market location of people with psychiatric diagnoses as a reserve army of labour, likely only to be employed in times of labour shortage. Nevertheless, the importance of the analysis produced by Levitas (1998) is to emphasise the prevalence of exclusion among those in paid work due to low pay, thus refuting New Labour's strategy of achieving social inclusion by coercing people into paid employment by the use of welfare-to-work schemes.

Numerous studies identify the key defining factor in social exclusion is its multi-dimensional nature (Kennett, 1995; Golding, 1995; MacPherson, 1997). De Haan

(1998) argues that social exclusion definitions converge on suggesting the multi-dimensional nature of the concept as being the opposite of social integration. Social exclusion is also defined as involving deprivation of significant duration and marginalisation from mainstream society (Golding, 1995). However, Ratcliffe (1999) argues that the meaning of social inclusion is ambiguous given the difficulty of defining mainstream society. He also argues that social exclusion is an ill-defined term, lacking in theoretical precision and running the risk of representing “crass sloganeering” (p.2). He argues that the term tends to be used uncritically without specification of whether the concept refers to a socio-economic process, discrimination, an outcome, or is meant in a particularistic or universalistic sense. For instance, use in a particularistic sense depicts a dichotomy between the included and the excluded in relation to specific institutions (e.g. the labour market, housing) whereas the universalistic sense refers to the exclusion of entire groups that are located on the margins of society (e.g. the ‘underclass’). Ratcliffe argues that a more subtle use of the concept would relate social exclusion to the broader concept of citizenship in order to extend analysis beyond economic aspects of social exclusion.

Walker (1997) postulates an explicit link between social exclusion and citizenship by claiming:

Social exclusion...may be seen as the denial (or non-realisation) of the civil, political and social rights of citizenship (p.8).

By arguing that people with mental health problems constitute a group who are located on the margins of society, a universalistic interpretation of social exclusion is suggested. However, such an analysis runs the risk of constructing an entire class of non-citizens subject to the stigmatisation associated with the concept of an underclass. It is important to consider whether people with psychiatric diagnoses constitute a sub-group within the underclass (Lewis et al., 1989) and whether such an analysis would simply reproduce existing discrimination.

Nevertheless, Dunn (1999) conducted a large-scale inquiry into social exclusion affecting people with mental health problems by hearing evidence from a broad range of individuals and organisations. The Inquiry found exclusion “in every sphere

of public and private life” (p.3) and ascribed exclusion to prejudice and discrimination rather than to mental health problems.

The remainder of this chapter will examine evidence indicating exclusion of people who use mental health services from a wide range of institutions in public life; therefore examining whether people with mental health problems constitute a discrete group located on the margins of society, sharing common experience of impediments to social participation. Therefore, the current analysis combines the particularistic and universalistic orientations referred to by Ratcliffe (1999).

## **Employment**

Much research on employment in relation to people with mental health problems examines the psychological sequelae of unemployment. For example, Warr and Jackson (1984) estimate that 20-30% of unemployed men reported deterioration in their mental health since becoming unemployed, especially increased anxiety, depression, insomnia, lack of confidence and lack of energy. However, other research emphasises the high rates of unemployment amongst people with mental health problems. For example, Sayce (2000) indicated that, in the late 1990s, 70-90% of Britons with a diagnosed mental health problem were economically inactive; the rate is higher for black mental health service users and mentally disordered offenders. The direction of causality appears to flow in both directions: unemployment renders people more vulnerable to mental health problems (Mullen et al., 1998; Perkins and Silver, 1994; Anthony et al., 1995; Link et al., 1997) and mental health problems render people more vulnerable to unemployment due to employer rejection (Read and Baker, 1996) and discrimination in the workplace (Dunn, 1999).

Explanations of such findings differ. For instance, Hutchins and Gower (1993) argue that mental health problems might impede job seeking, although they fail to explain how this might occur. Midgley (1990) critiques such individualistic hypotheses by indicating the prevalence of employment discrimination experienced by people with mental health problems. Midgley argues that people with mental health problems

might be disadvantaged in the labour market by rejection in job applications, unfair dismissal and denial of promotion.

Boardman et al. (2003) argue that the majority of people with mental health problems want to work, which they define as 'activity done for others' and as distinct from employment which is defined as paid work. They link lack of employment to social exclusion in that unemployment means denial of the opportunity to participate in society as an ordinary citizen. Most research appears to refer to paid work but fails to specify the distinction made by Boardman et al. between work and employment. Nevertheless, work, paid or unpaid, is associated with numerous advantages over lack of work, including personal responsibility, higher self-esteem, structure, distraction from problems, social participation, social contact and productive behaviour (Rowland and Perkins, 1988).

Warr et al. (1988) identified eight major consequences of unemployment: less variety in life, fewer goals, reduced opportunity for decision-making, less practice of skills, psychological disturbance, insecurity, social isolation and diminished social status. However, Stansfield (2002) indicated that employment could have negative consequences for mental health if it involves a high level of stress and a low level of control (known as the 'job strain model') or a high level of effort for low reward ('effort-reward imbalance'). However, Stansfield also indicated that support from work colleagues and personality can serve as protective factors, although he fails to examine whether people with mental health problems are less likely to receive support from work colleagues due to prejudice or discrimination.

In summary, research emphasises intervention either on an individual level (on the supply side of the economy) by providing assistance with job seeking (e.g. Hutchins and Gower, 1993) or provision of employment support from community mental health teams (Boardman et al., 2003) or on a structural level (on the demand side of the economy) by addressing employment discrimination directed at people with mental health problems (e.g. Midgley, 1990).

## **Poverty**

Lister (1990a) has argued that debates on poverty should be central to discussions of citizenship due to the inter-dependent relationship between civil, political and social citizenship rights. However, poverty is a contested concept, involving a range of definitions and measurements.

Poverty research has postulated a fundamental dichotomy between absolute and relative definitions of poverty. Absolute poverty refers to falling below a level of income required to meet basic physical needs whereas relative poverty is defined as falling below an average standard of living (Alcock, 1997). Townsend (1979) is particularly associated with the development of relative definitions whereby he examined exclusion from everyday life and proposed measurement according to key indicators of deprivation. The relative definition of poverty was developed due to dissatisfaction with absolute definitions due to their negation of social norms and due to their prescriptiveness based on expert definitions of basic needs (Gordon, 2000). However, the dichotomy has been regarded as an over-simplification because even absolute standards inevitably refer to social norms that vary across place and time (Alcock, 1997).

An additional definition of relative poverty was proposed by the United Nations (1995) in which 'overall poverty' referred to a lack of resources and opportunities to engage in taken-for-granted activities due to lack of material resources or due to discrimination (Gordon, 2000).

A number of approaches to the measurement of poverty exist that are clearly influenced by the definition adopted in relation to the concept of poverty. Recent approaches have examined the level of income required to live adequately. One method is to calculate the median income for Britain and examine individuals' or groups' incomes in relation to a certain percentage of the median income. Flaherty, Veit-Wilson and Dornan (2004) estimate that poverty is 60% of the current median income level. This is referred to as 'income poverty'. An additional method is to establish a list of essential items and measure poverty according to lacking in certain

items. This is the approach adopted by the Poverty and Social Exclusion (PSE) survey and is referred to as the 'deprivation indicator' approach (Gordon, 2000) or the 'budget standards' approach (Alcock, 1997). Lacking in three or more items on the list indicates poverty but is based on a very frugal standard of living (Alcock, 1997). The same criticism is directed at approaches which measure poverty according to income support levels because such levels are designed to meet only the most basic of needs and thus are no longer used to measure poverty (Flaherty, Veit-Wilson and Dornan, 2004).

Gordon (2000) estimates that £178 per week is required to avoid absolute poverty and £219 per week is required to avoid relative poverty. Therefore, income below these levels is thought to place the individual at high risk of poverty. Flaherty, Veit-Wilson and Dornan (2004) indicate that, in 2001-2, 22% of the British population were living 60% or more below the median income level in comparison with 13% in 1979. They note that 26% of the population were living at this level at the end of 1999. Therefore, there has been a significant increase in income poverty since 1979 but a slight decrease in poverty since 2000. In addition, between 1979 and 2002, the number of incapacity benefit claimants trebled to 2.7 million. There has also been an increase in the number of people claiming means tested benefits from 17% in 1979 to 25% in 1999.

A number of social groups have been identified as being at high risk of poverty (Flaherty, Veit-Wilson and Dornan, 2004). Unemployment is the predominant indicator of income poverty: 75% of the poor are unemployed. The long-term sick are second most likely to be poor, 63% of whom are poor. 20% of the poor are disabled, according to the PSE. The employment rate for disabled people is 46% for women and 51.4% for men in comparison with 75.3% of non-disabled women and 85.8% of able-bodied men. Therefore, the unemployment rate is twice as high for disabled people than the non-disabled population. However, people with mental health problems experience the highest rates of poverty amongst disabled people; 74% in comparison with 66% for people with a learning disability (Flaherty, Veit-Wilson and Dornan, 2004). In addition, one third of disabled people who move into employment will be unemployed by the following year (Flaherty, Veit-Wilson and Dornan, 2004). Unemployment is strongly associated with poverty. Flaherty, Veit-

Wilson and Dornan claim that disabled people are more likely to experience poverty because they are likely to lack formal qualifications; endure disability-related expenses (e.g. heating, transport, paying for care); be employed in manual and low paid jobs and live in social housing. Disabled people are also more likely to be excluded from the labour market by discrimination derived from employers' expectations of incapacity and unreliability and due to structural obstacles to participation (e.g. access to buildings, lack of flexible working, ect.) (Alcock, 1997) and earn an average of 25% less than their non-disabled counterparts (Martin and White, 1998). Disabled people are also more likely to be caught in the 'benefits trap' caused by low pay and entry into the incapacitated role in order to continue to receive disability benefits (Alcock, 1997). Alcock does not appear to be suggesting that disabled people want to be considered incapacitated but that the disability benefits system demands that claimants prove their incapacity to work and thus reinforces the view of the disabled person as incapable of working. However, Alcock asserts that poverty is not an inherent accompaniment to disability because the problems that disabled people experience in entering the labour market are socially produced. This view is comparable to the social model of disability in which impediments to social participation are structural rather than inherent within the individual (Oliver, 1996).

Women also run a high risk of experiencing poverty (Alcock, 1997), being 14 times more likely to experience poverty than men (Flaherty, Veit-Wilson and Dornan, 2004). This has been attributed to the concentration of women in low paid, part-time or insecure occupations; exclusion from contribution-based benefits due to periods of absence from the labour market and due to the competing demands of caring responsibilities that dictate the type of working patterns available to women and which influence attitudes that regard women as financially dependent on men (Flaherty, Veit-Wilson and Dornan, 2004). Lone parents are particularly at high risk of experiencing poverty in that only 53% are engaged in paid work (Flaherty, Veit-Wilson and Dornan, 2004) and 90% of lone parents are women (Alcock, 1997). Lone parent poverty has been attributed to sole financial responsibility for running the home and the sole responsibility for the expense of childcare (Flaherty, Veit-Wilson and Dornan, 2004).

Ethnic minorities are also at high risk of experiencing poverty. Only 58% of people from ethnic minorities are engaged in paid work compared with 76% of white people. People of Pakistani or Bangladeshi origin are least likely to be employed and most likely to be poor (Flaherty, Veit-Wilson and Dornan, 2004). The reasons postulated for this higher risk of poverty is that ethnic minority people were previously likely to be employed in the heavy industries that were severely affected by the recession beginning in the 1970s and thus have borne the brunt of unemployment (Flaherty, Veit-Wilson and Dornan, 2004). Ethnic minorities are also more likely than white people to be poorly paid and to work part-time, with Pakistani and Bangladeshi people being the lowest paid of all full-time workers in Britain (Flaherty, Veit-Wilson and Dornan, 2004). Asylum seekers are the social group most likely to experience extreme poverty due to restrictions on benefit entitlements (Alcock, 1997).

Researchers appear to argue that most poverty is short-term (Room, 2000; Flaherty, Veit-Wilson and Dornan, 2004), although they fail to define the division between short-term and long-term poverty. Flaherty, Veit-Wilson and Dornan claim that 62% of people escape poverty by obtaining employment. However, if the unemployment rate of disabled people is twice that of non-disabled people and one third of disabled people return to unemployment within one year of obtaining work, this may suggest that their exclusion from the labour market leads to periods of chronic poverty.

Focus on Mental Health (2001) conducted a survey of the experiences of poverty amongst people with mental health problems, with a total of 556 respondents. 47% of the sample were unemployed and 85% were in receipt of benefits. 72% described their income as low and 66% reported experiencing problems making their income last all week, representing 68% of those on benefits. 50% of respondents stated that they felt excluded from the local community by their financial circumstances. An interesting finding was that 70% of Asian respondents (although the percentage of the total number of respondents that were Asian is not specified) felt excluded by their financial situation. Low income impacted on respondents' abilities to access mental health services, especially due to the cost of transport and childcare. Respondents also reported a lack of basic items such as food and clothing and as not being able to pay utility bills. Respondents suggested that the impact of poverty



could be ameliorated by an increase in benefit levels, greater ease of application for benefits, especially Disability Living Allowance, and greater availability of concessionary access to facilities. The report concluded that people with mental health problems are doubly excluded, by mental ill health and by poverty.

Poverty is strongly associated with unemployment and is a major determinant of social participation, for example, participation in the consumer society and in leisure activities. Hutton (1996) argued that income is the key determinant of citizenship, although as an economist this assertion is perhaps unsurprising. He states:

...the capacity to be a citizen depends on spending power, without which citizenship disappears (p.218). (see also Lister, 1990).

In a consumer society, consumption is the norm and low income severely impedes participation in consumption (Bauman, 1998). However, Beresford (1996) argues that such an analysis is problematic in imposing dominant values associated with the consumerist ethos in that consumerist values may not be aspired to and that poverty extends beyond material deprivation. He argues that conventional debates on poverty effectively emphasise the dependence of disabled people as inevitably reliant on state benefits and tend to adopt an individualistic emphasis rather than examining poverty as the broad denial of citizenship rights.

Beresford et al (1999) also critique traditional poverty analysis for excluding poor people from the process of defining poverty, therefore presenting an argument for the inclusion of poor people's definitions of poverty in qualitative research.

## **Housing**

The majority of research into the housing experiences of people with mental health problems examines whether such people are more likely to be homeless than other members of the population. A smaller amount of research examines the process of deinstitutionalisation in comparing the experiences of long-stay hospital residents and those transferred from long-stay institutions to small group homes.

Estimates of homelessness amongst people with psychiatric illness vary widely from 15% (Snow et al., 1986) to 91% (Bassuk, Rubin and Lauriat, 1984) but most studies provide estimates of around 30% (e.g. Bean, Stefl and Howe, 1987; Piliavin, Westerfelt and Elliot, 1989; Bines, 1997). The reason estimates vary so widely is that studies adopt differing definitions of homelessness and mental illness. The study that provided an estimate of 91% (Bassuk, Rubin and Lauriat, 1984) included emotional and psychological problems in its statistics. The finding is confounded by the question of whether mental health problems precede or follow homelessness (Bines, 1997) and thus it is difficult to specify whether mental health problems cause homelessness or whether psychological sequelae are an inevitable consequence of homelessness (Bean, Stefl and Howe, 1987). Marshall and Reed (1992) found that psychiatric admissions had preceded homelessness in their sample.

Another problem with homelessness research is that some studies assess the presence of mental health problems using instruments that conflate psychiatric symptoms and behavioural manifestations of homelessness (e.g. dirty clothes, poor hygiene and flattened affect: Bean, Stefl and Howe, 1987). Moreover, Bean, Stefl and Howe indicate that their estimate of 31% is lower than in other studies due to sampling from a rural population. Studies presenting higher estimates of homelessness amongst the mentally unwell tend to sample respondents from urban populations (e.g. 40% in Westminster: Fisher et al, 1994) and urban areas have been found to feature greater numbers of mentally unwell homeless people (Burrows, 1997). Similarly, a number of studies have indicated the co-existence of homelessness, mental health problems and other forms of social adversity such as unemployment, poverty, lack of social support, poor physical health and high levels of substance misuse (Scott, 1993).

The risk of homelessness is highest for black people (although lower among Indian, Pakistani and Bangladeshi people), lone parents and single males (Burrows, 1997), although women are more likely to comprise the 'hidden homeless' (defined as inhabiting temporary accommodation) (Scott, 1993). The female homeless are more likely to have been married and have children, thus indicating greater social stability prior to homelessness (Marshall and Reed, 1992). However, there is disagreement about whether homeless women are more or less likely to have mental health

problems in comparison with homeless men. Scott (1993) argued that homeless women are less likely to have mental health problems whereas Fisher et al. (1994) argued that homeless women are more likely to experience mental health problems in the over 30 years age group. The typical picture of homeless mentally unwell females in Marshall and Reed's study was early psychiatric hospitalisation, followed by stable housing but low skill employment, followed by numerous subsequent admissions and eventual loss of housing after the age of 30 years. This picture indicates the potential impact of psychiatric hospitalisation on housing for women (and probably men) with mental health problems.

One possible explanation of a link between mental health problems and homelessness is the finding of transience in samples of homeless people with mental health problems. Caton and Goldstein (1984) found a high level of transience in a one-year longitudinal study of people diagnosed with schizophrenia. Transience was defined as at least one change in housing in the previous year whereby 50% met this criterion and 21% had changed accommodation at least twice in the previous year. Their study concluded that psychiatric hospitalisation leads to loss of housing through repeated admissions. Their finding that the highest likelihood of a change of housing was within three months of hospital discharge might indicate poor discharge planning.

Deinstitutionalisation has also been cited as a cause of elevated rates of homelessness among people with mental health problems (Lamb, 1990) whereas Cohen and Thompson (1992) claim that the deinstitutionalisation argument is erroneous due to the time lapse between the beginnings of deinstitutionalisation in the US and in the 1950s and steep increases in homelessness from the end of the 1970s onwards, largely due to a decline in the post-industrial economies of the West that has led to less availability of affordable housing and rendered certain social groups more vulnerable to poverty and homelessness (Mossman, 1997). Indeed, Bohanon (1991) found that higher rents and higher rates of unemployment were correlated with rates of homelessness in 60 cities across the US. Therefore, it is postulated that homelessness is an economic rather than an individual problem. Moreover, Hamid, Wykes and Stansfield (1993) claim that the 'mentally ill homeless' argument is employed merely to discredit community care.

Cohen and Thompson (1992) offer a structural analysis of homelessness that blames increasing rates of homelessness on a decrease in affordable housing, low pay, stigma and victimisation. However, they also claim that the mentally ill do not constitute a discrete subgroup within the homeless population because they are subject to the same socio-economic forces that cause homelessness. They also fail to adequately explore whether people with mental health problems are disproportionately disadvantaged by such socio-economic conditions. Research on income and employment suggests that people with mental health problems are disproportionately disadvantaged in relation to income and employment. Rowe et al. (2001) argue that the mentally unwell homeless are non-citizens due to the dual impact of mental health problems and homelessness. However, they also suggest that assertive outreach interventions are likely to enhance citizenship by promoting community involvement. Their analysis is incongruous because researchers who adopt an individualistic emphasis in their work tend to recommend assertive outreach as a response to homelessness amongst people with mental health problems but also recommend removal of this population through involuntary outpatient treatment (e.g. Lamb, 1990) on the assumption that people with mental health problems are incapable of maintaining independent housing (see Dilks, 1995). Assertive outreach has also been recommended to encourage engagement in general medical and mental health services due to low levels of engagement in such services by the homeless (Scott, 1993).

The other branch of research into housing and mental health compares community integration and perceived quality of life of long-stay hospital patients and those residing in small group homes. Leff and Trieman (2000) found higher levels of satisfaction amongst residents of care homes than long-stay patients but Lewis and Trieman (1995) discovered that people residing in residential care homes were not engaged in rehabilitation and did not access community facilities. They concluded that low turnover of residents and lack of rehabilitation indicated that such homes were intended to be homes for life. Similarly, Shepherd et al. (1996) concluded in their study of care home residents that some homes retained the restrictive features of larger institutions.

## **Social Networks**

The social networks of people with mental health problems have been found to be smaller than 'normal' social networks and tend to comprise other mental health service users rather than comprising a combination of different types of social contacts. Albert et al. (1998) found dependent relationships with other service users were common and likely to produce poorer clinical outcomes (Holmes-Eber and Riger, 1990). However, Chamberlin (1988) argued that having social network members who also use mental health services could be a source of mutual support derived from shared experiences. Nevertheless, a social network that comprises solely of mental health service users may indicate a combination of social isolation and social rejection by non-mental health service users.

Estroff (1981) found that users of an assertive outreach programme (PACT) made a basic distinction between 'crazies' and 'normies', the latter being people who do not experience mental health problems, thus indicating a them-and-us dichotomy. Insiders and outsiders was an additional distinction made by the service users in that insiders were people with whom the clients shared resources and intimacies, information, time and space whereas outsiders were people with whom PACT clients had either cursory or indirect contact with minimal, if any, sharing of resources.

A further distinction made was between 'inside crazies', 'outside crazies', 'inside normals' and 'outside normals'. Each category referred to a degree of symmetry in relationships whereby relationships with inside and outside normals were asymmetrical because normals determined access to resources. Inside crazies shared experience of illness and treatment and had similar access to resources (money, living space and unemployment). Outside crazies were simply people with mental health problems who did not share resources or interactions with the PACT clients. Inside normals were family members and staff with whom the PACT users shared resources but in an asymmetrical manner. Estroff observed that inside crazies were not regarded as able to provide true friendship and emotional support but this finding is refuted by research conducted by the Mental Health Foundation (2000) which found that friendships with other users are valued due to mutual support in such

relationships. The research found that people were most likely to value contact with mental health professionals if they lived alone or experienced familial conflict, thus suggesting a link between social isolation and evaluation of the role of professionals in the social networks of mental health service users. Estroff (1981) found that friendships with 'normals' was rare and attributed this finding to feelings of inadequacy that PACT clients felt in relation to people without mental illness. She suggests that clients actively chose to relate to other 'crazies' and thus were not passive victims of social rejection, as suggested by research examining public attitudes. Estroff also argued that the patterns of social relationships of mental health service users serve to reinforce the mental patient role by reminding the individual of their inadequacies in relation to 'normals' and commonality with 'crazies'.

However, 'Strategies for Living' (Mental Health Foundation, 2000) suggested that the social networks of mental health service users are likely to be smaller due to negative public attitudes and because of social withdrawal associated with illness and the impact of poverty and unemployment on opportunities to develop social relationships. The research found that service users were more likely to socialise with other mental health service users due to the greater commonality and sense of identity that this entails.

Similarly, Green et al. (2002) found that the social networks of mental health service users mainly comprised family, professionals and other service users whereby loneliness was a common problem due to small network size and asymmetrical social relationships. Friends known prior to illness were more likely to drift away rather than reject the service user outright but respondents also indicated social withdrawal following illness and the negative impact of medication on the ability to socialise. Hospitalisation also disrupted social relationships through the removal of the individual from the community (Green et al., 2002).

However, research on the social networks of people with mental health problems encounters significant methodological problems in possibly failing to reach the most socially isolated by virtue of their isolation (Rose, 2001) and an emphasis on quantitative aspects of networks fails to examine the quality of social relationships within those networks (Green et al, 2002).

## **Parenting**

Sayce (2000) identifies a common belief that people with mental health problems do not make good parents. Read and Baker (1996), for example, found that 48% of female respondents and 26% of male respondents with mental health problems felt that their parenting abilities had been unreasonably questioned.

There exists a large body of literature that indicates the potential harm posed by mentally unwell parents to their children. However, Sayce (1999) claims that there exists an entrenched stereotype that people with mental health problems are incapable of providing adequate parenting whereas she depicts parenting as a basic citizenship right that should be available to all. She argues that the application of anti-discrimination principles demands that parents with a mental health problem should not have to meet higher standards in order to prove the adequacy of their parenting. However, literature on the impact of a mental health problem on parenting appears predominantly pessimistic. Such literature almost unanimously assumes that parents with a mental health problem are incapable of providing adequate parenting.

For example, Pound (1996) argues that children learn social norms from their parents whereby depressed parents may withdraw from social networks and experience resultant social isolation, producing inadequate opportunities for modelling of appropriate social interaction by parents (Hall, 1996). However, Webster (1992) associated poor social support networks of mentally unwell parents with high levels of unemployment. Similarly, Pound (1996) argues that high levels of emotional and behavioural disturbance in children of mentally unwell parents are difficult to attribute to depression due to high co-occurrence of poor social environments. Rutter and Quinton (1984) claimed that children of parents with mental health problems are more likely to be exposed to disturbed behaviour, hostility and anxious or depressed behaviour, principally associated with high rates of marital discord in such families (see also Hall, 1996). They indicated that when such risk factors were controlled, high rates of childhood emotional and behavioural disturbance were eliminated. They also noted that behavioural disturbances in children may elicit higher rates of hostility from parents and thus the direction of causality is ambiguous. Hall (1996)

found that mentally unwell parents were twice as likely as well parents to be single parents and more likely to experience marital discord and recent separation. However, controlling psychosocial disadvantage between an experimental and a control group produced similar rates of behavioural disturbance in the children in the study.

Beck-Sander (1999) argues that the social withdrawal associated with depression may produce over-dependence in the relationship between parent and child and that depressed parents fail to provide adequate stimulation for their children due to reduced motivation associated with illness. She argues that an assessment of the risks posed to the child should include questions relating to whether the parent is compliant with medication and whether the parent can monitor symptoms and seek help when necessary. However, research exists that indicates the potentially harmful impact of services on parenting amongst people with mental health problems (Phillips and Hugman, 1999).

Weir (1999) argues that services are faced with a dilemma between protecting the right of children to receive adequate care and the needs of parents with a mental health problem. However, Sayce (1999) counters that this argument negates the shared interests of children and parents. Sayce argues that research and practice must acknowledge the difficulties people with mental health problems might experience in their parenting role but that generalisations on the inadequacy of parenting are potentially very damaging for parents and children. Furthermore, children of socially disadvantaged and mentally unwell parents are most likely to be placed in local authority care (Webster, 1990), children with a mentally unwell parent remain in foster care for longer periods than other children (Adcock, 1996) and the chances of returning home are significantly reduced with longer substitute care placements (Milham et al, 1985).

Moreover, Cohler, Scott and Musick (1996) indicate that changes in adult service provision from long-term care to short-term crisis provision leads to a higher number of repeated psychiatric hospitalisations, thus producing greater disruption to the child's continuity of care. However, regardless of length of stay, psychiatric hospitalisation invariably disrupts contact between parent and child, therefore



leading to the question of whether institutional treatment is at least as detrimental to the child as living with a mentally unwell parent. Indeed, Turner (1993) (who is a mother with a diagnosis of schizophrenia) argues:

Rather than dump their children into foster homes, it seems more humane and efficient to help people with schizophrenia to learn to deal with the situation of raising kids while dealing with long-term illness.

Parker (1999) argues that parents with mental health problems face discrimination in the provision of mental health services, indicating that both inpatient and outpatient services rarely have facilities to accommodate children and that caring responsibilities may exclude parents from day services, psychotherapy or counselling. Phillips and Hugman (1999) interviewed 24 parents with mental health problems and identified loss as a recurring theme in parenting. Loss was associated with loss of the parenting role through hospitalisation, side effects of medication, attachment of stigma to the child and loss of authority as the parent due to a blemished status as a mental health service user. Parents regarded professionals as intrusive and as providing an unwelcome service. They were also regarded as emphasising pathology and as neglecting practical issues such as housing and benefits. The participants expressed a desire for greater practical support at home and more child-friendly services. Sayce (1999) argues that parents might mistrust services due to the fear of losing their children and thus unsupportive services might be a barrier to help seeking amongst parents with mental health problems.

Therefore, discrimination appears prevalent in both professional attitudes towards the ability of parents with a mental disorder to provide 'good enough parenting' and in the practice of either removing parents from children through hospitalisation or removing children from parents in the higher use of substitute care than in comparison with the children of other parents.

### **Mental Health Services**

Marshall (1992) argued that state welfare services enable the realisation of social citizenship by moderating the inequality caused by a capitalist economy. However, he later conceded that welfare services might impede citizenship through their

paternalistic and authoritarian nature (Marshall, 1981). For example, impediments to community participation have been attributed to the institutional nature of welfare services that reflect limited expectations of service users by welfare professionals (Barnes, 1992a). Social citizenship concerns access to valued resources in the community. However, mental health services might impede social citizenship due to medication-induced impediments to functioning, removal from the social environment by inpatient treatment and by the imposition of diagnoses that attract stigma. The evidence supporting this assertion will be examined in the following section.

The psychiatric system is based on the medical model (Parker et al., 1995) in which pathology is individualised, attributed to biological causes and is deemed incurable but treatable with medical intervention (see Corrigan and Penn, 1997). The medical model will be examined in terms of diagnosis and treatment of mental ill health.

Boyle (1999) asserts that psychiatric diagnosis claims legitimacy by asserting equivalence with physical medicine but that there is no evidence that symptoms cluster together reliably. Psychiatric diagnosis has also received criticism for locating pathology within the individual (Parker et al., 1995; Kutchins and Kirk, 1997; Boyle, 1999) and as negating the context of symptoms (e.g. the content of voices: Boyle, 1999).

Kutchins and Kirk (1997) argue that diagnostic nosology provides psychiatry with a veneer of scientific respectability by parading as a legitimate branch of medicine. However, psychiatric diagnoses lack the somatic referents that are usually present in physical illness (Bowers, 2000; Johnstone, 2000). Kutchins and Kirk argue that the Diagnostic and Statistical Manual (DSM) attempts to standardise diagnostic practices but fails to increase the reliability of diagnosis. For example, Williams et al. (1992) conducted a seven-centre study in America and Germany using a standardised interview schedule and DSM-III-R criteria whereby diagnosis still fell below an acceptable standard of reliability. Kutchins and Kirk (1997) also claim that diagnostic systems pathologise everyday behaviour and that diagnoses change over time. Anxiety is cited as exemplifying the latter two claims in that anxiety is a common response to everyday problems and is not inherently pathological. They also

indicate the changeability of diagnoses by highlighting that conceptualisations of anxiety have changed three times since 1979. DSM is also accused of allowing social values to impede its supposed scientific validity. For example, the removal of homosexuality from DSM in 1973 is frequently cited as an example of the influence of social norms on diagnostic nosology. However, Kutchins and Kirk argue that DSM retained some degree of moral conservatism in its inclusion of 'ego-dystonic homosexuality' until 1987.

A number of researchers have indicated the lack of validity of specific diagnoses. Boyle (2002) refers to the schizophrenia diagnosis as a 'conceptual dustbin' into which symptoms not attached to other diagnoses are discarded. Similarly, Pilgrim (2001) refers to the diagnosis of personality disorder as a 'dustbin category' for problematic behaviour that is not otherwise categorised as mental illness. Pilgrim describes personality disorder as a problematic diagnosis due to its lack of somatic indicators. However, this criticism could be levelled at all psychiatric diagnoses (Bowers, 2000).

Foucault (1994) argues that psychiatric power is three-fold in distinguishing competence over ignorance, reality over errors and normality over disorder. The power of the psychiatrist is derived from their constructed rationality in comparison with patients. Patients become discredited by constructions of their incompetence, irrationality and abnormality. Foucault asserts that constructed insanity strips the patient of knowledge and power in relation to illness. Therefore, psychiatrists possess the power not only to define mental illness but also to stipulate treatments for illness in the patient's 'best interests' on the grounds that the patient is incompetent in treatment-related decision-making (Pols, 1989).

The medical model specifies the biochemical view of mental ill health in which illness is attributed to defective neurotransmitter action. For instance, the dopamine theory of schizophrenia states that an excess of dopamine in the brain causes the illness (Bentall, 2003) whereas depression is thought to be caused by a deficiency of serotonin in the brain (Valenstein, 1998) or a deficiency of norepinephrine (Breggin and Cohen, 1999).

Drug companies promote biochemical causal explanations of mental health problems whereby 'magic bullets' are claimed to target specific neurotransmitter abnormalities in specific disorders (Valenstein, 1998). The notion of the 'magic bullet' is claimed to be erroneous because of the unknown number of receptors for each neurotransmitter (Valenstein, 1998) and because drugs affect a broad range of neurotransmitters alongside the target neurotransmitter because the brain is a highly integrated organ (Breggin and Cohen, 1999). Moreover, cause-and-effect in biochemical hypotheses is difficult to establish because the administration of psychopharmacological substances causes chemical imbalances per se (Glenmullen, 2001) due to compensation, sensitisation and tolerance of neuro-chemicals (Valenstein, 1998). For instance, Glenmullen (2001) refers to 'Prozac backlash' whereby the ingestion of serotonin-boosting anti-depressants such as Prozac causes the brain to inhibit re-uptake of serotonin at neurotransmitters, thereby increasing the amount of serotonin in the brain. An increase in serotonin is thought to produce a decrease in dopamine whereby it is the deficiency of dopamine that produces movement disorders sometimes associated with Prozac (Glenmullen, 2001).

The SSRIs (Selective Serotonin Reuptake Inhibitors) are thought to prevent removal of serotonin from synapses to produce increased firing of serotonin neurotransmitters (Breggin and Cohen, 1999). Therefore, the over-stimulation of the serotonin system can produce agitation, anxiety or insomnia (Breggin and Cohen, 1999). Healy (2001) has referred to the 'SSRI suicides' in indicating a possible association between SSRIs and suicide or violence caused by agitation attributed to over-stimulation of the serotonin system. Teicher, Glod and Cole (1990) found preoccupation with suicide in a small sample of subjects (N=6) following administration of Prozac but observed marked improvement following discontinuation of the drug. Healy (2004) observed alarming levels of suicidal ideation in a small sample of healthy volunteers with no history of suicidal ideation whereas the Teicher, Glod and Cole study was possibly flawed by including participants with a history of suicidal ideation.

Probably the most famous case examining a possible association between Prozac and violence occurred in relation to Joseph Wesbecker. Joseph Wesbecker shot twenty work colleagues (fatally injuring six of them), then shot himself dead following treatment with Prozac (Cornwell, 1996). The verdict (in a litigation case brought by

victims and victims' relatives) found in Eli Lilly's favour following a covert settlement which induced the litigants not to introduce damning evidence into the trial (Cornwell, 1996).

Research suggesting an association between Prozac and suicidality is in its infancy but it is clear that evidence is gradually accumulating to suggest adverse effects of anti-depressant medication. By October 1999, the Federal Drugs Agency (FDA) recorded over 2000 Prozac-linked suicides in America but this is likely to be an under-estimation (Healy, 2001). Indeed, even Eli Lilly's randomised controlled drug trials showed suicide rates of 12.5 per 1000 patients compared with 2.5 per 1000 on placebo and 3.8 on other anti-depressants (including the particularly lethal dothiepin) but this data was not published and not reported to the FDA (Healy, 2001). Furthermore, suicidality has been observed at challenge to Prozac (exposure to the drug), to disappear at de-challenge (withdrawal) and to reappear at re-challenge (re-introduction) and this is widely accepted as indicating a strong causal link between a drug and an effect (Healy, 2001).

Problems relating to discontinuation (withdrawal) of anti-depressant medication have also been publicised in recent times. Withdrawal is associated with 'poop out' (Healy, 2004) in which the anti-depressant loses its effect, thus requiring increasing doses to achieve the same effect. Healy also suggests the existence of 'stress syndromes' whereby drug withdrawal causes the brain to seek equilibrium following ingestion of an essentially alien substance. Glenmullen (2001) indicates specific symptoms of withdrawal from anti-depressants by citing common symptoms as involving disequilibrium (dizziness), gastrointestinal disturbance (nausea, vomiting), flu-like symptoms, sensory disturbance (tingling, electrical-shock type sensations) and sleep disturbance. Glenmullen indicates the general problem that withdrawal syndromes are frequently attributed to relapse of illness (see also Lehman, 2001) and thus met with an increase in dosage (Breggin and Cohen, 1999), thus exacerbating problems of physical dependency and increasing the risk of long-term damage (Breggin and Cohen, 1999; Crepaz Keay, 1999).

In addition, psychiatric medication is associated with serious side effects. For instance, the 'chemical cosh' effect of neuroleptics creates a perception in the patient

that the drugs are controlling them and this may explain high rates of non-compliance with neuroleptics (Healy, 1997). Classic side effects of neuroleptics include akinesia (lack of movement), dyskinesia (abnormal movements), dystonia (muscular spasm), tardive dyskinesia (involuntary movements of the mouth and face), akathisia (agitation) and demotivation (lack of interest). Non-dopamine effects include weight gain, dry mouth, stomach upsets, constipation and impairments in sexual functioning (especially a decrease in libido) (Healy, 1997). Classic side effects of anti-depressant medication include sedation or arousal, dry mouth, palpitations, headache, blurred vision, weight gain and nausea (Healy, 1997).

Martensson (1998) indicates the prevalence of disorders such as tardive dyskinesia as caused by the compensatory formation of new nerve cells due to the blocking of dopamine receptors by neuroleptics. Breggin (1993) has argued that neuroleptics cause the equivalent of a chemical lobotomy due to the inhibition of higher-order functions associated with the frontal lobes and that damage to the basal ganglia causes hyperactivity. Furthermore, the visibility of movement disorders can be humiliating and cause social withdrawal and isolation (Estroff, 1981; Breggin and Cohen, 1999). Indeed, Valenstein (1998) argued that chlorpromazine was initially adopted in institutions precisely because of the chemical lobotomy effect that causes detachment and indifference, thus rendering patients easier to 'manage'. The severity of such side effects indicates the toxicity of psychiatric medications (Breggin and Cohen, 1999).

The Joseph Wesbecker case illustrates the unethical behaviour of the pharmaceutical industry. Healy (2004) examines the tactics adopted by pharmaceutical companies to ensure a continuation of their dominance of psychiatric treatment. He describes how the drug companies aggressively promote their products by funding clinical trials; producing articles that are ghost-written by well-known names in the psychiatric profession but which involve the analysis of raw data by the pharmaceutical company; suppressing adverse findings of clinical trials; funding clinicians to speak at conferences and sponsoring trade fairs that promote their products.

The pharmaceutical industry is a multi-million dollar industry, second only to the arms trade (Kutchins and Kirk, 1997), whereby Healy (2004) argues that clinical

trials meet the needs of the industry rather than patients and that drug companies are only accountable to shareholders and not to the public. The failure of the Federal Drugs Agency (FDA) in America to protect the public from hazards associated with medication ingestion has been attributed to the excessive influence of the pharmaceutical industry on the regulation of medications (Healy, 2004). For example, it is alleged that Eli Lilly was aware of marked agitation associated with Prozac ingestion but conspired with the FDA to suppress evidence of a possible link between Prozac and violence (Glenmullen, 2001).

In addition, clinical trials of psychiatric medication have been described as fundamentally flawed due to methodological errors that skew findings in favour of the drug. The clinical trials of Prozac are described as flawed due to the co-administration of benzodiazepines to reduce agitation (Healy, 2004); suicidal ideation was labelled depression (Glenmullen, 2001); people who deteriorated on Prozac were labelled non-responders (Healy, 2004); and trials were conducted on mildly depressed individuals rather than on more severely unwell subjects (Healy, 2004). It is even alleged that Eli Lilly reported data from non-existent participants (Healy, 2004). More general criticisms of clinical trials is of the use of short trial periods (Valenstein, 1998; Healy, 2004), with some trials lasting only 5-6 weeks (Breggin, 1993); drugs are rarely more effective than placebo and positive effects that are observed tend to be time-limited (Breggin and Cohen, 1999); a double blind is difficult to achieve because the side effects of drugs often reveal the treatment group (Breggin and Cohen, 1999); certain types of patients are excluded (Valenstein, 1998), such as the omission of severely depressed patients in trials of Prozac (Healy, 2004); and the minimisation of reported side effects (Valenstein, 1998). Furthermore, research on the biochemical action of psychiatric medication is flawed due to the interference of foreign substances on normal brain functioning (Breggin and Cohen, 1999).

It is also affirmed that neuroleptics act on psychotic symptoms by producing sedation with no specific action on hallucinations or delusions (Breggin and Cohen, 1999) and therefore, the anti-psychotic label is misleading because neuroleptics do not exert a specific anti-psychotic effect (Martensson, 1998).

Martensson (1998) argues that treatment should only be administered if it is in the patient's best interests but asserts that the neurological damage attributed to neuroleptics precludes treatment on the grounds of best interests. The notion that the harm inflicted by treatment outweighs the potential benefits of treatment has led to demands for the banning of neuroleptics (Martensson, 1998) or the emergence of drug-free mental health services (Read, 2000).

In relation to inpatient psychiatric treatment, respondents to the Rogers, Pilgrim and Lacey (1993) survey indicated the paucity of community facilities as alternatives to hospitalisation in times of crisis: only 14.5% were offered alternatives to hospitalisation at such a time. The authors indicate the disruption hospitalisation exerts over community integration in producing a loss of status in the community. Hospitalisation also disrupts continuity of accommodation, employment and social relationships (Estroff, 1981). Rogers' et al. (1993) respondents cited the dehumanisation of enforced treatment in hospital and the brutal attitudes and incidents of abuse involving staff.

The Sainsbury Centre for Mental Health (1998) conducted a survey of 215 psychiatric inpatients and interviewed 112 patients prior to discharge from psychiatric units. The study identified particular problems in relation to lack of therapeutic interventions and lack of activity on wards. Boredom was reported to be very common amongst patients. Dissatisfaction was expressed particularly in relation to lack of freedom, rigid routines, negative staff attitudes and lack of availability of therapeutic intervention and lack of activity on the wards, high readmission rates, poor discharge planning with little involvement of community staff in the process and lack of alternatives to hospital care.

Walton (2000) produced findings that are remarkably similar to the Sainsbury Centre study in their research involving observation of wards by ASW trainees over a nine-year period. The trainees observed high levels of aimlessness and boredom in patients; they also noted the poor physical environment, replete with cigarette smoke and lacking fresh air. Patients suffered from a lack of physical activity alongside overall lack of therapeutic activity. Trainees also observed poor staff-patient relationships, indicated by lack of interaction between patients and nursing staff



whereby nurses spent the majority of their time engaged in administrative tasks away from the patients. This was not due to low staffing levels because the same patterns of interaction were observed on well staffed wards. The author concluded that inpatient admissions failed to meet the needs of patients by adopting a narrow biomedical view of problems and low value placed on patients, as evidenced by lack of interaction between staff and patients.

The dominance of the medical model in inpatient psychiatry is examined by Shaughnessy (2000), the founder of MadPride:

The medical model is in its element in Acute Wards [sic]. Stigmatised labels are handed out like Smarties on a daily basis with no regard to the long-term damage to the self-esteem of the patient. Symptoms of distress are dismissed as illusions.

Shaughnessy highlights the stigma inherent in the medical model that dominates psychiatry. Coleman (1999) argued that recovery involves a basic citizen right to make choices, including the decision to reject psychiatric treatment. However, informed consent is denied by the lack of information provided by psychiatric professionals on treatment (Crepaz Keay, 1999).

Rose (2001) surveyed 500 users on the Care Programme Approach (CPA) about their experiences of inpatient and community mental health care. She found that participants were not provided with sufficient information on the side effects of medication and one third reported being over-medicated and sedated by medication. Lack of information from staff extended to the CPA process and even the identity of the care co-ordinator. The majority of participants reported unpleasant side effects of medication and medication was found to dominate the lives of mental health service users. In relation to participants' experiences of inpatient care, respondents reported lack of interaction with staff and lack of alternatives to hospital in a crisis. Inpatient care was criticised for failing to provide opportunities to engage in meaningful activity and respondents complained of boredom, poor diets and the poor physical environment on wards. Therefore, research on inpatient care and users' experiences of medication present remarkably similar findings.

In summary, Coleman (1999) argued that the psychiatric system is characterised by alienation: alienation from comprehension of one's own experiences because experience becomes colonised by professionals; alienation from comprehension of one's own feelings due to ingestion of deadening drugs; and alienation from society by institutionalised care. Therefore, Marshall's (1992) claim of the equalising effect of state welfare services is clearly erroneous.

## **User Involvement**

Lister (1998a) argues that dissatisfaction with top-down approaches to citizenship has led to demands for greater user involvement in welfare services (see also Ignatieff, 1989; Beresford and Croft, 1989). User involvement is also described as an active form of citizenship that is proactive in demanding equal rights rather than awaiting the passive ascription of rights (Lister, 1997). User involvement is also a form of political citizenship but is included in the chapter concerning social citizenship because user involvement relates to participation in welfare services and Marshall (1992) represented access to state welfare as a key determinant of social citizenship. However, concepts such as 'user involvement' and 'empowerment' have been deemed opportunistic buzz-words (Thompson, 1998) and colonised by professionals (Adams, 1996).

The NHS and Community Care Act 1990 introduced the notion of service users as consumers (Barnes, 1997) whereby the NHS and local social service departments were exposed to market forces by an expanded role for the private and voluntary sectors in service provision. However, the service user is a 'quasi-consumer' due to limited power of exit from services, limited choice between alternatives and no direct purchasing power (Barnes, 1997). In fact, the notion of exit is clearly erroneous for service users subject to the imposition of compulsory powers of detention. Nevertheless, the National Service Framework for mental health argues for greater involvement of users in the development of services (DoH, 1999a).

The market-based conception of user involvement is contrasted with democratic notions of user involvement espoused by the disability movement (Beresford and

Campbell, 1994). However, a number of researchers have argued that the mental health user movement is not a consumer movement but a resistance movement based on opposition to the medical model (Laurance, 2003) or founded on common experiences of oppression (Barnes, 1999) or is a new social movement in comparison with the disability movement (Pilgrim and Hitchman, 1999), which challenges the ascribed inferior status associated with mental health service use (Campbell, 1999).

Beresford (2000a) argues that the successes of the disability movement in achieving anti-discrimination legislation and the establishment of the Disability Rights Commission should encourage a dialogue between psychiatric system survivors and the disability movement on how to advance the civil rights of the former. In contrast to the successes of the disability movement in advancing the civil rights of their members, mental health service users have witnessed a gradual erosion of their civil rights that appears likely to culminate in the introduction of compulsory community treatment orders by the Government.

Nevertheless, the establishment of the disability movement is relevant to mental health service users because it was founded on an objection to the paternalism and disablism of welfare services. It aims to re-conceptualise disability in a rejection of the medicalisation and resultant individualisation of disability. The disability movement was established on the basis of a challenge to the domination of disability organisations by non-disabled people and thus sought to challenge predominant notions of charity and professional determination of disabled people's needs (Campbell, 1997).

The conceptual foundation of the disability movement is a challenge the medical model of disability by asserting the social model. The social model draws a fundamental distinction between impairment ascribed to the individual and disability that is caused by society organised around the demands and needs of the non-disabled population (Oliver, 1990, 1996). Therefore, the disability movement demands societal change rather than individual change through medical intervention.

The disability movement also challenges the 'personal tragedy' model of disability that involves the notion that disability strikes people at random (Oliver, 1996;

Abberley, 1997; Priestley, 1999), thus implying impairment is a negative, undesirable state. The personal tragedy model represents the dominant medical hegemony (Priestley, 1999) or grand theory of disability (Oliver, 1996).

Medical hegemony is prevalent in the Government's (e.g. Frank Dobson: DoH, 1998a, 1998) discourse which is reiterated virtually verbatim in the forewords to *Modernising Mental Health Services* and the *National Service Framework for mental health* and which derive from Dobson's speech in the House of Commons on 8<sup>th</sup> December 1998 in which he states:

Mental illness is as common as asthma...it can leave people without insight into the consequences of their actions, which is very frightening. (Hansard: Col.145) (Dobson, 1998)

Inherent in medical hegemony is the suggestion of chronicity or incurability of mental health problems, thus suggesting that patients must continue to be dependent on medical intervention on a long-term basis. Strauss et al. (1989) assert:

Patients with schizophrenia are often told they have a disease like diabetes. They are told they will have the disease all their lives, that it involves major and permanent functional impairment and that they will have a life-long need for medication (p.131).

The disability movement aims to generate collective conscience recognising the disabled identity as encompassing a discrete social group who occupy an oppressed status in society: oppression derived from medical hegemony (Abberley, 1997) yet which serves to obscure social inequalities (Priestley, 1999). The disability movement seeks to present the obverse of medical hegemony by rejecting stigmatising labels in favour of celebrating differences and creating a shared identity based on the common experience of exclusion, prejudice and discrimination (Shakespeare, 1993). Therefore, the disability movement has developed a 'counter-hegemonic culture' (Priestley, 1999).

In challenging the dominant medical hegemony of disability, disability campaigners have advocated user-run services or greater democratic participation as alternatives to professionally dominated welfare services (Chamberlin, 1988). In addition, user involvement has been described as encompassing a number of forms of self-organisation, ranging from patients' councils to self-help groups or direct action political groups (Peck, Gulliver and Towel, 2002). Nevertheless, user involvement

operates on at least four levels, including on an individual level between professionals and service users in care planning; between users in self-help groups; in the planning of services and in the management of services on a local level (Peck, Gulliver and Towel, 2002).

On an individual level, users have complained of lacking involvement in their care. Peck, Gulliver and Towel (2002) found that 49-60% of their respondents were dissatisfied with the level of involvement in CPA care planning, especially in relation to lack of information on treatment (cf. MHF, 2000) and the CPA process (cf. Rose, 2001).

In relation to self-help groups, Bolzan et al. (2001) depict self-help groups as a challenge to the professional dominance of psychiatric treatment and as an expression of social citizenship that encompasses principles of autonomy (self-help), equality (based on commonality of experience) and democratic participation (mutual support). However, participants in Bolzan et al's study reported a reluctance of professionals to recognise the value of self-help groups, as evidenced by their reluctance to encourage users to attend such groups. The practice of self-help groups enables users to adopt a more active role in 'recovery' than when occupying the status of passive users of mental health services (Bolzan et al, 2001).

In relation to planning of services, research reveals that users are rarely involved at this level (Peck, Gulliver and Towel, 2002) whereby involvement tends to be restricted to the provision of information (Peck, Gulliver and Towel, 2002) or token consultation (Barnes, 1999). Rose (2001) found that users believed that their local user groups lacked influence over local services. In addition, lack of user involvement on a national level can be observed in the increasingly oppressive nature of national mental health policy (Peck, Gulliver and Towel, 2002, Laurance, 2003). The National Institute of Mental Health in England (NIME) (cited in Williamson, 2004) identifies a number of obstacles to the realisation of meaningful user involvement, encompassing lack of information on opportunities for involvement; the time and expense associated with involvement; professionals' ascriptions of lack of credibility of users; lack of resources and expertise in user groups; resistance from

professionals and experiences of mental health services as oppressive as a discouragement for involvement.

Croft and Beresford (1989) claim that user involvement tends to be interpreted in a narrow administrative sense and retains traditional power relations in restricting involvement of users to information provision and consultation. They argue that real involvement would encompass the power of the user to define their own needs. User involvement can also represent a mere public relations exercise in which involvement of users is tokenistic, involving post hoc participation rather than involvement in critical decision-making or the participation of relatively small numbers of users (Croft and Beresford, 1992).

Chamberlin (1988) argued that genuine user involvement excludes professionals because they tend to dominate users' involvement. Therefore, she argued, genuine user involvement encompasses user-run services due to the inability of conventional services to include users effectively. She argued that user-run services are based on voluntary participation, mutual self-help and needs defined by users.

Barnes and Whistow (1994) examined professionals' attitudes to user involvement and identified defensive reactions to challenges to professional dominance and autonomy and ascriptions of complaints by users to a manifestation of illness (such as paranoia). Beresford and Campbell (1994) claim that professionals frequently cite 'lack of representativeness' of users as justifications for negating user involvement (see also Barnes, 1999). Lack of representativeness is employed to undermine users' views and there appears to be a preference for relatively superficial consultation rather than users being involved in crucial decisions (Beresford and Campbell, 1994). Frequent problems with user involvement are cited as encompassing token involvement by a small number of users; involvement of individual users rather than organised groups; a particular failure to involve ethnic minority users and demands for representativeness of users but not of professionals (Beresford and Campbell, 1994).

Therefore, user involvement is problematic when it depends on the support of professionals and there is a danger of colonisation of user involvement by

professionals to meet their own agenda (Williamson, 2004), leading to demands that user involvement extends beyond influencing services (Barnes, 1999) to meaningful social inclusion and citizenship (Campbell, 2001). Moreover, some regard user involvement in services as collusion in an oppressive system and thus reluctance to engage in this form of involvement should be respected (Williamson, 2004). Campbell (2001) argues that the user movement in Britain is currently fragmented due to lack of overall co-ordination. Therefore, he suggests, greater power will be attained by collaborating with the disability movement to provide a more coherent campaigning collective.

### **Summary**

This chapter has considered a broad range of literature which examines, within a social citizenship framework, whether people who use mental health services are subject to social exclusion and therefore to a broad range of social inequalities.

The following chapters describe the research I have conducted to examine the citizenship status of people who use mental health services.

## **Chapter Five: Methodology**

The main research questions were:

1. Do mental health service users occupy the status of citizens?
2. Do mental health service users occupy the status of a socially excluded group?

I sought answers to these questions by conducting a series of in-depth semi-structured interviews with users of mental health services. Therefore, a qualitative methodology was employed to examine the research questions.

### **Qualitative Methodology**

The Mind Inquiry into Social Exclusion (Dunn, 1999) recommends the use of a qualitative methodology in order to examine how ‘multiple discriminations’ interact and how exclusion may develop over time. The question is why would qualitative methodology be most appropriate to examine social inequalities?

Bryman (1996) states that there has been a traditional dichotomy between positivist and interpretative approaches to research. However, Wight Felske (1994) argues that the qualitative paradigm has been superseded by critical social science, which depicts research as a form of social action and argues that critical research is particularly appropriate for the study of issues relating to citizenship (poverty, housing and social exclusion are cited as examples).

Epistemology and the question of the production of legitimate knowledge are of particular importance in the study of marginalised social groups, such as users of mental health services. The question of the possession of knowledge and location of expertise is integral to considerations of the status of people who use mental health services because recognition that users are possessors of expertise on their status and experiences challenges the conventional dominance of ‘experts’ in defining and determining the nature of mental distress. In particular, the user movement espouses the expertise of users to define their experiences (Campbell, 1999) and research that appraises users’



accounts as legitimate challenges the construction of the psychiatric service user as lacking in competence and credibility.

Furthermore, positivism parallels the medical model of psychiatry in its emphasis on a search for objective biochemical causes of mental health problems. Positivist research on disability in particular is said to resemble research on physical illness (Rioux, 1994) by placing an emphasis on a biomedical search for causes and cures, by locating pathology within the individual and by adhering to a positivist methodology of control, quantification and standardisation. Therefore, the adoption of a positivist paradigm would serve to replicate the power relationship between the psychiatrist and patient in the relationship between 'scientist' and 'subject'.

Holstein and Gubrium (1997) refer to a 'new language of qualitative method' that denotes a greater awareness of the mechanisms of knowledge production. Similarly, a 'crisis of representation' (Denzin and Lincoln, 1998) questions the authority of the researcher to construct legitimate knowledge. Holstein and Gubrium (1997) present a typology of the qualitative paradigm as involving a challenge to positivist assumptions, with the aim of understanding social worlds rather than attempting to change them (in the positivist sense of manipulation of variables); questioning taken-for-granted knowledge; emphasising the process of research rather than merely reporting the outcome; and expressing a concern for subjectivity where the researcher inhabits the social world under investigation and thus is also a legitimate focus of attention. The latter point relates to reflexivity in which the researcher examines their influence on the production of research. Finally, Holstein and Gubrium (1997) claim that qualitative research demonstrates a tolerance for ambiguity in contrast to the desire for control and prediction demonstrated by positivist researchers.

However, Ward and Flynn (1994), concurring with Oliver (1992), argue that positivism and qualitative research share the same approach to the 'social relations of research production' (Oliver, 1992). In other words, both retain the researcher's status as the 'expert'. Ward and Flynn refer to a 'new paradigm' of emancipatory research which supplants both positivism and qualitative methodology in emphasising the expertise of participants with the implication of significantly greater participation in the research process and hence, in the production of knowledge. It also implies disabled people as

researchers (Rogers and Palmer-Erbs, 1994), usurping the conventional dominance of non-disabled people in disability research, whereby non-disabled researchers are allies as long as they occupy a subordinate position to disabled researchers (Barnes, 1992b).

Wight Felske (1994) argues that critical social research is an empowering alternative to disempowering quantitative research in its emphasis on research as a form of political action that challenges the societal discrimination of disabled people. The critical social science paradigm postulates that research questions should be generated by disabled people; disabled people should be partners in research production; researchers should share the same value base as participants; dissemination of findings should be accessible to disabled people (suggesting that findings are made available in a range of formats) and knowledge is regarded as a resource available to all (Wight Felske, 1994). The latter point implies that findings should be published in publications associated with disabled people, for example *Openmind*, rather than scientific or professional journals.

It could be argued that participatory research retains the social relations of research production since the researcher retains overall control and ownership of the research findings. Nevertheless, Zarb (1992) argues that participatory research involves the researcher presenting themselves as a resource to be used by participants and places an emphasis on participants as a source of expertise of use to the researcher. However, Zarb (1992) and Oliver (1992) allude to the exploitation and alienation of research participants and thus effective participatory research would initiate a change in the relationship between researcher and participants in which the latter are acknowledged as the experts on disability and as valuable sources of knowledge. It would also imply participation in all stages of research production, from inception to conclusion and dissemination whereby the researcher relinquishes overall control over the research process (Rogers and Palmer-Erbs, 1994). However, most research is conceived by the researcher and therefore involves participants on a relatively post hoc basis.

It is also argued that disability researchers should acknowledge their political obligations by contributing to the disability network rather than treating it solely as a useful resource (Zarb, 1992) or by adopting a campaigning role, using research to highlight discrimination and social inequalities (Ramcharan and Grant, 1994).



However, although participatory research appears to legitimate political involvement of researchers (and thus legitimates eschewing the neutrality of research production), Oliver (1992) argues that research has exerted a minimal effect on policy and the everyday lives of disabled people. This may be due to the detachment of university-based research from the lives of disabled people (Zarb, 1992; Whitmore, 1994) and the pressure for researchers to conform to the expectations of a conservative research community (Barnes, 1996). Bury (1996), in a reply to Barnes (1996), argued that research *is* influential in revealing social inequalities and challenging the status quo. However, the British higher education system is part of the status quo and rarely challenges dominant approaches to knowledge production. For instance, Maclure (1990) argues that political and economic elites protect themselves by controlling knowledge production, as exemplified in positivist bias in research and professionalisation of researchers. However, initiatives such as user-focussed monitoring (Rose et al., 1998; Rose, 2001) and the employment of users as researchers (Mental Health Foundation, 1997, 2000) challenge the notion that only professional researchers can conduct research successfully. Nevertheless, Barnes (1992b) argues that emancipatory research is less politically acceptable than conventional research and its success depends on the researcher's willingness to challenge research institutions.

As Oliver (1992) asserts, much research on disability continues to adhere to 'methodological individualism' in which social problems are located in the individual whereas Barnes (1996) suggests that research should change its emphasis to studying the discrimination inherent in able-bodied society. Moreover, Taylor (1985) argues that professionals are rarely the focus of research because they are more able to erect barriers to scrutiny. Indeed, Rose (2001) reported that some professionals intervened to prevent the participation of their clients in user-focused monitoring of services. My research, in part, turns the spotlight on professionals by examining users' views of the behaviour and attitudes of professionals.

Furthermore, much participatory research has been tokenistic, adopted merely to secure funding and credibility and thus primarily benefits researchers rather than participants (Jahoda, 1980). Maclure (1990) argues:

...at its most commonplace it [participatory research] is weak research derived from a popular ideological agenda.

Having examined some of the problems associated with participatory research, it is useful to examine the feasibility and practical implications of conducting a participatory research project. The first task is to examine the fundamental pre-requisites of participatory research.

Researchers have claimed that conventional research is alienating for disabled people (Oliver, 1992) but has the potential to be empowering, depending on the adoption of a participatory paradigm (Oliver, 1992; Rioux, 1994; Rapp, Shera and Kisthardt, 1993). However, researchers remain the prime beneficiaries of research (Barnes, 1993), exploiting disabled people to advance their careers. The explicit aims of participatory research are to challenge discrimination of disabled people by highlighting social inequalities (Reason, 1994), raising awareness of oppression and forming alliances with marginalised groups (cf. Freire, 1970). Participatory research also challenges the social relations of research production by awarding primacy to experiential knowledge (knowledge based on first-hand experience) over propositional knowledge (knowledge that is not based on direct experience) (Heron, 1981; Reason, 1994).

In terms of the relevance of research to the real world, Reason and Rowan (1981) assert:

...we need to consider not only 'is it right?' but also 'is it useful?' and 'is it illuminating?' (p.243)

In this respect, participatory research aims to include participants in the generation of research questions and by providing feedback following completion of research, in contrast with the 'hit-and-run' approach to research which 'sucks the subject dry and leaves her by the wayside' (Reason and Rowan, 1981: 248). However, Humphries (1997) argues that emancipatory research continues to define legitimate knowledge through reference to a 'metanarrative of emancipation' which argues that the goal of research is prescriptively associated with emancipation, therefore marginalised groups continue to be excluded from defining the goals of research.

The distinction between emancipatory and participatory research is not particularly clear and the two are said to overlap (Beresford et al., 1999). However, emancipatory

research has been described as a set of principles whereas participatory research prescribes rules of the research process (Zarb, 1992). Moreover, participatory research has been deemed more flexible than emancipatory research whereby the former involves participation in the research process and the latter involves control by participants over research (Zarb, 1992). Furthermore, participatory research is thought to be more easily achievable because research is thought to exert relatively little influence over political or material conditions affecting disabled people (Shakespeare, 1996; Zarb, 1992). Nevertheless, emancipatory research aims to be relevant to the lives of disabled people and influential in improving the material conditions of participants (Beresford, 2000b). Furthermore, Barnes and Whistow (1992) indicate that the benefits of research encompass participants' satisfaction with a number of factors, including with altruistic participation, solidarity with other participants, being listened to and exerting influence over services. Therefore, the benefits of research do not necessarily extend to social or political change but can be personally beneficial to participants.

Nevertheless, participatory and emancipatory research are preferable to alternatives due to the politicisation of research; by examining social inequalities; by constructing participants as active producers of knowledge rather than as passive subjects; and by highlighting issues relating to the ownership and production of knowledge about marginalised groups. The question remains, however, on the success of participatory research in changing the social relations of research since researchers appear likely to retain overall control of the research process and ownership of data, prestige and remuneration as a consequence of their status as disseminators of knowledge gained from disabled people.

Given the acknowledged limitations of participatory research and the problems in realising genuine participation, the next question to arise concerns how research can strive to become less exploitative and of more use to disabled people. Firstly, numerous researchers have argued that participants must be involved at every stage of the research process (Reason, 1994), including prior to initiation (Oliver, 1992) through to interpretation and dissemination (Rogers and Palmer-Erbs, 1994). In particular, participants should determine research questions (Wight Felske, 1994; Rogers and Palmer-Erbs, 1994) and participants should exert an influence over methodological decisions (Zarb, 1992).

A strong version of participatory research would suggest that disabled people become researchers (Rogers and Palmer-Erbs, 1994) whereby a professional researcher provides training in research methods, thus their knowledge is treated as a commodity available to disabled people (Ramcharan and Grant, 1994; Barnes, 1992b; Zarb, 1992) and involves the researcher relinquishing the expert role (Rowan and Reason, 1981). A modified version would involve consultation rather than genuine power sharing (Maclure, 1990) and would restrict involvement to providing information and obtaining feedback rather than enabling influence over crucial decisions.

Importantly, it would be impossible to conceive of research into citizenship as undermining the citizenship of research participants. Therefore, a modified version of the participatory approach was adopted to ensure at least a measure of congruence between research aims and methods.

The research described in this thesis aimed to be emancipatory in publicising the experiences of citizenship of people who use mental health services, although this depends on broad dissemination of research findings. The research was participatory in recognising service users as credible reporters of their experiences; it recognised participants' expertise in financial terms by remunerating them for participation (an essential element of involvement in research: Barnes and Whistow, 1992); a small discussion group influenced the construction of a topic guide for use in the individual interviews; and participants were asked to provide feedback on their experience of research participation at the end of the series of individual interviews and were sent a copy of the findings chapter and asked to provide feedback on their views of the findings.

The research was not as participatory as it could have been due to the resource constraints experienced by a lone PhD researcher working with a limited budget, given that participatory research is acknowledged to be more time-consuming and financially expensive than conventional research (Telford and Faulkner, 2004).

## **Grounded Theory**

The previous section indicated problems associated with conventional research. However, the participatory research paradigm is too diverse and ambiguous to suggest methods of data collection since it primarily relates to the conduct of the researcher and the power relationship between the researcher and participants. Some of the features of the grounded theory approach are useful as general guiding principles to research without necessarily being followed in an over-determined manner. In particular, grounded theory is congruent with the aims of participatory research in the development of research questions and conduct of data analysis in accordance with the emerging themes provided by participants. Therefore, this section will examine the grounded theory approach and extract its most useful elements. However, the section begins with a warning that grounded theory must be approached critically due to its retention of some of the preoccupations of the positivist paradigm.

Grounded theory was originally conceived by Glaser and Strauss (1967). It has been described as a post-positivist approach (Denzin and Lincoln, 1998) due to having some aspects in common with positivism yet retaining the basic elements of qualitative research. Grounded theory was developed in an era when researchers remained committed to positivist principles of rigour in research (Seale, 1999). Glaser and Strauss (1967) and Strauss and Corbin (1994) explained the rationale for the development of grounded theory as involving an attempt to produce empirically-based theory as a reaction against positivist imposition of grand theory; to legitimate qualitative research which has traditionally been accused of bias and lack of rigour (Henwood and Pigeon, 1994); and to provide a guide to methods (Strauss and Corbin, 1994; Glaser and Strauss, 1967). Fielding and Lee (1998) describe grounded theory as a 'highly developed approach to qualitative data analysis.' (p.39)

Strauss and Corbin (1998) define theory as:

A set of well-defined categories (e.g. themes, concepts) that are systematically inter-related through statements of relationships to form a theoretical framework. (p.22)

Glaser and Strauss (1967) argue that theory should be derived inductively, directly from data, rather than deductively. Therefore, the emphasis in grounded theory is on theory generation rather than on theory testing. However, Glaser and Strauss (1967) admit to the combination of induction and deduction in theory development through the process of deriving hypotheses inductively and testing them deductively, thus leading to a cycle of induction on the basis of verification. The cyclical nature of grounded theory is termed 'iterative' and is defined as the exploration of new topics whilst retaining the fundamental focus of the research (Rubin and Rubin, 1995).

The inductive approach emphasises a need to avoid imposing a priori assumptions on data interpretation. However, Henwood and Pigeon (1994) ask 'what grounds grounded theory?' and argue that the imposition of prior assumptions on data is inevitable (Henwood and Pigeon, 1995) due to the academic convention of conducting a literature review prior to data collection and the way in which a review of literature is inevitably influenced by cultural assumptions held by the researcher. Henwood and Pigeon (1995) advocate the constructivist version of grounded theory which recognises multiple interpretations and clarifies the researcher's position in relation the interpretation of data (referred to as interpretive validity: Altheide and Johnson, 1998).

'Theory as process' is a central theme of grounded theory (Glaser and Strauss, 1967), implying that theory generation is a continual process, subject to many modifications as data collection progresses. A primary defining characteristic of grounded theory is that data collection, analysis and interpretation is simultaneous in order to enable data collection to be determined by findings from previous data collection, thus the findings are grounded in the data. This process is known as 'theoretical sampling' and suggests that the content of interviews will be changeable, eschewing the standardisation typical of positivist-inclined qualitative data collection. The grounded theory approach advocates data collection until theoretical saturation is reached whereby no additional data will contribute to further theory development or when no new insights are forthcoming (Ezzy, 2002).

Grounded theory has been the subject of a number of criticisms. For instance, Macmillan and McLachlan (1999) argue that grounded theory misrepresents theory development as involving the linking of categories whereas they argue that theory is



defined by its ability to explain rather than merely stipulating relationships between concepts. Moreover, Silverman (2000) questions whether much grounded theory analysis extends beyond merely producing a list of codes.

An additional criticism is that many qualitative researchers adopt grounded theory without grasping the full methodological and epistemological implications of doing so (Bryman, 1988; Fisher, 1995; Denzin, 1998). Furthermore, Denzin (1988) argues that grounded theory is often adopted as an 'ideological weapon' to convince others of the credibility of the research due to its emphasis on rigour and systematic data collection and analysis.

Denzin (1998) claims that grounded theory is often adopted without being fully understood; that the definition of theory is questionable; that there is an over-emphasis on theory development; that there is a problematic affinity with positivism; and that analysis often subordinates participants' explanations to those of the researcher. Finally, Denzin (1988) has also argued that the grounded theory approach has been superseded by the postmodernist approach to research as a reaction against grounded theory's emphasis on scientific credibility. Denzin argues that it is impossible to adopt a subjective interpretive approach on one hand and emphasise scientific canons of credibility on the other.

The commonality with positivism is the most problematic aspect of grounded theory and it is questionable how successful grounded theory is in grounding participants' accounts because the researcher retains overall control over the process. Therefore, although the systematic, procedural character of grounded theory is attractive, the researcher must be aware of the limitations of the grounded theory approach and utilise the creative, flexible aspects of theory development, bearing in mind the advantages of pursuing a participatory research paradigm in order to provide an account grounded in participants' reports.

### **Small Group Discussion**

A small group discussion was conducted in February 2000 and comprised three female mental health service users from London. One participant identified herself as black African-Caribbean and the other two participants were white. All three women were aged approximately between forty and fifty-five years. The group discussion was conducted in a London Mind office. The participants were contacted through a fellow PhD student who had met them previously through her employment as a researcher with Mind in London. The discussion group was conducted in a loosely structured way whereby the group members were almost co-interviewers and required minimal prompting into discussion by the researcher. The PhD student who had organised the discussion group also asked a small number of questions. I anticipated that the presence of the other PhD student would help put the group members at ease and facilitate the discussion, due to participants' familiarity with her.

Each group member was paid £5 per hour (or part of an hour) in cash and was asked to sign a receipt. Lunch was provided due to the timing of the discussion group. The discussion group lasted approximately three-and-a-half hours although one member departed approximately half way through the discussion due to having to attend a prior engagement. The group discussion was recorded on an audiotape machine with an external microphone attached. I had prepared a topic guide with which to focus the group discussion but the members largely determined the content of the discussion. The determination of discussion content was useful in providing an almost free association of topics that the members felt were relevant to them within the broad areas of citizenship and social exclusion and were useful in indicating some of the likely areas of interest for subsequent interviews.

The advantages of using a small group discussion in the initial stages of data collection are that they enable clarification of research questions and establish the relevance of research questions (O'Brien, 1993) and enable generation of new ideas and identification of potential problems with the research (Stewart and Shamdasani, 1990). Focus groups and small group discussions also enable the researcher to gather diverse views and emphasise the views of informants (Frey and Fontana, 1993) and increase the credibility of the research by collaborating with members of the group of interest (O'Brien, 1993).

## **Topic Guide**

The topic guide was given to prospective participants as an introduction to the research and prior to their agreement on participation. It was anticipated to be used as a general guide in that it was made clear to participants that the guide was intended to be employed in a flexible way and was not anticipated to be fully inclusive. Therefore, participants were encouraged to discuss topics they thought might be relevant but were not included in the topic guide. The topic guide for the small group discussion and the individual interviews encompassed:

- Public attitudes
- Housing
- Employment
- Income
- Education and training
- Social relationships
- Mental health services

At the point of construction of the topic guide, I intended to examine service users' views on their status in society by discussing subjective feelings of community membership and whether participants felt accepted as members of their community. Abuse from strangers, 'nimby' opposition and expressions of public attitudes were possible interview topics, alongside views on media representations of mental illness.

In relation to housing, I intended to question participants on their current and previous types of housing. I wanted to examine community membership in terms of geographical location, security of tenure and privacy, the latter especially in relation to supported housing.

In relation to employment, I wanted to discuss participation in non-supported employment and supported employment schemes. The issues of access and discrimination in employment were potential topics for discussion, along with whether employment really is a favoured route into social inclusion. I also wanted to examine the role of income in social participation in order to establish whether service users

share the consumerist ethos of mainstream society and how mental health status impacts on participation in consumption.

The meaning and nature of social relationships were examined in terms of whether social isolation and rejection had been experienced and whether choice is exercised in social network composition. Chamberlin's (1988) assertion that friendships with other service users can be a source of support was also examined.

Experience of mental health services was also included in the topic guide in order to examine whether such services impede or facilitate social participation. Interviewees were asked to evaluate services in relation to autonomy, decision-making, medication (including side effects and compliance), the notion of insight and experiences of compulsion.

The experience of mental health legislation is particularly pertinent because it is informed by notions of dangerousness and can produce tenuousness of community membership in terms of repeated hospitalisation. I also wanted to examine participants' experiences of the use of the Mental Health Act 1983 and awareness of rights under the Act.

The aim of the individual interviews was to gain an overall impression of community membership experienced by users of mental health services since social participation is identified as a significant defining characteristic of citizenship (Marshall, 1992; Rees, 1995a).

The current study is comparable to the study conducted by Barham and Hayward (1995) in their presentation of interviews with mental health service users in order to establish the nature of community membership and social participation. However, their interviewees comprised a relatively homogenous group of, primarily, young males, and failed to include ethnic minorities. My research differs from Barham and Hayward's study by examining a broader range of topics in accordance with broad surveys of discrimination conducted by Read and Baker (1996) and Dunn (1999) yet retains the in-depth interview data collection of the Barham and Hayward study.

## **Sampling**

Following the group discussion, semi-structured interviews were conducted with individual participants. A series of interviews was conducted with a total of 15 users of mental health services. The criterion for involvement in the research was previous or current use of mental health services. The interviewees were all aged less than 65 years. Eight of the individual interviewees were male and seven were female. All were unemployed at the time of the study but the standard of educational attainment was high, with at least two participants having university degrees, one participant held an HND qualification and two participants had been employed as teachers. One participant had been a successful businesswoman prior to her mental health service use; three participants had previously worked as civil servants and two participants had previously worked as teachers.

Participants were recruited through an introductory visit to a user group in the south east of England in December 2000, a poster presentation at the Mind annual conference in November 2000 and through the snowballing method. Three participants were recruited after seeing the poster presentation, a further seven participants were recruited following an introductory visit to a user group meeting, two participants were recruited from a self-help group and three participants were recruited via the snowballing method.

The participants lived in the Midlands, the south east of England and in East Anglia, thereby ensuring some degree of geographic distribution of participants. Recruiting participants from different areas of England enabled comparisons to be made in relation to user involvement, awareness of mental health policy and experiences of mental health services.

I approached the project co-ordinator of a user group with a written description of the research (see Appendix 1) and a request to attend one of the groups' regular meetings in order to introduce the research and discuss it in greater detail. The written description of the research was circulated to group members at a user group meeting and the members agreed that they would invite me to discuss the research in further detail at the following meeting. I spoke for approximately 15 minutes (see Appendix 3) and answered

questions about the research. It emerged that a number of members had found the written description of the research difficult to understand due to the prevalence of jargon. Members commented that the verbal description of the research had been more useful and a number of members indicated their interest in participation almost immediately. I left written details of the research, including my contact details.

The poster presentation (see Appendix 2) occurred at the Mind annual conference in November 2000. I met with a small group of interested conference attendees whereby one participant was recruited following this informal meeting. Another individual contacted me by email upon his return from the conference, having seen the poster presentation. A further participant was recruited after having been told about the research by his friend who had seen the poster presentation at the conference.

Upon establishing contact with interested parties, I arranged to meet them either at their home or, in two cases, at a local advocacy centre. One participant was interviewed by telephone due to the geographical distance between the researcher and participant and a further participant agreed to be interviewed at my office at the Tizard Centre at the University of Kent due, again, to the geographical distance between the researcher and the participant's home.

### **Demographic Characteristics of the Sample**

The sample of participants comprised ten females (including three females in the discussion group) and eight males. Participants ranged in age from early twenties to mid-sixties at the time of the interviews. The range in terms of duration of service use was 4.5 to 30 years. Data was not obtained from all of the participants on the number of years they had used mental health services, therefore it is not possible to provide an average number of years spent using mental health services for the entire sample. However, data was available on years of service use from 12 participants and the average number of years of service use for this sub-sample was 16.38 years. Therefore, participants had generally spent a significant period of time using mental health services.

None of the participants was engaged in paid work at the time of the interviews. Data was available from four participants on the exact year since their last paid employment. The average number of years of unemployment within this small sample was 21.5 years. Other participants indicated that they had not worked for over five years. None of the participants had worked in the year preceding the interviews. Therefore, the participants are characterised as having experienced chronic unemployment, defined as over one year of worklessness. One member of the small discussion group identified as African-Caribbean but all other participants were of white British origin.

## **Interviews**

I presented potential participants with a five-page introduction to the research in which the aims of the research were described along with my intentions for the presentation of findings. I also included practical details such as the rate of pay and requirement of consent. The prospective participant was then informed of their ability to exit from the research at any time and was assured that the initial meeting did not imply an obligation to participate in the research. I also included brief biographical information about myself. My full contact details were included at the end of the document. The anonymity of the research participants was also emphasised at this point. Potential participants were also presented with a topic guide outlining the main themes of the research (see Appendix 4) and a consent form (see Appendix 5) that participants would be required to sign if they decided to participate in the research. The consent form emphasised the voluntary and negotiable nature of participation, the anonymity of participants, the recording of the interviews, the potential dissemination of the findings and included the address to send complaints, if necessary.

Two participants decided not to participate in the research following an introductory visit but the remainder agreed to participate in the research and proceeded to discuss their circumstances during the initial visit. No discussions were tape recorded at the initial visit but preliminary discussions were used to structure subsequent interviews. The participants were informed that I would prefer to conduct more than one interview with a likely maximum of three interviews. Most participants agreed to be interviewed for as many times as was necessary. Following agreement to participate in the research,

an appointment was made for the first interview. Most interviews took place in the participant's home, with the exception of five participants who were met either at an advocacy office or, in the case of one participant, at a day hospital; another participant was interviewed at the Tizard Centre and one participant was interviewed by telephone. Participants were informed at the initial meeting that they would be paid £5 per hour or part of an hour and were paid at this rate at the initial interview, regardless of whether they subsequently participated in the research. The payments were made in cash. Two participants were partners and were interviewed together but paid separately at the individual rate. Participants were required to sign a receipt following each payment (see Appendix 6). Payments did not exceed the weekly earnings allowed under income support in that no interview involved payment of over £20. The participants were assured that their anonymity would be protected by the secure storage of the receipts in a locked cabinet at the researcher's home and that the University would only require inspection of the receipts in exceptional circumstances.

The interviews were audio recorded on a portable dictation machine. An external microphone was attached and the recording equipment was generally placed on a table on front of the participant. Two participants expressed discomfort at the sight of the recording equipment and so the tape recorder was placed to the side of the participant out of their line of sight. The telephone interviews were recorded using two telephones with one telephone located in another room of my home and set to speakerphone and recorded from the speakerphone while I spoke to the participant on the other telephone. The quality of the telephone recording was surprisingly good. The participant's payment was confirmed at the final interview and sent through the post immediately following the final interview. The participant then signed a receipt and returned it in a pre-paid envelope.

The interview structure was flexible and depended on the participant's individual experiences. Therefore, not all topics were covered in all of the interviews and the initial discussion with participants revealed the topics that were likely to be of particular importance to specific participants. Each taped interview was listened to prior to the following interview in order to avoid unnecessary repetition, to seek clarification if necessary and to determine the topics to be explored in the following interview. The majority of interviews were conducted within a short space of time and thus it was not



possible to transcribe every interview prior to the following interview for each participant. Therefore, a review of each interview tape prior to the following interview at least enabled a review of the content without the need to complete the time-consuming process of transcribing the interview prior to proceeding to the next interview.

At the beginning of each individual's first interview, the central research questions were reiterated and the participant was asked to discuss issues of particular relevance to them. The number of interviews conducted with each participant ranged from one to five, with a mean number of 2.79 per participant (three interviews rounded to the nearest whole number).

### **Data Analysis**

Computer Assisted Qualitative Data Analysis Software (CAQDAS) was used to analyse the data because literature suggests that CAQDAS carries the advantage of being able to handle the large amounts of data typically generated by qualitative research (Fielding and Lee, 1998).

The use of computers has been advocated for the analysis of grounded theory data (Richards and Richards, 1994, 1998) whereby the use of programmes such as NU\*DIST and NVIVO has been particularly associated with the grounded theory method, although not without significant criticism (Coffey, Holbrook and Atkinson, 1996).

The use of computer software is advocated for the analysis of qualitative data due to the fact that qualitative methods produce bulky, complex, unstructured, context-dependent data which is said to be recalcitrant in not yielding data easily (Fielding and Lee, 1998). It is argued that computers are used in order to enhance the credibility of research by enabling researchers to deal with large amounts of data, helping to organise complex data and by addressing issues of validity (Fisher, 1997).

Tesch (1990) argued that computers are useful due to their rapidity of analysis (thus enabling more efficient use of time), greater thoroughness of analysis, and enabling the

researcher to experiment with data to a much greater extent than when using manual methods of analysis. Furthermore, Barry (1998) identified advantages in software enabling a formal system of memo recording and the facilitation of conceptual approaches to data through the easy manipulation of conceptual categories.

Therefore, CAQDAS software enables relatively swift navigation through large amounts of interview data in order to identify patterns and repeated themes. I concluded that the manual analysis of data would be excessively time consuming and less efficient in that data would be more likely to be overlooked in the manual handling of data.

The interviews were transcribed either between interviews or shortly following the completion of interviewing with each participant. The issue of confidentiality was dealt with at the transcribing stage by referring to the participant by the initial of their first name. Many of the participants either did not want to remain anonymous or were not concerned if they were not presented anonymously in the research. However, some participants stated clearly that they wanted to remain anonymous and this meant that all participants were presented anonymously in the research report in order to protect the identities of those who wished to remain anonymous. Similarly, locations and names of services and professionals mentioned by participants were also anonymised by presenting a common noun in square brackets in the transcripts to replace the proper noun mentioned in the interview. I referred to myself as 'MF' in the transcripts in order to avoid confusion ('MF' was my previous initial) and the participants who particularly asked to remain anonymous were referred to as either 'P', 'P1' or 'P2' whereby 'P' refers to 'Participant'. A hospital that was frequently referred to by participants was referred to as 'KG' in the transcripts. I was faced with a dilemma in choosing the method of anonymising participants in that using the initial of the participant's first name could be construed as dehumanising and there was an additional problem that some participants actively wanted certain institutions to be identified in an attempt to publicise their negative experiences of the institution. However, to reveal the names of such institutions would risk revealing the identities of participants who wished to remain anonymous because the location of participants may be rendered apparent by identifying institutions.

Interview data was analysed using the NVIVO programme. The programme is particularly suited to the analysis of qualitative interview data because its main function is to enable the labelling and organisation of categories derived from such data.

The unlimited number of hierarchical trees in which to store codes was a major advantage of NVIVO. It was also selected for its reported ease of learning and ease of use, its flexibility and due to the developers' reported intention for use with precisely the kind of data generated in my research (Gibbs, 2002). In fact, I found NVIVO easy and quick to learn, given that the researcher can achieve a respectable level of analysis using only the most basic functions of the programme. The most useful functions of the programme were found to be the ability to import documents into the project in rich text format and directly from the Word programme, the ease and rapidity of coding and the organisation of codes into parent, child and sibling relationships, thus indicating the relationships between codes and sub-categories of codes. The ability to display and print the text coded at each node was ultimately the most time saving feature of the programme and represented the greatest advantage over the manual coding of data.

The aim of coding of interviews was the identification of recurrent themes, omission of themes that appeared in the topic guide but not appearing in interviews, identifying consensus and dissent within categories and the exclusion of topics that are interesting but not directly relevant to citizenship.

Coding was achieved by deriving general themes from literature, policy and the small group discussion that, in turn, generated the topic guide. The transcripts were coded initially by hand and then imported into NVIVO to attach codes to segments of text. The hierarchical organisation of nodes enabled the collapse of coding categories as the visual presentation of categories enabled duplication to be identified relatively easily. The codes were successively modified in response to themes emerging from interview data. NVIVO allows the researcher to define categories in the Node Explorer, thereby proving useful in ensuring consistency of use by referring to clear inclusion criteria.

It is the cumulative process of coding that appears to link the grounded theory approach to the use of CAQDAS software because the analysis of data is revised according to

interview responses. Interview data thus directs the generation of codes and subsequent data collection.

The group discussion was coded first and produced the framework for the coding of individual interviews. Transcripts were coded manually in the first instance and were coded in the order in which the interviews were conducted. One or two word codes were attached to data segments to summarise themes in each data segment. At the completion of the coding of the transcript, a list of codes was produced for the entire document. Subsequent transcripts were coded and compared with the list of codes already produced. Repeated codes were omitted and new codes added to the cumulative list of codes. Therefore, the coding involved the cumulative creation of codes and the collapse of codes into general categories, thereby enabling greater inclusiveness and minimising repetition.

The manual coding of transcripts was followed by transferring the transcripts into the NVIVO programme and then coding the data using the manual coding framework. Codes were then attached to data segments, enabling the printing of data segments under each code to allow comparison of participants' discussions under each code. Recurrent themes were identified, alongside patterns of consensus and dissent between participants (open coding: Strauss and Corbin, 1998). Overlapping themes between categories highlighted the inter-relationship between areas of citizenship (e.g. stigma and disclosure appeared in numerous categories, along with identity and difference). This represented axial coding (Strauss and Corbin, 1998) in which relationships between categories and sub-categories were analysed. The final stage of analysis involved selective coding whereby categories and sub-categories were examined in relation to the core category of citizenship.

### **Reliability and Validity**

Researchers have adopted the grounded theory approach in an attempt to increase the reliability and validity of qualitative research in response to criticisms that such research lacks methodological and analytical rigour. However, Hammersley and Gomm (1997) accuse qualitative research, and emancipatory research in particular, of bias. They

identify bias as involving either systematic error or deliberate manipulation of data. They claim that such bias is due to emphasis being placed on a particular viewpoint in the collection and interpretation of data in order to produce confirmatory findings. Such concerns are one reason that grounded theory has been described as a post-positivist approach due to its concerns with positivist notions of reliability and validity (Denzin and Lincoln, 1998). However, notions of reliability and validity differ significantly between qualitative and quantitative research, the latter encompassing notions of absolute truth (Seale, 1999) and thus greater commitment to concepts such as validity and generalisation.

Reliability is generally understood as involving the replicability of research findings (Perakyla, 1997; Seale, 1999). However, Seale argues that reliability is difficult to invoke in qualitative research due to researchers' creativity and the interactional nature of such research and that credibility is more pertinent to qualitative research whereby the researcher's methodology is transparent to enable other researchers to examine the precise process of research production. Mays and Pope (2000) argue that a clear exposition of the choice of methodology and procedures followed in data collection should enable others to evaluate the adequacy of the interpretation of data offered by the researcher.

Perakyla (1997) claims that reliability and validity is achieved by accurate recording of raw data which, in turn, is achieved by the use of multiple researchers, participant researchers, peer examination and the audio or video taping of interviews (see also Seale, 1999).

Validity is described as involving the accuracy of findings and is achieved by the clear explication of the role of the researcher in the research process and how research problems were defined and analysed (Altheide and Johnson, 1998), although Banister et al. (1994) claim that validity is more closely related to the adequacy of the researcher's interpretations of findings. Validity is generally regarded as achieved by reflexivity in the research process, describing the role and stance of the researcher (Altheide and Johnson, 1998; Banister et al., 1994; Seale, 1999; Perakyla, 1997).

Triangulation is presented as one way of demonstrating validity in the use of different vantage points from which to interpret data (Banister et al., 1994). Data triangulation refers to researching different roles (e.g. staff and patients) in a particular context whereas investigator triangulation involves the use of more than one researcher (Banister et al., 1994). Reflexivity of qualitative data collection and analysis allows transparency in the research process to enable readers to judge the impact of bias on the interpretation of findings (Banister et al., 1994).

Generalisation in qualitative research is distinct from generalisation of findings in quantitative research. Generalisation of findings from quantitative data is achieved by random sampling of a large number of cases whereas generalisation of qualitative data refers to the application of theory beyond the particular context studied (Maxwell, 2002). It is also referred to as external validity (Maxwell, 2002).

Furthermore, Mays and Pope (2000) argue that the credibility of qualitative research can be evaluated by examining the relevance of the research and whether it contributes to knowledge; whether the research questions are sufficiently clear, at least by the end of the research process; the appropriateness of the design to the research questions; whether the range of theoretical sampling was sufficiently broad to allow conceptual generalisation; whether data collection and analysis was systematic; and whether sufficient data was included in the report to assess the adequacy of the researcher's interpretations and conclusions.

In relation to Hammersley and Gomm's (1997) accusation of bias against qualitative research, it is the case that I have adopted a specific viewpoint in the interpretation of the research findings: that of the participants in the research. I have attempted to present their views and experiences as accurately as possible. It is also the case that research examining the experiences of users of mental health services adopts a distinct viewpoint. For example, possibly less credence would be awarded to participants' views by a researcher committed to the medical model of mental distress whereas a researcher committed to the emancipation of mental health service users is more likely to seek the views and accounts of such individuals. Moreover, the research was conceived as a result of listening to mental health service users' experiences of discrimination and disadvantage. Therefore, bias is inevitable in the conception of research but can be

reduced through a commitment to presenting participants' viewpoints as accurately and faithfully as possible and acknowledging the sources of the formative development of research questions. Furthermore, I have attempted to include a sufficient amount of raw data in reporting the findings of the research to enable readers to evaluate whether participants' discussions support the conclusions drawn from the interview data. I also recruited participants from a range of settings and geographical locations in an attempt to sample a range of viewpoints, although this does not attain the triangulation described as enhancing validity of findings. I have also included disconfirmatory and unexpected findings in order to capture the complexity of experiences and opinions expressed by participants.

Furthermore, the research was conducted systematically and described accordingly and thus fulfils Mays and Pope's definition of rigour in qualitative research. Furthermore, the research contributes to the current state of knowledge in this area because it is the first study to examine a broad range of areas of Marshall's (1992) conceptualisation of citizenship using in-depth interviews with mental health service users.

The current research also attempted to maximise reliability and validity by clearly explaining the process of the research and rationale for research decisions. The research involved an attempt to increase the accuracy of data collection by audio recording of interviews and by checking the accuracy of transcripts by comparing the interview tapes with the transcripts at least twice per interview, until I was satisfied that the transcripts were absolutely accurate. In relation to Mays and Pope's question of whether the research method adopted is appropriate to the research questions, the choice of qualitative data is the most appropriate method of examining mental health service users' experiences of social participation and views of citizenship status because it enables an examination of the complexity of human experience whereas quantitative methods might be suitable for a more general overview of discrimination experienced by this population, as in Read and Baker's (1996) research, but is not the most appropriate method of examining the complex concept of citizenship.

### **Ethical Considerations**

The discussion of ethics in social research emphasises that harm to participants should be minimised and the benefits of the research should outweigh harm or disadvantage to participants (Gregory, 2003). Researchers are urged to be particularly aware of issues in relation to informed consent and privacy (Rees, 1991; Fontana and Frey, 1998), deception (Punch, 1998) and confidentiality in the storage of data (Homan, 1991; Punch, 1998).

Punch (1998) argues that participants in research have the right to be informed that they are participating in research, thereby eliminating the prospect of covert research. Homan (1991) asserts that fully informed consent depends upon the provision of sufficient information on which to make an informed decision. He argues that consent must be voluntary which involves the exercise of choice in participation without the use of coercion, fraud, deception or duress. Participants should be presented with comprehensive details of the research, including aims of the research, expectations of participants, the time and effort involved and data collection and dissemination (Gregory, 2003).

The participants in the current study were presented with full written details of the research prior to an introductory visit to each individual and thus were able to consider the implications of participation in the absence of the researcher. However, Homan (1991) questions whether payment constitutes undue duress into participation. This is a difficult potential criticism to counter. Participants were offered £5 per hour whereby every participant accepted payment and could be perceived to have been induced to participate by the payment. However, payment was an important recognition of the contribution made by participants to the research.

Punch (1998) asserts that participants should be informed of their rights to withdraw from the research. Participants were informed of this both verbally and in the written details of the research provided prior to participation. However, Homan (1991) argues that participants may experience a sense of obligation to continue once participation has commenced.

The cost of research participation is also an important consideration. Potential costs might encompass the difficulty of discussing sensitive issues; placing trust in the



researcher to anonymise data and respect privacy; provision of time (at least one hour per week for an average of three weeks); the effort of engaging in in-depth discussions and the intrusion involved in being interviewed at home and being audio recorded. However, in relation to the penultimate point, participants were asked where they would prefer to be interviewed and most chose to be interviewed at home.

Maintenance of privacy is also a crucial issue in relation to ethical considerations. Punch (1998) recommends that not only should researchers avoid naming participants, but they should also avoid identifying the location of participants and avoid providing details that might lead to identification of participants (Gregory, 2003). Every attempt was made in this study to anonymise participants by not naming institutions, services or individual professionals.

Finally, Dworkin (1992) claims that the ability of people with mental health problems to provide informed consent might be compromised by cognitive deficits due to illness or reduced autonomy due to institutionalisation and thus consent should be continuously confirmed. However, this view represents a somewhat paternalistic approach to the welfare of people with mental health problems. Participants in the study appeared to understand fully the implications of participation in the research and determined whether they wished to be interviewed further and when and where this should occur.

The research was given ethical approval by the ethics committee sitting at the University of Kent prior to any contact with potential participants.

### **Methodological Limitations**

A serious shortcoming of this research was the lack of diversity of participants in terms of their ethnicity, sexuality and disability. This may have been due to the way in which many participants were drawn from a single user group (7 of 18) which comprised relatively homogenous members in terms of ethnicity, age and physical disability. Ten of the 18 participants were women but the interviews did not include questions specifically concerning the impact of gender on citizenship. Only one of the participants was black, being of African-Caribbean origin. A large body of literature exists to

indicate the prevalence of racial discrimination in mental health services yet my research failed to include more than one participant from an ethnic minority. This is clearly a significant omission.

Secondly, the study was not fully participatory because participants did not determine the research questions, nor were they involved in the analysis of the findings. However, participants directed the interviews in that the interviews were determined by the topics that participants defined as being of particular personal importance. In addition, early interviews directed topics for discussion in later interviews, in accordance with the grounded theory approach. However, the research diverged from a strict grounded theory paradigm in that findings were not comprehensively analysed until the completion of the interviews. Rather, interviews were reviewed immediately following completion of each interview in order to allow the topics of discussion to determine the content of later interviews with the same participants and other participants. Therefore, data collection and systematic analysis was not simultaneous, as directed by the conventional grounded theory approach.

Furthermore, the discussion group was too small to be accurately described as a focus group, given that a focus group should comprise six to twelve members (Stewart and Shamdasani, 1990); it is more accurately described as a directed discussion with a small number of group members. The study may have benefited from a number of focus groups consisting of at least six to twelve people in order for the topic guide to be more comprehensively directed by mental health service users.

The sampling method did not involve random sampling and mostly involved recruitment from a user group in the south east of England. However, the snowballing method enabled recruitment of people not actively involved in a user group and a poster presentation at the Mind annual conference enabled the recruitment of participants from other parts of England. However, Rose (2001) indicated that the snowballing method requires at least a minimal social network and thus may exclude particularly excluded people. Moreover, none of the participants lived in residential care and thus it was not possible to examine the impact of living in residential care on citizenship. Furthermore, the majority of the participants lived in towns rather than large urban areas whereas a sample derived from urban areas might have generated data indicating greater social

exclusion than was found in the current study. For example, the experience of homelessness was relatively rare amongst the research participants whereas rates of homelessness might have been higher if the research had been conducted in a large urban area (see Burrows, 1997).

Finally, the interviews were conducted in 2001 whereby it could be argued that the social situation of mental health service users and mental health services has improved since this time. However, the similarity between my own findings and those of earlier studies demonstrates some degree of consistency in findings; for example, between my own findings concerning social networks and the findings of a study conducted by Estroff in 1976.

## **Chapter Six: Findings**

### **Introduction**

The following chapter is divided into three sections in presenting the findings according to T.H.Marshall's (1992) tripartite model of citizenship. The chapter begins with an overview of participants' conceptualisations of social exclusion and citizenship. The first section of the chapter examines social citizenship in terms of employment, income, housing, education, social networks, public attitudes, community mental health services, inpatient treatment, medication and parenting. The second section examines civil citizenship, primarily in relation to mental health review tribunals and the use of the Mental Health Act 1983, although the process of compulsory detention is largely examined in the section on inpatient treatment. The third section is entitled political citizenship and examines mental health policy and user involvement.

A brief explanation of the transcription conventions adopted might facilitate reading of the findings. I have attempted to ensure anonymity by anonymising not only participants' names but also proper nouns of services, professionals and locations by replacing the proper noun with a common noun in square brackets. Inaudible speech is indicated by 'Xxx' in the transcription and edited speech is indicated by '...' at the end of the quote. A dash (-) at the end or in the middle of speech denotes an unfinished sentence uttered by the speaker.

## **Social Exclusion**

The discourse of social exclusion is integral to New Labour policy, including mental health policy. Standard One of the National Service Framework for mental health (DoH, 1999a) refers to 'tackling discrimination and social exclusion'. Social exclusion has been defined as deprivation of significant duration and marginalisation from mainstream society (Golding, 1995). The question addressed in these findings is whether people who use mental health services experience significant deprivation and marginalisation. However, I wanted to examine how participants might define social exclusion and whether they regarded themselves as members of a socially excluded group.

In relation to Golding's definition, deprivation is interpreted as the deprivation of opportunities anticipated to be enjoyed by people who do not use mental health services. This may be regarded as a description of discrimination, defined as involving unfair treatment (Sayce, 2000) that leads to deprivation of opportunities ordinarily available to citizens. This chapter is intended to provide a brief overview of the ways in which participants believed that they were excluded from ordinary opportunities and the discrimination that underlies such exclusion. The following sections will identify numerous instances of discrimination against participants: being excluded from holding office in a student organisation, being excluded from voluntary work, being denied access to employment and being subject to verbal harassment at work. Participants' descriptions of discrimination concur with the specialisation paradigm described by Silver (1994) in which discrimination and unenforced rights form the basis of social exclusion.

More general problems were reported in relation to obtaining paid and unpaid work, in developing social networks and in being subject to negative public attitudes. Furthermore, service delivery was reported to further undermine citizenship status through the loss of personal liberty by compulsory inpatient incarceration, by treatment of mental health problems based on assumptions of incapacity or dangerousness and by the negative impact of medication on everyday functioning. Furthermore, participants' descriptions of hierarchical, dichotomous relationships between service users and

professionals also indicate a reference to the monopoly paradigm in which exclusion is caused by hierarchical power relationships (Silver, 1994). Moreover, participants identified mental health policy as coercive, discriminatory and counterproductive.

Therefore, it is important to examine the way participants felt about their position in society generally and to establish whether they believed that people with mental health problems are socially excluded. The following sections examining social exclusion and citizenship are not intended to provide a detailed analysis of these concepts but are intended to provide an introduction and overview of some of the main issues that arose in the following research. The discussion of social exclusion will be guided by the following questions:

- How did participants define social exclusion and inclusion?
- Did participants regard mental health service users as an excluded group?

### **Defining Social Exclusion and Inclusion**

There was general agreement amongst participants that people who use mental health services are socially excluded. Participants defined social exclusion as being outside of 'normal' society, as being excluded from access to certain resources and by reference to an underclass and downward social mobility. More specifically, some participants referred to social exclusion as indicated by isolation and lack of choice in life, as the following participant states:

*A: "...but generally I would say that we are isolated and a lot of us do have some sort of choice about where we spend our money but if you read books on social policy, social policy nowadays exclusion, social exclusion tends to be things like where you live, the transport you use and your access to information. Many of us are falling behind in the race to live in comfortable conditions, with independent transport and ability to access information systems. But we are falling behind quite drastically, some of us."*

Such lack of choice implies a lack of agency that has been deemed particularly important to social inclusion (Askonas and Stewart, 2000). Although the participant refers to social policy definitions of social exclusion, he compares what he regards as the living conditions of many mental health service users with the definition and argues that such people do experience social exclusion. The participant employs the metaphor of life as a race and argues that people who use mental health services are unable to compete on an equal basis with other citizens. One participant referred to living outside of 'normal' society and not being expected to participate in the consumer society. However, she bases her argument on the proposition that the choice of opting out of mainstream society is one of the advantages of mental health status, involving different expectations within the group:

*K: "...one of the advantages of living outside of normal society is that you don't have to be normal, like normal society you have to dress up for certain occasions, you've got to look good, you've got to have this, you've got to have that; the video, the tee-shirt, the this, the that. In mental health, we don't expect that."*

The participant indicates one of the common themes of the analysis, that of the advantages of mental health status. Her comments indicate the problematic nature of the assimilationist aims of New Labour rhetoric concerned with the assimilation of marginalised people into dominant norms (Bowring, 2000; Beresford, 2001), such as into the work ethic through inclusion by participation in paid work (Levitas, 1998). Her comments also indicate problematic zero-sum conceptualisations of the included and excluded that assumes consensus on the nature of integration and social membership (Silver, 1994).

Two participants spoke of social exclusion in terms of the existence of an underclass. The following participant draws an explicit link between social exclusion and the underclass within a normative classificatory system:

*A: "...I think there's proposals to re-classify social groups from the five groups there are at the moment. It's A, B, C1, C2, D, E and I think there are plans to bring in an eight group classification and part of group eight, which is the bottom group, is long-term sick and ill people who are likely to suffer most from social exclusion... Yeah. That is the underclass, yeah."*

*MF: Would you describe people with mental health problems as part of that underclass then?*

*A: I think we must be, yeah."*

Such comments suggest a universalistic analysis, referring to an entire class of excluded people (Ratcliffe, 2000), although notions of an underclass are problematic in being utilised to morally condemn members of the underclass (Robinson and Gregson, 1992). However, the participant also described the Marxist view of class in that people with mental health problems were said to be part of the lumpenproletariat. His discussion was reminiscent of Warner's (1987) representation of mental health service users as surplus labour, likely to obtain employment only during periods of full employment. The existence of an underclass is associated with the concept of downward social drift in the comments made by the following participant:

*T: "Well obviously there are different grades of citizen and psychiatric patients – really, they talk about an underclass don't they? Like many of the working are like middle class but now there's this smaller underclass. And psychiatric patients, it's a kind of downward mobility. So you can be someone who's brought up in a middle class family but you're downwardly mobile and you end up being regarded as being in the underclass, as a third class citizen...If you've been in [county asylum] like what happened to me, you try and get a job with the bank, the same bank that your parents originally worked for, and the bank manager says 'oh no, he's been in [county asylum], sorry'."*

The participant attributed his failure to obtain the same employment as his parents to the prejudice and stigma attached to mental ill health and psychiatric hospitalisation. This is an example of the 'social drift' hypothesis in which mental health service users are thought to drift into lower status employment or unemployment (Warner, 1987). Moreover, downward social mobility was observed among participants in comparison to their unemployed status at the time of the research and their prior employment. Participants described a gradual loss of status as others' responses and illness impeded their ability to engage in paid employment. For instance, prior to mental health service use, one participant was a successful businesswoman; two participants had been civil servants, one participant had previously been a housing officer; one participant was an actress and two had been teachers. As stated previously, none of the participants were



employed at the time of the study. Moreover, a number of participants were graduates and thus would be expected to enjoy greater opportunities in relation to employment that is associated with graduate status.

**Did participants regard mental health service users as a discriminated against group?**

Only one of the participants who offered a response to this question felt that mental health service users were not a discriminated against group, although with the qualification that some people may invite discrimination by the nature of their illness.

*D1: "But there are some people that are so obviously not right, you know, not people that just go in and out of depressions, but people that – who are in and out all the time. Or someone like [friend] who has definitely got a problem and is what [another friend] calls 'a lost cause' because he just won't ever move on. You know, he just goes round in circles. He gets better to a point and then he goes right back round, back down to the beginning again. People like that I can imagine would be discriminated against because other people lose patience with them. And the likes of [patient] who sees aliens that fixed a radio torch to her. You know, other people I would imagine would discriminate against her because of that. They wouldn't bother renting her a home or whatever because she's very strange."*

Therefore, perhaps the visibility of an individual's mental health problems might determine the level of discrimination that they experience. The participant suggests that chronicity of illness or service use may also be instrumental in attracting discrimination. She also indicates another of the common themes to emerge in the findings, namely a distinction made between different categories of illness whereby she links discrimination to severity of illness and level of service use. Another participant (M) argued that he expected to enjoy the same opportunities as others as long as he could control disclosure of his mental health status but commented that he would expect discrimination if his use of mental health services was revealed.

The following participant provided a definition of discrimination:

*G: "To be treated differently to anybody else for the way I am."*

This definition is simple yet a very useful measure of whether people with mental health problems are discriminated against. However, it omits the way discrimination against marginalised groups involves unequal and not simply different treatment (Sayce, 2000). One participant identified the phenomenon of multiple discrimination involving mental health, physical disability and sexuality.

*P2: "Yeah, well in a way I think the real issues get blurred by having three eggs in a basket in a way. So if there was just one issue like [partner] was my sister, we were heterosexual and she had a mental health problem and I was working to support her, then we could identify any prejudice and that sort of thing as being due to her mental health issues. But because there's the three together, you can't quite work out which one is creating the most discrimination in a way. Where people's attitudes are coming from. It all gets fudged over really."*

The participant indicates the complexity of discrimination that is comparable with an analysis of citizenship whereby it may be difficult to tease out the specific strands of discrimination that impact on citizenship. However, a number of participants provided clear examples of discrimination. Participants reported discrimination in relation to employment, education, parenting, mental health policy and media representations of mental health issues. Such experiences will be examined in the following sections.

Another example of exclusion was exclusion from primary care services. The following participant was struck off his GP's list whereby his mental health worker was informed rather than the participant as the patient:

*T: "Yes, well to take an example, I was struck off by my GP six years ago and what normally happens is that a patient is given seven days notice by the doctor who's striking you from his list. Well, I didn't even get that because the doctor didn't notify me directly, he notified my case manager. And that's an example of psychiatric patients not being treated the same as other people."*

Similarly, a number of participants expressed concern about the neglect of their physical health problems by mental health and general medical professionals in that professionals were described as attributing physical illness to psychosomatic factors and therefore physical complaints were not investigated nor treated. Furthermore, one

participant (P) identified a tendency of professionals to make an artificial division between physical and mental health problems despite the two sharing a symbiotic relationship. She identified the commonality of her experiences to the extent that she established a self-help group for people with co-occurring physical and mental health problems and did report receiving the support of a liaison psychiatrist, from whom she also described having received a good service. Nevertheless, Wahl (1999) attributes neglect of physical health problems to lack of credibility ascribed to people with mental health problems. Neglect of physical health problems might also partly explain elevated mortality rates amongst users of mental health services.

A common theme in participants' discussions of social exclusion was that mental health services and policy contribute to social exclusion, as the following participant summarises:

*T: "Yeah the Government go on about social exclusion and they've got this unit to deal with it but they haven't – I mean, you're excluded, I mean exclusion is like, for example it's like being put on the supervision register...like it's going to be with the community treatment orders. I mean, that's excluding people. And people being sectioned for long periods and this idea of locking people up with personality disorders who haven't committed an offence. That's a way of excluding people isn't it?"*

This concurs with the view of Dunn (1999) who argued that mental health services exclude by emphasis on medication due to detrimental side effects, containment, negation of physical health problems, and paternalism based on 'best interests' that implies incapacity in decision-making. The exclusionary nature of mental health policy will be discussed in the section concerning mental health policy. The following participant had been ousted from his role as president of a student union at a further education college on the grounds of his mental health and forensic history.

*M: "Well that definitely makes me think that I'm not seen as a sort of usual person, Mr Joe Average, because they went out of their way to say 'look, you can't do this because of your background' and well yeah, they discriminated against me because in their mind I wasn't fit to be a governor so er my opportunities there and what I was doing was affected by my involvement with*

*mental health services and prison as an off-shoot of that. Hopefully, I will be able to put the college right. I wouldn't want them to think that they could do that."*

The latter comment reflects the way many participants wanted to publicise their experiences in the hope of reducing discrimination for other people with mental health problems. However, the following participant links social inclusion to de-institutionalisation:

*A: "...If you manage to get out of residential care and you're careful with your budgeting and you save and things like that, you can afford occasionally to go on holiday or to go out for a meal or things like that, so you're not entirely socially excluded financially, like you used to be. Social services and health is becoming more joined up so if you need to go into hospital there is some kind of continuity of care and we've got new treatments for mental illness. The atypical medications, so that kind of is a good thing which acts against social exclusion as well...I can use a supermarket a couple of times a week, you know, and rather than getting a clothing grant or a voucher for clothes, you know, at the hospital clothes sale, I can go onto the high street and buy a pair of jeans for myself, so yeah, we are part of the consumer society as far as that goes, which is a lot more satisfactory than having the institutional kind of affair that used to be the case."*

It is clear from the comment 'I can use a supermarket' that people who use mental health services can derive a sense of inclusion by having money to participate in everyday activities such as shopping, going on holiday, eating, ect. His comments contradict the way in which many participants defined their own exclusion in relation to the consumption engaged in by ordinary members of society. This point will be clarified in the following section examining participants' definitions of citizenship.

### **Summary**

There was general agreement among participants that exclusion meant being part of an underclass, being subject to downward social drift and not having access to valued resources. Inclusion, on the other hand, was defined as having access to resources to participate in everyday activities. Discrimination was reported to be a reality in the lives of people who use mental health services.

## Citizenship

Citizenship is an ambiguous and contested concept (Lister, 1997) that required exploration of definitions produced by participants. I hoped that participants would be able to elucidate the concept using their own terms. The three fundamental questions that were explored were:

- What is citizenship?
- Do users of mental health services enjoy full citizenship status?
- Are there barriers to citizenship for people who use mental health services?

### Defining citizenship

Participants defined citizenship in terms of a comparison between themselves and other people and by suggesting that they do not participate in the same activities and enjoy the same lifestyle as people who do not use mental health services. Unsurprisingly, participants identified aspirations that are shared with people who do not use mental health services (cf. Bauman, 2000). I refer to these as 'normative aspirations'. The following participant, a man aged in his thirties, defined a citizen as someone who is not subject to the stigma of psychiatric hospitalisation and to the debilitating effects of medication. He argues that a citizen has access to employment, family ties, property and possessions and financial stability. The implication of his argument is that people who use mental health services do not enjoy the opportunities to realise such aspirations.

*R2: "Well a normal person hasn't got to worry about any stigma, they've never been in a psychiatric hospital. Start work at eight o'clock feeling fine, without any tablets drugging them up. They finish at five o'clock, they go home to their wife or their husband. They've got children. They've got a house. They can afford to put the heating on. They've got a new car. They're doing all right in life, which is what everyone wants to do, getting somewhere in life. And there's me who can't do that, who hasn't settled down, still living at home with his father, money's*

*short, haven't settled down, haven't got the girlfriend, haven't got the children. It is hard to describe what is citizenship, yeah. I feel terribly left out. Most of my friends now, my actual normal friends, have settled down. They've got girlfriends...I'd like to be doing some sort of car racing. If I hadn't been ill, I'd be doing my own mechanics to the car, the race car. Settle down and married with children, live in the country. I'd be really happy if all that happened. I'd do some sort of car rallying I suppose..."*

Therefore, citizenship was also associated with participating in the property-owning consumer society. Marshall (1981) claimed that consumption is a key desire held by citizens due to its significance for community membership. Moreover, Bauman (2000) argued that the socially excluded share the same norms as the included, particularly in relation to a desire for consumption and share the same aspirations as other consumers. Furthermore, he argued that identity is determined by ownership of material possessions in a consumer society. One participant observed the following:

*K: "...I'd like to be a part of mortgage earning and I'd like to be able to earn a mortgage but then again, the only place I'd want to live – because I've lived outside of [area of London] and the facilities I'd like to live in [area of London]. I'd rather stop at [area] and the same mental health facilities which I notice you don't get elsewhere. It's very, very expensive to live in [area]. Very expensive...I mean, I've had a good life. I'm not unhappy now because I feel better but erm sometimes you think 'well, it's a shame, you know.' It could have been different. But one would like it to be substantially better. You know, like being able to afford a home or even the council flat that I have. If I won a hundred thousand on the lottery, I'd buy the council flat, that might cost me sixty or seventy thousand. I'd take a holiday. I'd spend my money. I'd redo up the flat then I'd go back to living on benefits."*

Therefore, a sense of citizenship derives from being part of a consumer society. The previous participants indicate a common theme to emerge in the analysis, that of the prevalence of normative aspirations amongst participants. The participant referred to as R2 made an explicit comparison between himself and his friends to suggest that he is disadvantaged in comparison with his friends. The participant K expressed normative aspirations in terms of property ownership, although her comment 'I'd go back to living

on benefits' is interesting in terms of her lack of commitment to inclusion through paid work. The latter comment indicates the problematic assumption of cultural homogeneity based on dominant norms that underlie universal notions of citizenship (Oliver and Heater, 1994).

Finally, one participant questioned whether citizenship is a concept that is relevant to British society by referring to classical notions of citizenship.

*T: "There is one remark I want to make about that. Is it not the case that we aren't citizens in this country, we're subjects? We're subjects of the Queen as head of state. We are not citizens as such at all. For people to be citizens, there needs to be a republic..."*

It is the case that the British are subjects rather than citizens in a civic republican sense (Wilson, 1998a; Pattie, Seyd and Whitely, 2004) but citizenship in Britain has been cited as specifying the relationship between individuals and the state whereby citizenship rights are passively acquired from the state (Turner, 1990; Pattie, Seyd and Whitely, 2004).

It is interesting to note that participants defined citizenship in terms of citizenship as a status (Prior, Stewart and Walsh, 1995), according to the attributes that define the status rather than citizenship as a practice in terms of activities performed by citizens. Therefore, participants appeared to implicitly espouse a liberal view of citizenship rather than a civic republican concept of citizenship.

### **Barriers to citizenship for people who use mental health services**

Participants identified barriers to citizenship as comprising illness, treatment and social responses to people with mental health problems. Therefore, barriers can be categorised as broadly individual, institutional and societal.

The following participant blamed lack of recovery from illness and cited his own illness ("I'm not able to cope") as a barrier to citizenship. He also cited treatment as a barrier to citizenship whilst providing a useful definition of citizenship as involving access to training, education and employment. More importantly, he attempted to explain the

distinction between mental health service users who don't become excluded and those who do suffer significant deprivation and disadvantage:

*E: "Er I suppose it's the difficulty they have with relating to situations in society, perhaps those that don't recover. Those that recover and get on with life get back into the flow of things, get back into training, back into education, back into different jobs or start a new career and I think that people like myself that would like to achieve that way of life, because I'm not able to cope with the challenges confronting other individuals is something that the stress of that would just throw up the psychosis. And it's – the disadvantage I have is that I'm not able to break away from the system. And er – but as long as I remain stable and I'm quite content with how the system operates at the moment and then I feel I've recovered as far as I can but the disability prohibits me from making a total recovery. And with the ECT, the disadvantages in study and concentration is really frustrating because I think 'why can't I concentrate?' It's almost like you've got very mild Alzheimer's Disease at times, which obviously I know I haven't but it's like you've lost a little bit of the brain operation that would make things flow smoother, the memory, the concentration, being able to assimilate knowledge and then write about it and talk about it."*

Therefore, the participant attributed his own disadvantage to the impact of ECT treatment on his cognitive abilities but also the impact of lack of recovery from illness on social participation, especially in relation to employment.

The organisation of services was regarded as an impediment to citizenship by identifying the individual purely in terms of their 'patienthood' (Barham and Hayward, 1995) and as negating their identity as a person outside of service use. I asked the following participant for her response to the premise of the current research, that people who use mental health services do not enjoy full citizenship status whereby citizenship was equated with membership ("you don't quite belong"):

*P1: "I think certainly the feeling is of not being a full citizen. That sense that you don't quite belong. But also, I think that the system creates that as well. It sort of, you know, I told you about going for a meeting with the CPN and she you know, I went for an agreed meeting and there's no rooms available so she sends me back home. It was like there was no regard for the fact that you've got a life and that*



*you've bothered to come down at all. It's just – there's a sort of feeling that you actually haven't got a life, that all you have to do is make your appointments, take your medication, make your appointments and then go away and wait for the next one. Nothing else goes on."*

The impact of mental health services on citizenship will be explored in greater detail in sections on medication, community mental health services and inpatient treatment. The following participant suggested that people who use mental health services lack status as citizens and laid the blame decisively at the door of societal responses and familial reactions to those diagnosed with a mental illness.

*T: "...Using mental health services has aggravated things. They've exacerbated the situation I've found myself in because as soon as you're branded a mental patient, a schizophrenic or whatever, you have no credibility...So I think that the way mental health services are constituted and the very concept of mental illness or mental ill health is like a social evil because people are suffering because of it. And like I was saying earlier, the mental health services, you know, the psychiatric nurses, the doctors, what have you, they should take on board the idea of families being abusive rather than caring. The whole concept of the family member being a carer of someone with mental ill health, I think is an absolute scandal. It's a denial of the truth."*

Therefore, the participant attributed lack of citizenship to lack of credibility caused by diagnosis and service use. The participant's comments also allude to some of the complexities of the relationship between users and carers. Of fundamental importance is the suggested refutation of Marshall's claim that state welfare services facilitate social citizenship by moderating social inequalities. The impact of mental health services on citizenship suggests that state welfare undermines equality and this was eventually acknowledged by Marshall (1981) in his admission that state welfare services undermine citizenship through their authoritarian and paternalistic nature (cf. Ignatieff, 1991; Rees, 1995a).

## **Summary**

It was clear from participants' responses that they regarded themselves as having fewer opportunities for enjoying the advantages of citizenship in comparison with those perceived as inhabiting mainstream society. Barriers to citizenship were thought to encompass factors relating to illness, service use and societal and familial reactions to psychiatric status.

The following chapters will examine in greater detail the participants' experiences of employment, housing, education, social networks, parenting, mental health services and the impact of public attitudes and policy on the citizenship status of people who use mental health services. Moreover, the significance of user involvement for citizenship will also be examined.

## **Part One: Social Citizenship**

Social citizenship encompasses economic welfare and social participation (Marshall, 1992). Economic welfare relates to employment and income whereby social participation includes participants' experiences of housing, social networks and parenting. Mental health services and psychiatric inpatient treatment are examined in this chapter due to Marshall's (1992) claim that the impact of capitalist-based inequality is moderated by provision of welfare services. Therefore, mental health services are examined in relation to their impact on social participation.

### **Employment**

The Labour government has identified paid work as a key to the social inclusion of people with mental health problems (SEU, 2004). Therefore, I wanted to explore the meaning of work for participants by examining whether they regarded work as important and whether they were engaged in paid or unpaid work. I constructed a number of questions that are relevant to the area of employment for people with mental health problems:

- What were participants' general attitudes towards employment?
- Did participants regard paid employment as desirable?
- Were there particular barriers to obtaining and maintaining paid employment?
- Did mental health status impact on experience of paid employment?
- What were participants' experiences in relation to voluntary work?

### **General Attitudes Towards Employment**

I wanted to examine participants' expectations of obtaining paid employment and whether they had aspirations to find paid work. It is of note that none of the participants were engaged in paid employment at the time of the study. A small number of

participants were or had previously been engaged in voluntary work. At least four participants expressed a desire to enter into paid work. However, the majority of participants were pessimistic about the likelihood of obtaining paid employment.

*S1: "...I don't think any of us are really that employable."*

*D2: "...It is virtually impossible to get a job if you've had a breakdown. And if you've had a long-term problem like schizophrenia or manic depression, you won't get a job..."*

Most participants anticipated that, if successful in obtaining employment, they would obtain only low paid, relatively menial work due to employers' negative expectations of their abilities (e.g. D2). A number of participants referred to the possibility of obtaining work as a professional user representative, due either to a perception that this is the only work they could obtain or due to perceptions of their particular suitability for such work. However, all of these participants expressed regret either at being restricted to such opportunities or that they had experienced difficulties obtaining such employment.

*K: "No and the job I applied for was within mental health as a user, an employed user. I couldn't apply for anything else because of the rejection you face..."*

The following participant complained about the lack of opportunities for employment as a user consultant whereby his comments demonstrate that service users may experience exclusion from user representation work even when they possess qualifications equivalent to those held by professionals.

*A: "But you know, I thought I'm now qualified with an MA which is the same degree as is held by four people that I know in health and social services. And getting the degree that I got advanced their position. They became more senior and they had a greater depth of understanding of their jobs by doing the MA. So it's got them somewhere but it hasn't got me anywhere...I've had no offers that would say take me off benefits and into some kind of work in mental health, which you might have expected would have been available. Or even some kind of paid work in mental health, but no...And I think the main difference between those people and myself is that I've got a history of mental illness and they haven't."*

The participant attributed his disadvantaged position specifically to his mental health status by comparing himself with professionals who have advanced their status with an identical qualification. The lack of opportunities in relation to user representation may reflect the fact that no paid user representation posts were available in the participant's local area. Only one participant (M) expressed optimism in being able to obtain and maintain paid employment, stating that he had worked at an arduous job in his father's company the previous summer. He was aged in his twenties and perhaps older participants were more pessimistic due to experiencing greater years of rejection. Indeed, one participant (E) cited the dual impact of mental health and age discrimination on the difficulty he experienced in obtaining paid work. One participant (S) commented on the number of service users who express a desire to work in mental health services (cf. Wahl, 1999). She attributed such aspirations to either wanting to improve services or to use their experience of using mental health services to benefit other users.

### **Did participants regard paid work as desirable?**

Some participants identified disadvantages associated with participation in paid work and some advantages of unemployment and of mental health status in relation to employment. Paid employment was regarded as desirable because it conferred benefits on employees and thus the unemployed are excluded from such advantages. Employment was particularly desirable because it was associated with status and a network of social contacts. One participant illustrates this through her experiences of becoming unemployed:

*K: "When I lost my job erm I knew a lot of people, mainly people like with my own background, African community, graduate level. When I lost my job, I lost the whole of that because they didn't want to know me. They were afraid that they could easily lose their jobs. Plus I didn't have status any more. I wasn't a person in the know...It's very difficult when everybody's quick to, say, networking, 'what do you do?' It's very difficult for me to say I'm on benefits, far more sickness benefits and things like that."*

Many participants expressed difficulty in explaining their unemployment to strangers or their families. Moreover, employment was therefore regarded not only as conferring

opportunities for social contact but also enables the individual to occupy a valuable role within society, as the following comments demonstrate:

*D2: "And then when I became too ill to work any longer, there was a terrible time for about three years when I was very isolated because I no longer was meeting people. I was no longer going out and meeting people. Certainly became a loner which didn't help the illness and I felt very isolated. I didn't know how to go out and make contacts and I certainly didn't feel part of society any more because I wasn't out there in society. I withdrew and became very much a recluse really...Well, looking back, I think for myself, I don't know about the rest of people, but when I was working I did feel very much part of society and you know, a contributing member. Even though I was still ill at the time, I was actually part of society because I went to work, I mixed with other people. I had social contact. And that was my way, I think, of contributing and being part of society."*

The comment, "I withdrew and became very much a recluse" indicates 'resigned adaptation' in which unemployment produces social withdrawal and withdrawal from job seeking (Warr, Jackson and Banks, 1988). Such comments raise the question of whether employment confers an alternative to the patient role of individuals. It is interesting to note that the participant expresses the view that not only does unemployment inhibit social inclusion, but also that the isolation accompanying unemployment inhibits social functioning and may further reduce the individual's ability to forge new social contacts. However, some participants discussed the disadvantages of work in terms of being caught in the poverty trap and the impact of employment on illness and individual freedom. A number of participants discussed a notional income on which they could live comfortably and used this income to demonstrate the impact of low wages on their willingness to participate in paid work. The following participant described the hardship involved in working for low pay:

*K: "Because like I used – I went to the church across the road – because on Sunday morning they gave out tea and after I paid ninety pounds for my rent and er I paid the monthly direct debit on the electricity and all the rest of it and the insurance and all the rest of it, I didn't even have enough money for milk to have a cup of tea on the Sunday. I was so broke and I wasn't entitled to anything. I was earning eight and three quarter thousand and I didn't have money for anything and I had to spend a lot of my money on my British Rail pass to my place...And*

*then now I'm living on full benefits, I'm now doing more things than I imagined myself to do. And I'm entitled to it. If you belong to Mind, you go on holiday once a year and then you have a day trip to Littlehampton."*

The participant's comments introduced the concept of a notional income in which participants contemplated the level of income required to obtain an adequate standard of living. Participants not only identified advantages to unemployment, they also identified some advantages associated with mental health status. Largely this was expressed in terms of concessionary prices for daytime activities and more time in which to enjoy leisure activities, although K indicated that not all mental health service users are likely to be so fortunate:

*K: "...The only thing you get in this borough is mental health. And we're just so lucky to be mental health in this borough. And that gives a whole gloss to everything we do because on the whole, I think if you tried another borough you'd find that it's very limiting. But you've got your own time, you're not being ruled, you can get your bus pass, you can go where you like. During the day, you can see cheap cinema, you can go swimming free, you can join the gym free. Ten pounds then it's free. You can do a lot of things..."*

The participant demonstrates the second response to unemployment identified by Warr, Jackson and Banks (1988), that of 'constructive adaptation', involving engagement in leisure activities, although Rowland and Perkins (1988) warn that absence of work is not necessarily equated with greater leisure.

A specific advantage of a mental health status identified by participants is the avoidance of coercion into work. Some participants compared themselves with people who are expected to be available for work whereas this is not necessarily expected of people with an illness or disability. However, one participant illustrated how the administration of disability benefits might leave people with mental health problems vulnerable within the context of unemployment (cf. O'Kelly, 2004).

*K: "...They've got a new regulation that came in three or four years ago which makes it harder to claim mental health and I met somebody at [group], they had a craft fair. Her husband had left her, he'd taken the dog, the children didn't want to live with her, she'd lost her job, she'd lost everything. Now she was having to*

*work as a demonstrator at the craft fair because of this law. She was in [hospital] for five months and they said all she had was emotional difficulties and it wasn't anything wrong with her and she was in for five months. She wasn't able to claim incapacity."*

A further disadvantage of employment that a number of participants identified was the difficulty in managing to maintain paid work and cope with a mental health problem. Becker et al. (1998) identified this as more problematic than obtaining work although participants did not make this distinction. A common theme to emerge was that participants were reluctant to engage in paid employment due to fears of work exacerbating their mental health problem and they associated employment with an increased risk of 'relapse'. Some participants commented on the disadvantages associated with employment that seems to render employment less desirable. For example, being in employment meant that individuals have less free time and more restrictions on individual freedom. Participants also generally felt that their mental health problems would not be accommodated in mainstream employment either due to lack of tolerance of sickness absence or lack of tolerance of behaviours possibly associated with mental health problems.

*G: "...If you said something strange in the workplace, it might be totally unacceptable. If you did something strange down here [day centre], well they would take it as a joke you know, 'that's just so-and-so, that's the way he is.' Behaviour in settings in a hospital or day centre setting is different to what they would be in the workplace...It's probably because some of these people had very strange behaviour and quiriness and that they're not going to be able to get jobs in the outside market because their behaviour's going to be considered strange and unacceptable."*

Therefore, lack of employment was associated with lack of social contacts, lack of status and lack of a valued role in society. However, participants also identified various disadvantages with involvement in paid work. Furthermore, they identified certain advantages to being able to opt out of employment on the basis of their mental health status.

### **Barriers to obtaining and maintaining paid employment**



As mentioned previously, none of the participants were involved in paid employment at the time of the study. Given this observation, I wanted to examine the obstacles to obtaining and maintaining paid employment. Barriers were identified either as associated with personal factors such as illness; environmental factors such as harassment from colleagues at work; and social factors such as the stigma associated with mental illness. Chronic unemployment, defined as more than one year spent out of paid work, was described by a number of participants. The consensus appeared to be that mental ill health represented a significant barrier to obtaining employment. One participant (P1) referred to a belief amongst service users that an individual stands more chance of obtaining employment as a convicted offender than if they have a mental health problem.

Some participants cited their illness and vulnerability to stress as a significant barrier to maintaining employment. One participant commented:

*D2: "Well I suppose what happened with me was I got to the stage where I realised the stress of work was actually making the illness worse. I was told that and I wanted to give myself a chance, to reduce the amount of stress. What jobs nowadays aren't stressful? I had an option of not working and trying to have to keep well or trying to work and not coping very well. I mean, I had tried to do some courses at the college and I found it far too stressful. A few weeks is all I managed."*

The participant identified stressful elements of employment as a competitive environment and coping with cognitive deficits caused by illness and medication. Factors associated with illness were described as interacting with the impact of psychiatric treatment and the reactions of work colleagues as accumulating to form powerful impediments to maintaining employment.

*E: "...My understanding of my disability, it seems that one of the problems for me is that I have this very bad concentration and short-term memory still...Well I believe it's due to ECT, yeah. Now when you're in a job and you're asked to do something, you can't always write it down as an aid to memory. So if I'm told something and then I go 'what did he say? What did he say?' and I've forgotten and I've got to go back and ask again, and then that's just one aspect. But*

*gradually things build up in such a way that the psychosis kicks in, so I just try to avoid it. A stable life because I know what to expect if I have to be admitted, you see. It's not something I would look forward to...I suppose really it's difficult to say specifically that a job is bad for me, it's just that's how the mind works. Because with schizophrenia, it's the delusional problems and the thought processes that get out of hand. And when you're earning a wage or a salary, you are expected to do a certain amount of work a day and I think this is where my disability really makes it difficult to stay in a job. So in a way, that's also helped keep me stable. But one of the problems with motivation with me is that some days I just stay in all day and that's not normal so to speak. And – one of the problems with schizophrenia or certain psychoses is that it can be very disruptive on being able to get back into the routine of things...I think I would find it really difficult to get into a job because I am aware that under stress or sometimes you get backbiting situations at work where they look for the weakest individual, they pick on them, which would be me."*

Therefore, barriers to employment are attributed to treatment in that ECT treatment impacts on memory and concentration, illness reduces motivation to work and harassment and stress are regarded as inherent aspects of paid employment ("it's a stressful pressure element"; "they look for the weakest individual"). When examining participants' descriptions of the stress of paid work, the use of language conveys participants' views of illness and provides an insight into aetiological explanations adopted by some participants. A number of participants appeared to adopt biological explanations of aetiology or the basis of problems in functioning, as evidenced by the terms 'latent defect' and 'chemical disturbance':

*G: "Well I don't know how long I'm going to be well for. There's still that latent defect. I wouldn't want to be doing anything full-time, just something part-time. But there again, you've got to re-arrange all your benefits. There are various benefits for disabled folk that are trying to get back into work. I don't think I'll ever be able to do full-time employment. The (last) work I do at the moment is all voluntary...Because of the chemical disturbance I've got. I've tried working on lithium before and the lithium hasn't withheld and I've collapsed, not literally, but I've had another breakdown...it's a stressful pressure element. I suppose I could work in a managed situation but you're not going to get very many managed*

*situations that are understanding. There's only something maybe within the mental health field that may be understanding but they're only going to have a certain amount of understanding when it comes to time, time off for being sick, it still remains the same as anybody else. You're still costing them money."*

Therefore, the unpredictability of illness was regarded as too disruptive and paid work too much a threat to mental health to consider paid work as a realistic option. These comments indicate why some service users may be keen to work in mental health services in that they may expect greater acceptance of illness in such work environments but the last comment indicates that even work in mental health services is subject to the same expectations of regular attendance. The participant and many others were unequivocal in attributing problems maintaining employment to the adverse side effects of medication. Participants complained of medication impeding concentration and motor co-ordination and producing sedation yet the following participant also stated that his functioning would be reduced regardless of medication:

*G: "The medication keeps me reasonably well but it also stops me working because it's a concentration problem, it's a co-ordination problem. There's also the fact that I'm pretty convinced that without the medication, there's some sort of chemical defect which is prone to pressure and stress. I've tried doing things like night-shifts and collapsing in six weeks and ended up back in hospital."*

The following participant not only concurred that medication exerts an adverse effect on the individual's ability to work but also reiterated the fatalism of the biomedical view in the use of terms like 'incurable' that echo the previous participant's use of the terms 'latent defect' and 'chemical disturbance':

*S1: "But manic depression is incurable and you're only as well as far as I can see as long as we take our medication. You get very severe side effects from medication. I spend most of my life by typing, having secretarial jobs, and my hand shakes so much now that I can't hit the right keys because they're shaking. I can't write my name. And they don't take into effect the side effects of medication or what would happen if you stopped that medication. I feel like sort of stopping my medication if I'm requested to go for a medical. I feel like stopping it for two weeks and saying 'well this is how I am when I'm not taking it' and I'd be all over*

*the place then, you know. And how can they expect you to go back to work if you're on medication? It makes you terrible."*

A previous participant (G) made reference to working in 'a managed situation', by which he may mean something akin to accommodation in employment. Another participant (R2) complained that he would be unable to work because his medication sedates him to the extent that he does not wake up until late morning and this would prevent him from working conventional daytime hours. Such comments raise the issue of adjustments in employment, possibly through the use of flexible working hours and support to overcome specific difficulties. However, two participants expressed some doubts about supported employment due to a fear of being differentiated from work colleagues and being perceived as "not pulling their weight" (D2). In addition to factors relating to illness and treatment, obstacles to employment cited by participants included stigma, discrimination and unfair treatment. The following participant made an association between the stigma linked to mental health problems and the likelihood of being excluded from employment but he also appears to refer to the dominant stereotype of a psychiatric patient as being violent and dangerous:

*T: "Well if you're considered to be a chronic psychiatric patient and there's a suggestion that you're aggressive or violent, then people don't want to employ you, even as a voluntary worker. And I last tried finding paid work several years ago. I remember I tried to go on courses teaching English as a foreign language teacher. I tried to work. I tried to become a member of the [organisation] but they wouldn't have me because there are people I know who have said things about me, so you know...it's prejudice. It's the stigma attached to mental ill health. The stigma attached to psychiatric hospitals themselves and so on."*

A major difficulty participants mentioned in relation to employment and housing is that of having a 'known address'. This is an address that is known to house people with mental health problems.

*T: "...Like I say, I went to [area] in 1978, to the Richmond Fellowship hostel and the doctor helped me to get there but I applied to [council] for a job but they knew that address and they thought 'ah nutter, nutters' house.' So they didn't want to know. It's like I'm saying, once you get psychiatrized, once you have a psychiatric label, they kick you when you're down and then they call you lazy. They call you*

*workshy. They call you a sponger. You are the victim. You are the victim of your family and you are being victimised by society.”*

The participant's experiences of attempting to find paid work contradicts any notion that mental health service users are capable of finding work but are merely lazy in not succeeding. In addition, the stigma associated with mental illness resulted in a fear to disclose mental health status in job applications. Many participants discussed disclosure in relation to job applications whereby the consensus appeared to be that participants would prefer not to disclose rather than risk being rejected by a potential employer.

*M: “I think I'd probably lie when it comes to filling it [application form] in. It's like catch 22, you fill it in and you say all these things, you're not going to get the job. You get the job and you don't tell them and they find out, they'll sack you for xxx.”*

A number of participants related first-hand accounts of rejection from employment either at the application stage or from jobs following disclosure of mental health status. Such accounts demonstrated that participants' fears of rejection if they disclosed were well founded.

*M: “...I think it [disclosure] would definitely lessen the chances of getting a job...Because you don't meet the person do you? You just see a bit of paper and I think they would just see it as 'oh this could be a problem.' Yeah, hassle. Problems. No employer likes those so I tend to think 'oh we'll disregard that one.' I applied for a job at a supermarket once, a part-time shelf stacker, which I had done for a couple of years at Safeways while I was at university. A few qualifications. I applied. I sent in a letter. I didn't even get a letter back saying 'thank you, we got your application.' I purposely put depression, ie. manic depression, and I didn't even get a word back. And to be honest, not many people with – I don't know, what's an HND? Half a degree. I can't remember how many A'levels, three A'levels and nine GCSEs and years and years of working at Safeways. This is for a part-time person that works at the freezer. I didn't even get a sort of thank you.”*

These findings reiterated those by Read and Baker (1996) that 59% of their respondents reported non-disclosure for fear of losing their jobs and 69% had been discouraged from

applying for a job for fear of unfair treatment (see also Wahl, 1999). Participants reported harassment from work colleagues as a common experience following the revelation of their mental health status.

*J: "Yes, yes. I've gone into jobs where I haven't declared it because they haven't asked me at the interview or on the form, about mental illness. I've gone into jobs and I've been accepted, taken out to the pub at lunchtime and all kinds of things and then in one case, my mother died and a month later I went completely haywire and I was requested not to return. They said 'you can't do the job you were doing, you're not well enough and we haven't got another job to slot you into.' You see, as long as I kept it hidden, everybody was fine. I was a different person. I was still the same person. I was rational by the time I went back to talk to them and they didn't want to know."*

Such experiences strongly suggest that loss of employment is directly related to mental health status because participants attributed loss of employment directly to disclosure of mental health status. A common complaint from participants was of experiencing bullying and harassment at work and that no action was taken to protect the individual from bullying to the degree that participants reported having to resign from jobs. There was general agreement that the harassment was directly attributable to the individual's mental health status, as the following participant illustrates:

*R2: "Well in those days I just didn't want anybody to know because it would have been, it would have been terrible. And it did actually come out later on in a job, that my sister had said something to her boyfriend in [village] when she was fifteen and a chap overheard it and when I started work, I was teased terribly by a chap who knew I'd been ill. And I had to leave the job eventually and that job I liked so much that when I left and went to a new job, it wasn't long before I was out of work through terrible manic depression and I've never worked since 1989."*

Participants' experiences refute Wahl's (1999) claim that employment discrimination against people with mental health problems is difficult to attribute to mental health status due to gaps in work history and poor social skills impacting on interview performance. Furthermore, it was not uncommon for participants to have been forced to resign from jobs because their working lives were being made miserable by bullying

from colleagues. The following case is typical of the reported effects of harassment on participants. The interesting aspect of this account is that the participant's judgements and authority were questioned by colleagues following compulsory psychiatric inpatient admission.

*D2: "...Then I got a job in a residential boarding school [as a teacher] and I was fine for three years and then I became ill and I was unfortunately sectioned and it was quite unpleasant. The police were after me and I was away for about six months and when I went back to work, I was fine but the rest of the staff really treated me very differently. They kept looking at me as if I had two heads and they didn't trust me making judgements any more and I mean, I was fine because I had been signed off and then signed back on so I was actually well and you – I could just tell that they really felt uneasy with me being there and it was extremely difficult because I didn't have any authority any more, because, you know, I would say something and then somebody would say 'oh I'll just go and ask so-and-so.' And I found the children weren't as bad as the adults. I did know that there were a couple who were quite naughty children and difficult children and they did use it. They would say something like 'you can't make that decision, you can't do that to me, you're mad.' And you know, so I did have to put up with quite a bit. And I had intended to stay at the job because I had actually liked the place there and the accommodation and it was all going quite well and I just felt very upset afterwards because I felt it was untenable. I couldn't continue in that environment really. It was making me more ill, sadly, so I resigned..."*

Therefore, a number of participants had been forced to leave jobs because of either explicit or subtle forms of harassment from colleagues and this was a more commonly cited reason for leaving jobs than illness. These findings reflect the discrimination reported to Read and Baker (1996) in that their respondents reported high levels of harassment, intimidation at work, dismissal and constructive dismissal. None of the participants had been offered support to retain their jobs and had not been protected from bullying, which is an indication of the level of discrimination and lack of protection that people with mental health problems experience in relation to employment. One of the participants suggested that there is a need for anti-discrimination legislation to be extended to people with mental health problems to protect them from issues such as harassment and unfair dismissals. However,

Woodhams and Corby (2003) argue that anti-discrimination legislation fails to protect disabled employees from discrimination because employers can justify non-implementation by citing resource constraints, disability is construed narrowly and claimants bringing a complaint to an employment tribunal are confronted with the difficult task of proving their disability and its impact on everyday functioning.

The determining factor in relation to likelihood of rejection, according to the following participant, is the level of responsibility of the job whereby the assumption by employers appears to be that a person with a mental health problem would be unable to manage a job involving more than a minimal level of responsibility.

*D2: "So I mean, I suppose if you were applying to clean floors or something, you would get a job. Anything higher up with responsibility and stress levels, they would be disinclined. I mean, it's always been an issue I think, in mental health, that the discrimination has made most people omit to tell people they have that illness..."*

Finally, a number of participants commented that their pessimism in relation to obtaining paid work was also due to having a poor work record and the difficulties this caused in relation to explaining gaps in the individual's employment history. This was explained in terms of a dilemma of whether or not to disclose mental health status in an attempt to explain a poor employment history and the likelihood of rejection following disclosure. One participant (E) commented that the lack of positive discrimination in employment of mental health service users leaves users to compete with others in the labour market but participants' comments indicated that they are unable to compete on an equal basis due to gaps in employment history, employers' avoidance of sickness absence, stigma and prejudice against people mental health problems and the stress of paid work.

### **Participants' experiences in relation to voluntary work**

Ellis and Davis Smith (2004) indicate the importance of voluntary work in providing structure, direction, social contact, development of skills and access to other vocational and educational opportunities. One participant (T) commented that employment was so difficult to obtain that he could not even secure voluntary work. A small number of



participants were engaged in voluntary work and did not mention any difficulties. Indeed, one participant (M) mentioned that he had worked in a charity shop whilst being treated at a forensic rehabilitation hostel and stated that his address had been no obstacle to him obtaining such work. However, another participant had applied to be a volunteer counsellor with The Samaritans and experienced the rejection of her application following an interview. The participant had expected that her experience of mental health problems would make her particularly suitable for helping people experiencing emotional distress and therefore she disclosed that she had been treated in a psychiatric inpatient unit. Nevertheless, her application for this voluntary role was rejected. No specific reasons were provided but the participant strongly suspected that she had been rejected as a result of her disclosure of her previous psychiatric treatment. Another participant experienced a clear example of discrimination in relation to voluntary work.

*D2: "...because I did try voluntary work in 'normal' society and experienced quite a problem whereas I was actually told I wasn't able to do it because of my illness and felt very difficult to integrate into that normal job, voluntary work... It was a playgroup for children and I had been there for about three months when they did a social services check and found that I had a mental illness and said I couldn't work there. I had done nothing wrong. I was not a threat. I was never working on my own with the children anyway. I had previously been a teacher, working as a teacher full-time. So it was all ludicrous but I was – so to me that was like a real shove from society saying 'you've got a mental illness. You can't even do voluntary work with us normal people. Out you go.' And I was quite thrown back by it because that was like a xxx. I was making an effort to try and get out into society and do something, make a contribution, which I thought would work two ways, help me and be a volunteer in a group. But it wasn't to be. So yes, I suppose that made me retreat back even further into my own subgroup of mental illness groups."*

Therefore, at least three participants had experienced rather explicit instances of rejection from voluntary groups. Only one participant related an instance of acceptance as a voluntary worker. Paradoxically, this participant felt that his status as a resident of a forensic rehabilitation hostel might have caused volunteer organisers to be cautious in employing him as a volunteer. Nevertheless, the denial of voluntary work demonstrates the additional denial of a role that is an alternative to the patient role. The findings

failed to replicate the claim made by Ellis and Davis Smith (2004) that barriers to voluntary work typically encompass factors such as lack of confidence, financial concerns and concerns about the impact of illness. Participants expressed the view that obstacles to voluntary work were located in others' attitudes to their mental health status.

It is interesting to note that many participants spoke of finding alternatives to employment in recognition of the difficulty of obtaining employment. Interestingly, the most commonly cited alternative to employment was involvement in user groups.

### **Summary**

Participants expressed general pessimism in relation to opportunities to obtain paid work and identified a number of disadvantages to engaging in such employment. Participants did not feel that they could attract a salary that was sufficient to ensure that they could meet everyday expenses, especially given the additional expenditure associated with paid employment. The kinds of barriers to obtaining and maintaining paid employment encompassed factors associated with illness, treatment, harassment from colleagues and the stigma and discrimination associated with mental illness. Some participants related how they had been forced to leave their jobs due to harassment from colleagues. Such behaviour included placing unreasonable demands on the individual and thus making the job particularly stressful. Other participants had to leave jobs due to deterioration in their mental health. A small number of participants mentioned difficulties in obtaining voluntary work or as being asked to leave a voluntary job following disclosure of a mental health problem. Disclosure was a major issue in participants' considerations of the likelihood of obtaining paid employment.

At the time the study was conducted, not a single participant was engaged in paid employment. All participants had experienced unemployment of more than one year and many participants had experienced more than ten years of unemployment and thus could be described as being chronically unemployed. It is notable that a large proportion of participants held advanced academic qualifications and thus should have enjoyed greater opportunities for employment than the general population. Therefore, it seems clear that the critical factor in impeding access to employment was participants' mental

health status, explained by participants as being due to gaps in employment history, to reluctance of employers to risk sickness absence and due to experiences or expectations of rejection and harassment. Whilst some participants regarded illness factors as an impediment to employment, the majority of participants identified others' reactions to their mental health status as a major obstacle to obtaining and maintaining employment and this was true even of voluntary employment.

## **Income**

During discussions of the impact of unemployment on social inclusion, participants identified low income as an impediment to participating in leisure activities. However, paid employment was also associated with the poverty trap whereby participants felt that they would be unable to earn a sufficient income from employment to be able to meet all of their financial responsibilities, especially as paid employment was associated with additional costs and low pay. I wanted to examine the impact of income on social inclusion. Because none of the participants were engaged in paid employment at the time of the study, they were all in receipt of welfare benefits. Unemployment is strongly associated with poverty (Alcock, 1997) and therefore it is important to examine whether participants defined themselves as poor, especially given Alcock's assertion that the analysis of poverty should address qualitative as well as quantitative aspects. The interview schedule was designed to answer the following questions:

- What is the impact of income on social inclusion?
- Did participants consider themselves to be poor? How did participants define poverty?
- What are the implications of living on disability benefits for citizenship?

### **The impact of income on social inclusion**

Some participants observed that dependence on welfare benefits impeded their ability to engage in social and leisure activities.

*G: "...at the moment I'm on income support and I'm in receipt of housing benefit. The house will never be mine. I'd like to have my own house. Xxx xxx by the fact that I'm unwell. It's – that's not to say I don't have things that I like because when you're on welfare benefits you have to choose what you spend your money on. So I'm able to either spend it on excessive smoking and drink but I don't smoke and I've got a computer. But it's – that's my entertainment. I can't afford to go out every night of the week."*

The comment, “the house will never be mine” indicates Bauman’s (1998) assertion that poor people are ‘flawed consumers’ in being unable to participate in the consumption expected in a consumer society. Another participant (R2) complained that he could not afford to pursue favoured leisure activities, such as tenpin bowling, due to insufficient income. However, the participant who explained the advantages of having a mental health status in the previous section (K) as involving access to concessionary fares and admission to leisure activities, complained in a later discussion of social networks, that her ability to socialise with non-users is limited by lack of money.

*K: “...I can afford a cinema ticket because I can go how I want to go. I don’t have to dress up for the cinema and I can go during the day. I can go with my friends, fellow users, and it all makes sense. We get cheap tickets. It’s all quite fun. We eat out afterwards and so on and we’re home by six, seven o’clock. But with ordinary society, you’ve got to dress up for every occasion, which costs you money. You’ve got to pay the fares, taxi fares. Everybody’s going in taxis. But when you say ‘I can’t afford it,’ you’re not on their level, you can’t really mix in with them...”*

Therefore, although the participant espoused the advantages of concessionary admission to leisure activities, she also acknowledged that she is restricted to socialising with members of her own group, mental health service users, because her income is not sufficient to be able to socialise outside of this group (“you can’t really mix in with them”). The participant appears to be describing overall poverty, which is defined as insufficient income to participate in taken-for-granted activities (Gordon, 2000). The participant also made a clear distinction between similarity based on service use and comparable income and differentiation from non-users on the basis of income. Furthermore, several participants referred to their own frugality to demonstrate how they are able to engage in social activities despite their low incomes.

Such comments lead to the question of whether participants regarded themselves as poor and how they would define poverty. Participants generally defined poverty as relative whereby they produced a notional income at a level they felt would enable them to meet their needs. They then compared their own position to a notional (or hypothetical) income. Participants also compared themselves with non-service users and used a normative standard of living as a benchmark with which to compare their own

financial situation. A notional income is comparable to the minimum income threshold discussed by Townsend and Gordon (2000), below which poverty is indicated.

*G: "I'm not poor but there are others who are – it depends on the reason you're saying you're poor. It depends on what you consider being the average standard of living. I've got a brother who's on sixty five thousand pounds a year. I'm lucky if I get seven...I suppose if I was to go and get a job and hold it down, I suppose about twelve-and-a-half thousand to fifteen thousand a year, which I don't think is unreasonable because I wouldn't do manual work anyway. I'd be happy with something administrative or in a hospital, something related to computers."*

An interesting finding was that many participants did not define themselves as poor, citing that other people, including other categories of mental health service users, experience greater disadvantage. This finding has arisen in other poverty research (e.g. Beresford et al., 1999). However, some participants also explained lack of self-definition as poor as being due to their own frugality rather than to the stigma of poverty.

### **The implications of living on disability benefits for citizenship**

Two participants referred to disability benefits as an important vehicle for social inclusion, thus suggesting that basic benefits are not sufficient to meet the needs of people with mental health problems. Therefore, the loss of disability benefits would have a very serious impact on the social inclusion of people with mental health problems. This must be borne in mind when considering the views of participants towards the administration of disability benefits, particularly in relation to disability medicals. The following participant not only discussed disability benefits as a route to social inclusion, but also provides an interesting insight into how some participants construct their illness as a biochemical imbalance.

*G: "...Basically, I've got an imbalance in my brain, a chemical imbalance, that hopefully if there was any questions, the medical professionals would give me my backing, their backing. That's when I do need them sort of thing. Otherwise, if I had all my benefits withdrawn I would be absolutely devastated because I wouldn't be able to get any reasonable sort of employment, my income would probably be low and I would probably would try and kill myself again or something."*

Disability benefits were reported to have additional advantages such as enabling people to purchase domiciliary care (cf. Beresford and Croft, 2001).

However, several participants objected to the requirement to prove their incapacity in order to remain entitled to disability benefits. In particular, participants objected to the disability medicals associated with certain disability benefits on the grounds that they felt vulnerable to withdrawal of benefit and dehumanised by the process. Comments made by members of the discussion group suggested that it is becoming more difficult to prove one's disability and therefore fewer people are able to claim disability benefits. The experience of claiming disability benefits rendered participants vulnerable to scrutiny and subjected them to humiliating questions about their 'incapacity'.

Participants made an observation that disability benefits appear to be directed towards people with physical disabilities to the detriment of claimants with mental health problems, especially due to the number of questions about physical incapacity and the quantification of disability on the claim form for disability living allowance (cf. O'Kelly, 2004). An added dimension was that the process of applying for benefits is so complex and stringent that it prevents many people from applying for the benefit.

One participant made an interesting point in relation to the disability benefit system reinforcing dependency by requiring proof from mental health professionals of the individual's incapacity:

*P1: "...But the point is, unless you are – even if you don't need assistance with daily living and quite a lot of people don't qualify almost unless you're up to your neck in services, which kind of makes you part of that system in order to get what you need in a way, in financial terms. Because people who I know who are managing okay on their own and who are still unwell but not – have decided to be separate from the services for whatever reason, do not qualify for the benefits they need to live. So that's another way really of dehumanising you and making you – impoverishing you, keeping you part of that system."*

Such comments reiterate Alcock's (1997) claim that disability benefits encourage the adoption of a disabled identity.

The process of attending disability medicals was generally regarded as a humiliating experience and as a further instance of mental health service users being subjected to scrutiny.

*P1: "The doctor barely looks at you and all the time they're assessing you. It's a terrible experience really. And if you've been diagnosed as having manic depression or multiple sclerosis, I don't think you should have to then prove that you're unfit for work, but they're saying you've got an incurable illness and, you know, it doesn't make any kind of sense at all."*

Such comments allude to the vulnerability to scrutiny by the state that accompanies receipt of welfare benefits (Flaherty, Veit-Wilson and Dornan, 2004). A related observation is that a number of participants did not appear to regard themselves as disabled and viewed such a description with some amusement, therefore refuting Alcock's assertion that disability benefit claimants will identify as disabled. Some participants thus regarded claiming disability benefits as an additional advantage of a mental health status rather than as an essential entitlement, as the following comments exemplify:

*M: "Yeah I'm on income support. I get the standard money but with an extra amount because it says on the sheet 'you get an extra amount because you are disabled,' which I think is quite funny. I suppose it's just the terminology they use but you get extra money because you are disabled. I always think it's quite funny."*

*D1: "I've just had my medical this week actually, for them to decide if I'm still entitled to it because you have to be reviewed every year. But the DSS say I'm eighty per cent disabled. It's ridiculous... Yeah because they say I need constant monitoring. But if they want to give me an extra twenty quid a week for it, then let them. I'm not doing anything else so let them."*

A further example of vulnerability to scrutiny and also vulnerability in the administration of benefits involved access to housing benefit. Delays in the payment of housing benefit emerged as a particular source of complaint. One participant reported that she had lost her home because the local council failed to pay housing benefit for her



tenants whereby her house was repossessed whilst she was detained in a psychiatric inpatient unit. Two participants described anti-fraud measures adopted by the local council in relation to housing benefit entitlement that exemplify the undermining of basic human and citizenship rights by the benefits system.

*P2: "...a man came from the housing benefit office and just knocked on the door. And you answered it didn't you? And he said 'oh I'm from the housing benefit,' and you got into a panic and let him in. My social worker was here at the time and she introduced herself, said who she was and he said he was here to make sure that who we'd said was living here was living here. And he asked [partner] to identify herself. You know, and it's like well this is who I am, here's my social worker, she'll tell you who we are, look at this great big file, this is who we are. No. No. He needed a driving license or a passport...Yeah, so [partner] went and got her passport and showed it to him. He made [partner] sign a form which she did without thinking about it and we were reading it and then he went off. And I passed that information to the Disability Association and they took it up with them and they're perfectly entitled to do that. And you know, it has quite a funny effect on you, being asked to identify yourself in your own home where you've been living for three years and claiming housing benefit, you have no rights."*

The question that arises from the above comments is whether the intrusion on the couple's family life was due to the fact of one of the couple being linked to mental health services or whether this is a situation that arises in relation to all housing benefit claimants. Nevertheless, the fact that none of the participants were employed at the time of the study and were therefore claiming benefits means that they are disproportionately more likely to be subject to such intrusions of privacy than the general population.

## **Summary**

One participant defined poverty specifically in relative terms and several participants referred to the benefits trap. These participants did not feel that relinquishing welfare benefits in favour of income from employment was a realistic prospect due to low pay and employment discrimination. The loss of disability benefits was regarded as a serious threat to social inclusion and some participants felt vulnerable to the removal of disability benefits due to stringent procedures for the review of benefits. The application

and review process for disability benefits was experienced as dehumanising and as not targeted appropriately at people with mental health problems.

Complaints were made about delays in the payment of housing benefit whereby the experience of one participant demonstrated the potential result of such delays as being homelessness. Finally, two participants expressed horror at the infringement of privacy caused by anti-fraud procedures adopted by the local housing benefit department.

## Housing

Three main issues in relation to housing emerged from interviews with participants:

- Visibility within the neighbourhood as a person with a mental health problem
- The experience of homelessness
- The experience or perception of supported accommodation

A number of participants referred to a concern about their visibility within their local neighbourhood as a person with a mental health problem. Participants linked such visibility to the arrival of emergency services during detentions under the Mental Health Act 1983. The following comments refer to a number of factors associated with such visibility.

*S: "Yeah and it makes you feel different as well. I mean, even now, I feel like I have some sort of sticker on my back or something when I walk through the town or like when I get in my car. Because when I get in my car, especially because of the neighbours. I mean, I talk to my neighbours but when I think of how many times the ambulance must have pulled up outside and all the noise, you know, And me being marched off out the door and all the psychiatrists, because they used to come to my house and I'd have social workers here and people, you know. They must have thought 'what the hell is going on in that house?' you know. So even now I do think I have some sort of sticker on me saying 'oh by the way, I'm mentally ill,' you know, or 'I'm a right raving loony' sort of thing, 'stay away'."*

The participant relates a perception of difference in relation to other members of the community, she also refers to the stigma of the mental illness label and she indicates implicitly that her home was not a place of refuge and that she experienced lack of privacy or protection from invasion by professionals. Concern with visibility in the neighbourhood suggests a perception of tenuousness of community membership.

A second experience that related to visibility in the neighbourhood involved being the victim of crime. This experience also relates to the common reference to the 'known address' in which participants' accommodation is singled out due to being an address known to house people with mental health problems. Being a victim of crime is one example of the harassment that Read and Baker (1996) found to be an important aspect of discrimination and Berzins, Petch and Atkinson (2003) found 'violent victimisation' in the neighbourhood is a common experience for mental health service users. One participant had been a victim of crime but this had been directed specifically at his personal property and thus was experienced as particularly distressing.

*R2: "Oh yeah, my car was messed about with on the driveway several times. Petrol stolen. Tools stolen out of the boot. Stones thrown, smashed the windscreen. No split the windscreen should I say, not smashed. Tyres let down. One chap threw a brick at my window. Luckily it was double glazed, hit the glass, it didn't smash, while I was in bed."*

On further probing on the reasons for the damage to his property, it became clear that mental health status played a significant role, illustrated as follows:

*R2: "Because they knew it was basically a house full of mentally ill people...it was deliberate. Oh yeah, it was targeted because we'd have fire engines and police and ambulances outside, regularly...People knew what was going on. People weren't getting on right in there. And my car was targeted. I got to a stage of xxx paranoia or just frightened. I couldn't walk up the road to the shop to get a newspaper or anything because I thought people know I'm from that house. I still feel strange about going over there in the daytime to see my friend because I feel it's a worry walking in the door. It's a known house in [town]."*

The second issue to arise in the interviews in relation to housing is the experience of homelessness. At least three of the participants had spent significant periods of time as homeless, including one (G) whose discharge from an inpatient unit was delayed due to having no home to be discharged to. One participant (A) had slept rough and emphasised the risk of becoming the victim of violence for rough sleepers, although he made no suggestion that he had been the victim of violence whilst homeless. A number of participants indicated vulnerability of people with mental health problems to homelessness caused by delays in processing housing benefit claims. Although this

problem is not confined to people with mental health problems, greater vulnerability to unemployment and therefore receipt of welfare benefits suggests that mental health service users may be more vulnerable to housing benefit delays than others. Indeed, one participant (D1) lost her property because the housing benefit claim made by her tenants was so delayed that her house was repossessed. She then became homeless due to losing her rented property whilst in a psychiatric hospital. This was the second way in which service users might be more vulnerable to homelessness than others. The participant D1, spent time living in bed and breakfast accommodation and a hostel during an extended period of homelessness. She described her experiences in some detail whereby her descriptions provide a graphic illustration of the poverty and squalor involved in living in such accommodation. It is also interesting to note that this period of homelessness followed a period of hospitalisation and that the house she had owned had been repossessed during this period of inpatient psychiatric treatment.

*D1: "Well I was sleeping rough on friends' sofas and floors. Went up to London and didn't sleep at all for a couple of days. Then I stayed with a friend up there and then he sent me back to get it sorted out. So I went to the council and they said they would put me in a bed and breakfast while they investigated my homelessness. So they put me in [hotel]. That was costing about ninety-five pounds a week bed and breakfast...and the council only pay about sixty pounds for rent so I had to find the rest out of my giro so I was paying them thirty pounds a week out of my giro, which was leaving me a tenner a week for everything else. And that was just bed and breakfast, that was no meals or anything. And the room was about five feet wide and ten feet long. It was just like a little broom cupboard. The broom cupboard was bigger than the room. And it was at the back of the hotel and it was crap for the money...So yeah, I didn't want to stay in the [hotel] because I couldn't afford it anymore so they moved me into bed and breakfast in [road], which was a total nightmare. That's the road behind the shopping centre. And it was a really ghastly old building and the kitchen was open for an hour in the morning between seven and eight o'clock...and the room, I wouldn't keep a dog in it. It was horrible, really disgusting..."*

The last comment indicates the unsuitability of the accommodation not only for the individual participant but also for anyone with a mental health problem. Such conditions following discharge from a psychiatric hospital would never be conducive to recovery

and cast doubt over the adequacy of the discharge planning and provision for people with mental health problems.

The relatively low rates of homelessness amongst the study participants might reflect the fact that only two of the four study areas were large urban areas whereby homelessness is highest in urban areas (Burrows, 1997).

The third issue to emerge from the interviews was the experience or perceptions of supported housing. None of the participants were resident in care homes but at least two were living in supported accommodation at the time of the interviews. At least two participants owned their own homes. One participant (A) commented that people who live in residential care homes are particularly disadvantaged due to a low income. He had previously lived in such establishments. However, a more frequently discussed aspect of supported accommodation was a perception of dependency on professionals in such housing. Observations were made about the general problem of being reliant on professionals' assessments of suitability for independent living and a reliance on their recommendations to housing agencies:

*G: "...the only trouble is with public sector housing either provided by the local authority or a housing association, you have to have a recommendation of a health professional. They just don't give it to you because they want to know that you're stable enough to take on the tenancy. They don't want to put somebody in the property and then the tenancy collapses. You're gonna look after the property et cetera. The housing authorities work hand in glove with the health authority so there's some kind of conspiracy. So if a social worker says 'you can't have a flat G' or the housing authority won't offer you a flat. So you're being dictated to all the time...When I tried to move from Tower Hamlets, which is in east London, to [town], they turned round and told me basically 'see how you are in three years' time, you can't move now'...They wanted me to go through their system. But as soon as I tell them I wanted to go to [county], I felt my rights were being taken away. They turned round and said 'you can't do that, you've got to get better first'."*

The problem of "being dictated to all the time" reflects another participant's (T) complaint about staff in supported housing demanding compliance with medication.

This complaint indicates vulnerability to scrutiny and authoritarianism in housing services. Another participant reiterated the problem of dependency on professionals in supported housing:

*J: "I've been offered some supported housing and, quite frankly, I felt I would feel even more of a user in a supported house with nurses coming in there to visit people in the house who might be worse than I am at times, you know. And I felt it was ghettoising my life and everybody told me I should have taken that...I thought I'd feel more dependent and more of a user, you know."*

However, another participant (E), who was resident in a supported accommodation project at the time of the interview, had divergent views and felt that it was beneficial for him and beneficial generally due to rapid access to professional support in times of crisis. Another observation on supported housing was the lack of privacy due to sharing communal living areas and that personal business did not remain private.

Finally, because people who use mental health services may be less likely to be able to buy their own property, they are likely to rent property in the private sector at some point in time. One participant (D1) commented that, following the Housing Act 1988, tenants enjoy much less protection in the private rented sector and are particularly likely to be subject to insecure shorthold tenancies.

## **Summary**

It is clear that participants had experienced housing conditions that ordinary citizens should not be expected to endure. Participants experienced lack of privacy and high visibility in their neighbourhood due either to the appearance of the emergency services outside their homes or due to the behaviour of other tenants. This means that people who use mental health services may experience difficulty in maintaining their dignity and privacy within the neighbourhood. Secondly, one participant's experience of homelessness conveys the squalid conditions of the bed and breakfast establishments that homeless people are expected to inhabit and the sheer expense involved in staying in such accommodation. There was an indication that poor discharge planning allowed the participant to live in such poor conditions. Therefore, adequate discharge planning could have prevented homelessness. Thirdly, participants' experiences and perceptions

of supported accommodation were of dependency on professionals and a lack of privacy that most people would prefer not to experience.



## **Education**

Dunn (1999) identified exclusion from education as an aspect of the social exclusion of people with mental health problems, citing both practical problems and low expectation of mental health service users as significant barriers.

At least six participants had attained advanced qualifications, including university degrees and at least one participant held a postgraduate degree. However, being qualified to degree level seems to become redundant in the context of mental health status whereby mental health stigma means that individuals are likely to be excluded from employment, regardless of their educational attainment.

One participant (D2) discussed difficulties she had experienced in attending a college course whereby the college environment had been competitive and learning proved problematic due to the cognitive deficits caused by her medication and her illness. In addition, the participant had previously studied for a professional qualification at college and had experienced ejection from the course following a period of absence. The interesting point to be made about rejection from that particular course is that the profession was one in which members are likely to work with people with mental health problems and thus the rejection of the participant from that course raises questions about professional attitudes towards mental health problems.

There was a minority view that support was available for students with mental health problems. The more common view, however, was that discrimination against people with mental health problems in the education system is widespread.

One participant had experienced explicit discrimination at his local further education college. He had been elected as president of the students' union but the college authorities had requested his resignation following disclosure of his mental health and forensic history. The participant stated that he felt terribly discriminated against and that the college was clearly contravening its own equal opportunities policy. I will relate the participant's experiences in some detail because his experience is a recent example of how discrimination against people with mental health problems not only exists but also

is sometimes blatant. It is of note that, although the participant related his experiences in relation to education, the following case study highlights the persistence of explicit discrimination against people with mental health problems.

### **Case Study: M**

*M: "...I was the sports secretary for the students' union. And then just before Christmas of the same year, the president left the college, so I took over as acting president. And then I went to – because the president at [college] sits on the Board of Governors, so I became a student governor. I attended their meetings, went to a residential weekend with all the governors to become a better governor. And then in May there was an election, an election proper for the next year and I got elected as the president. And everything was going fine. The last term before the term broke up in July, I gave a presentation about better funding for the student union. All the governors were quite happy, then out of the blue in July, I was sent a letter from the college saying 'could you come in urgently to see the vice principal, in charge of personnel and planning.' So I went into the college, I didn't exactly know why and then I went up to his office and sitting in his office was the chairman of the governors, a local magistrate and another governor who's a solicitor. And they said 'we've found out quite a few things about you.' And I said 'really? What sort of things?' They said 'well, we've found out that you are actually a care in the community patient with a criminal record and we think' – And they said 'we've found out that you've been in trouble with the law and looking down at the' – the chairman, he had a list of things I'd been up to and how long I'd spent in hospital, what medication I was on, everything. They even had more detail than I knew. The police officers involved in [city] in the case and I was just blown away by it. And they said 'what we'd like you to do if you could, is write a letter now resigning as president and therefore you don't sit on the Board of Governors. And then at the bottom you could write you'll never stand for election for anything at the college, even of that meant just on a course.' Because each course has a course rep. 'Don't stand for those sorts of things if that's your right.' And they said 'look at it from my point of view, imagine – I don't know, some prospective parents send their sixteen year-old to the college to do A' levels and they find that the person that represents their son or daughter is you. Doesn't*

*that look bad for the college?’ And I thought ‘er’. I was quite shell shocked by it all. So I resigned but then I went back to the student union offices, I thought about this and I thought ‘this isn’t right.’ You can’t just – I was democratically elected and why – they can’t do this. So I phoned up the NUS, which has got a legal department, and they said ‘well as long as he hasn’t got bankruptcy or fraud or something like that, you’re all right.’ And they said ‘this other thing about health needs, that’s just ridiculous. You can’t start telling people they can’t do a job because they’ve got an illness or something or they don’t fit in with what would look good to parents.’ So I said ‘put like that, yeah, you’re right.’ So I phoned up the vice principal and withdrew my resignation and then after that it was very difficult...”*

The authorities of the college eventually found a loophole in which a small gap between courses meant that the individual was technically not a student and was not, therefore, eligible to represent other students. The participant therefore had no choice but to tender his resignation on the basis of a technicality.

*M: “I just want to point out that for a college that prides itself on its inclusive policy and non-discrimination and things like that, equal opportunities, it’s a joke. And so I just wanted to point that out to people...I don’t want revenge, I just want someone at the college to acknowledge that, all right they might have seen me as some sort of criminal who looked bad for them, but I see it as someone that – well I see it as discrimination against someone that’s disabled. I mean, you can’t – supposedly discrimination covers even people that have offended. I was reading a definition of discrimination, according to – this is an equal opportunities – ‘prejudice and discrimination are unjust, disagreeable and unlawful. They may impact on women, minority ethnic groups, people with disabilities and those who have been in prison. Groups who make up the majority of the adult population in Britain. To exclude or neglect their contribution to the economy and society is to deny them the chance to fully realise their skills and talents. It makes us poorer by reducing productivity and profitability. The Director General of Employment and Training agency.’ And that’s exactly what the college did and I’ve looked through as many – I got hold of the college equal opportunities policy statement and it actually says ‘the college will not discriminate against people with disabilities.’ But they have and no one seems to have realised that at the college.”*

Therefore, the participant identified his experience as an example of mental health prejudice and discrimination. I was interested to learn how the governors had managed to obtain the information about the participant's health and criminal records. It seemed to me that there had been some sort of breach of confidentiality.

*M: "This is the exact words, 'we've been talking to friends of ours,' i.e. people in the legal profession. Because one's a magistrate and one's a solicitor. And I was thinking, when you sign up to a current governor, you have to fill in a form, have your declaration, and everything date marked, your business interests. Mine was very blank but it did have a section that says 'have you ever been sentenced or served more than three months in prison?' And I haven't. I've never been sentenced to a prison sentence and I've never served more than three months so I said 'no'. But then, what gets me, I cannot work out how they've just found this out. Why? Because a couple of weeks before, I was giving a presentation to the corporation and that was fine. Everyone thought that it was great. And then a couple of weeks down the line, I'm - God if they saw me they'd cross the road. So I still can't work out what happened that they found first of all to find those things out and then the way they went about finding out, which was basically through people they know in the legal profession."*

Therefore, the participant clearly explained that his forced resignation was not due to his behaviour whilst serving as the president of the student union but due solely to his mental health and forensic history. Finally, I wanted to hear from the participant how the college could accommodate students with mental health problems.

*M: "Well first of all, not discriminate against (them) I would say and then assess their needs. And I would just give them support. Well, it depends on how much support because there's - I was actually involved in a - I sat on a tribunal for a student that had assaulted another student and he was - yeah, he had mental health problems and his CPN came to the tribunal which I was sitting on with the vice principal, [other staff], like a panel. And what had happened is he had attacked another student but he said he did it in self-defence, that he was provoked. And the CPN came along with reports from the psychiatrist because he'd not been taking his medicine. No, yeah he'd not been taking his medication*

*and the college expelled him but they said they didn't have the level of support that he could stay at the college."*

Therefore, the discrimination the college subjected the participant to was not an isolated case of discrimination and, furthermore, the college had, according to the participant, admitted that they were not able to provide support for students with mental health problems.

### **Summary**

Participants held a varied range of views on the accessibility and suitability of post-compulsory education for students with mental health problems. One participant reported professional support and encouragement to advance his education and another participant had received support from a college once she had informed them of her mental health problem. One participant reported expulsion from a professional training course and another participant reported experiencing the most explicit and humiliating discrimination that one could imagine within the education system. He also reported that his experience was not an isolated incident of discrimination against students with mental health problems.

## **Social Networks**

I wanted to examine the opportunities participants experienced to develop social contacts and whether participants encountered barriers to forming social networks. Qualitative research into the nature of social networks is required (Green et al., 2002) in order to examine qualitative aspects of networks rather than merely focusing on size of network as an indicator of the adequacy of social relationships (Hall and Nelson, 1996; Albert et al., 1998).

Many participants discussed disclosure in relation to social networks and I was interested to consider this relationship. Finally, participants discussed their attitudes towards the formation of relationships with partners and their experiences of family reactions to mental illness.

The literature on the social networks of people with mental health problems assumes the importance and beneficial nature of social networks (Green et al., 2002). However, I wanted to examine whether participants defined friendship as important in order to be able to evaluate the impact of opportunities and barriers to the formation of social networks. I defined social networks as including friends, family members and people encountered during contacts involving a special interest. Most participants regarded friendships as important yet identified numerous barriers to developing and maintaining friendships.

### **Barriers**

By far the most frequently discussed aspect of social networks was the barriers or impediments to developing friendships. A number of common impediments were identified and included fear of rejection or reference to previous experiences of rejection, fear of mental illness among the public, poor social skills associated with mental illness, stigma and lack of opportunities to develop social networks. There was agreement that stereotypical attitudes about mental illness influenced the potential development and maintenance of friendships, as is illustrated by the following comment:

*P1: "...And I told some friends of ours who refused to talk about it and who I have since lost contact with very strangely. So I think it's very frightening for people, it seems to me, because they don't mind depression because everybody gets depressed but manic for people means mad. I don't think they can accept that."*

Green et al (2002) found that participants described friends drifting away rather than explicit rejection but the above comments suggest that loss of friends is due to negative evaluations of ill health by friends. Participants seemed to be aware of the impact of negative public attitudes on their ability to maintain friendships, but also attributed rejection by friends to their behaviour while unwell. For example, one participant (M) described how his illness had affected his friendships in that friends noticed a change in his behaviour and personality following the onset of illness but that they had remained friends and would actually prove useful in indicating the onset of illness, should it recur. He felt that he had not lost any existing friends due to his illness, despite their reluctance to socialise with him when his mood was excessively elevated. Indeed, he commented, *"They're all the same people I used to go round with before I came into contact with the mental health services and they're still the same people I go round with now."*

Another issue raised was the difficulty of forging new friendships following the onset of mental health problems.

*K: "And the stigma – my old friends know me and they still talk about how well I did academically and that's very patriotic [sic] of them but I don't make new friends. I belong to an African-Caribbean women's group in the east end, or [area], that's north-east London. I don't take any activities, whereas before, I used to teach and help with children. I have no children myself but I was quite active. But now the thought of meeting people, and them telling their children 'oh she's not normal' or 'we don't want her in your class,' I don't bother with it now. I belong to the Labour Party and they invited me to become a school governor and I thought 'no I don't want to' ...No, because when people find out your past, why you have time to devote to this type of work, then you're open to ridicule, stigma."*

Participants commonly mentioned the impact of mental health problems as a major impediment to forming and maintaining friendships. Participants particularly mentioned lack of reliability, which renders regular contact with friends somewhat problematic.

*D2: "...I'm unreliable and inconsistent. I might be well for a while and then not so well so that anything like meeting and going to people's houses or meeting up and doing things, I might not actually be able to fulfil. And when I'm feeling more well I actually can be outgoing and I would perhaps want to do a lot of things and then suddenly wouldn't be able to, so my experience is that people would be a bit confused by that, you know. One minute I would like to meet them and the next, retreat backwards and withdraw from everything...and I find it extremely hard phoning people up and talking to them. I find it very difficult using the phone and I also find it difficult to say to people 'oh would you like to come round?' But also I think I hold off because my past experience is that, you know, if you do trust somebody and you do allow them to get close and become a friend, they're going to reject you in the end anyway. So I actually probably withdraw for self-preservation."*

Therefore, the participant described a fear of rejection as a significant barrier rather than solely lack of confidence or poor social skills associated with illness. Nevertheless, she and other participants associated poor social skills with illness.

*D2: "It's a thing I've become aware of recently that – I'm not saying for everybody but, well, certain people with schizophrenia who I know have a reduced ability to communicate and tend to be much more withdrawn, tend not to say very much and it's actually very hard to get a conversation going with them. People, when they're manic, can be the complete opposite. They don't stop talking and are oblivious to anybody else's need to talk as well and that's a definite no-no in social skills, you know. You're certainly not supposed to do that. But it appears to me that when people are in their state of illness, you're unaware or maybe if you are aware, you don't care anyway, so no. And I know that happens with me as well. There's periods you can either say too much or not say anything at all. Also, things like eye contact can be very, very difficult with people with mental illness. I always find that very difficult myself but I didn't know until recently that that seemed to be quite a common factor. And sort of like not having any awareness of the rules of conversational communication or friendship even, intimacy. It seems*



*strange sometimes that I know I went through a phase when I was totally oblivious to everything and whether I lost them because I was ill or whether I never really had them, I don't know but I know I actually bought a book on it and actually had to read up on several things because there was this hole in my ability to function and I knew that if I wanted to try and function in a group, social groups and things, I had to sort of learn the rules I suppose."*

Another participant attributed poor social skills to depression that reduces her motivation to meet with other people. However, she also indicated the importance of social as well as illness factors as presenting impediments to maintaining friendships:

*P1: "Yeah and the depression is just as physical because if I'm very depressed, then I won't want to be around people and if I am then I won't have any real social skills, so that's very difficult for people as well and I think there's a very able-bodied society where you are physically fit, mentally fit and you hold down a job and you have two point four children and are all heterosexuals and everything else and if you belong to that society, you're okay but once you step out of that, it's very hard to have relationships with people in that society, I think."*

The distinction made by the participant of insiders and outsiders in an 'able-bodied society' indicates exclusion. The question that arises from participants' descriptions of poor social skills associated with mental illness is whether the paucity of such skills is due to lack of practice of such skills or due to lack of confidence or due to expectations of rejection that might undermine confidence. It may be the case that a number of factors interact to produce a network of impediments to forming friendships. For instance, lack of practice of social skills might be due to lack of opportunities to engage in social interaction and such paucity of opportunity may be due to the stigma surrounding mental illness. Furthermore, participants may lack opportunities to interact socially due to confidence that has been undermined by previous experience of social rejection. On the other hand, poor social skills may derive from impaired functioning directly associated with mental health problems (social withdrawal) or with medication (e.g. sedative effects might reduce one's ability to socialise). Barriers to the development of social networks are complex in that several factors were said to interact to inhibit the development of social networks. In addition to poor social skills and the

stigma of mental illness, one participant identified the barrier of different resources available to users and non-users that makes socialising with non-users problematic:

*K: “No I don’t have a choice about having friends that are non-users. If you knew somebody – for example, some users are married...and they have children and they continue to have the same family friendships, friends of the family, and their partner and their children and the children have the same friends despite their illness. They can move in and out...But if you didn’t know many people before you were ill and then you become ill, it’s very hard to move into non-user, ordinary everyday people because you’ve got the time during the day, they haven’t. You don’t have their money. Time and money is it.”*

Thus, lack of resources means lack of choice in the composition of social networks. The participant makes a very interesting but enigmatic comment that people with friendships prior to illness can ‘move in and out’ whereas people with few friends prior to illness do not have that mobility to socialise with people who are not mental health service users. The barriers identified by participants led to the consensus that friends were drawn from the mental health community but there were different appraisals of the desirability of this finding. It was reported that the stigma of mental illness caused participants to socialise with other mental health service users.

*A: “But I’ve found in my ten years in [town] that personal relationships and friendships that I’ve had, and that other people I know with mental health problems have had, those friendships don’t last if they’re outside the mental health sphere and people tend to make friendships within the mental health group and I suppose I’ve got to conclude from that there is still a lot of prejudice and bias, a lot of stigma against people with mental health problems and that it doesn’t really matter what you do, you will always be left in that group.”*

Once again, this comment implies a distinction between insiders and people with mental health problems as outsiders or between the socially included and people with mental health problems as part of a socially excluded group.

## **Disclosure**

I was interested to examine participants' attitudes towards disclosing their mental health problems to social contacts because attitudes to disclosure possibly reveal whether participants expected rejection on the basis of their mental health status. The overwhelming response was that disclosure was difficult because it could lead to rejection and therefore would be avoided or would be considered very carefully before disclosing. However, two participants described incidents in which they disclosed in order to test the reaction of the recipient of the disclosure. The reactions to such disclosure demonstrated the stigma attached to mental health problems.

*R2: "It depends on who I'm talking to. I went into a fish and chip shop, I've been going there for several weeks and there's a lady there about fifty and she was looking at me saying – well she started talking to my friend who was saying 'I work, I do this, I do that.' And she came to me and she said 'oh have you got a job?' I said 'no, I haven't worked for eleven years.' She goes 'why?' I said 'I'm a manic depressive,' And it just blew her away. She just stood there and she didn't know what to say. She was embarrassed. It just took her so quickly from her fish and chip shop. She was just so absolutely blown away by this statement. She couldn't understand it.*

*MF: Why did you tell her?*

*R2: I just felt like telling. For once in my life I felt like telling a total stranger and the reaction I got, she didn't know what to say. She couldn't get them fish and chips put in a bag and paid, we'd gone as quickly as possible basically."*

However, the participant qualified this description by explaining that he did not usually disclose his mental health status and that his disclosure was due to loss of inhibition due to alcohol consumption prior to the incident. Nevertheless, the comment, "*For once in my life I felt like telling a total stranger...*" indicates the frustration experienced in response to constant avoidance of disclosure. The following participant was much less reticent in relation to disclosure:

*M: "So I like the idea of saying to people – I've actually set people up and then stopped myself. 'Oh see that, God, he's a schizophrenic. Another care in the community patient gone and done something.' And the person's 'oh yeah, God, they should never be let out, blah, blah, blah.' And then I'll go 'yeah, funny that because I'm actually the same.' And they go 'oh, erm, urm, uh' and they just feel stupid. 'Oh er I didn't know. Well you can't tell can you?' Oh yeah, exactly, so*

*why say 'oh f\*\*\*ing nutters?' I hate that. It really winds me up...So that sort of thing, I go out of my way to just try and get people to change their view of things."*

The latter participant was clear that his rationale for disclosing his mental health problem was to challenge the ignorance he identified amongst members of the public. However, other participants were more cautious about disclosing or had experienced rejection following disclosure.

*E: "I tend to be really discrete about that. I'm all right with other people who have had insight, have suffered or are working in the profession, in the mental health field...But I think the reason I'm reluctant to come out in a general sense about my mental health is because of the stigma...I don't think I would gain anything other than being looked at as a loony...Because schizophrenia has such a negative connotation to it, that's why I tend to be careful who I speak to."*

The comment, *"I'm all right with other people who have had insight, have suffered or are working in the profession..."* indicates expectation of greater acceptance by people who have direct contact with people with mental health problems, as suggested in numerous surveys on public attitudes in relation to mental ill health (eg. Brockington et al., 1993).

The following participant reiterated the problems of explaining lack of employment to strangers or acquaintances and the rejection that follows disclosure.

*A: "And I make no secret of the fact that I have got mental health problems. And maybe as soon as they hear what you do for a living, 'oh well I'm on the sick, sort of thing, and I've got mental health problems,' well mental health problems means something really dire to a lot of people...I think it all adds up to some kind of stigma and – which is a real barrier to people getting out and forming relationships outside the mental health sphere."*

The latter participant disclosed his mental health problem as a way of explaining why he does not work and because he believes that people would eventually discover the truth anyway. The participant who disclosed his mental health problem in order to challenge ignorance (M) had no problem with disclosing his mental health problem

because he did not perceive his history of mental health service use as problematic. However, frequent reference to the stigma of mental ill health suggests that participants avoided disclosure in order to manage a stigmatised identity, referred to as 'passing' by Goffman (1963).

### **Service User Friends**

The overall finding about social networks was that participants tended to express a preference for socialising with other people with mental health problems. The reasons provided for this encompassed greater acceptance from fellow users, greater trust that they would not reject the participant, a sense of safety and support and commonality of experience. However, participants also identified potential sources of stress associated with having friends that use mental health services. Such stress was associated with feelings of helplessness when a friend becomes ill, emotional demands made by such friends and the trauma of witnessing a friend experiencing deterioration in their mental health. However, a frequent comment made was that user friends understand illness and thus are less judgemental.

*R2: "They [users] are more on my side if you know what I mean, because they understand it. They don't look at it funny do they? They look at me like it's a big friendship isn't it? They say to themselves 'oh he's the same as me,' you know. The normal people I feel I want to shut myself away from them, keep away from them, yeah...people with some sort of mental illness, I can bond with them straight away because we're all in the same boat basically...My friends who I've met through mental health services are better friends than my normal friends because they understand. I can be completely open. We're all in the same boat..."*

The comment, "*I want to shut myself away from them*" suggests an avoidance of people who do not have mental health problems, referred to as 'outside normals' by Estroff (1981) and the comment, "*I can be completely open*" in relation to 'insider crazies' (Estroff, 1981) indicates the relative ease the participant experienced in disclosing to other mental health service users. It also confirms Goffman's (1963) hypothesis that stigmatised people tend to seek out other marginalised individuals due to common identity and provision of moral support. The participant's comments can be interpreted

as reiterating the insider-outsider dichotomy but with service users as insiders and non-users as outsiders.

*D2: "Well, for me, the first thing is that people understand some of your experiences and pain and difficulties. It's a great leveller, the fact that people have all been through a rough time. To me, I don't feel threatened because I don't feel that they're going to hurt me. I mean, that's a big thing for me. I feel quite safe. It's very supportive and quite empathic a lot of the time as well. You get the odd people who aren't but probably it's their problems. A supportive and empathic feeling really. And it's very much an element of safety. And you can quite often trust people."*

However, not all participants agreed that confining oneself to friendships in the mental health community is particularly desirable whereby one participant used the metaphor of illness to describe his views of this yet he proceeded to suggest that he gains acceptance from those friendships.

*G: "I do not have any normal friends. All of my friends are mental health service users, which is a bit unhealthy."*

*MF: In terms of – you say that all of your friends use mental health services, what do you get out of those friendships?*

*G: Support that the health service doesn't provide. Like an internal support system...you can be as zany as you like as long as you don't do it to the extreme. You can be zany in front of your friends, have peculiar quirkisms, peculiar behaviour and it's acceptable. We're just accepted because we know we've all been unwell and you're not really gonna change anybody's personalities..."*

Therefore, participants identified support and safety within social networks comprised of fellow service users, referred to as mutual aid by Chamberlin (1978). Participants also identified commonality of experience and resources as a key factor in feeling most comfortable with user friends. However, it is interesting that one participant commented that a social network comprised exclusively of user friends is 'unhealthy'. Nevertheless, there was no evidence to support the finding by Green et al. (2002) that service user friends are regarded as poor substitutes for lost friendships with non-service users. However, the following participant concurred that restricting oneself to user friends involves self-imposed exclusion.

*J: ...You see, people get to go out with other users but we're isolating ourselves. We're saying we're not as good as the rest of society and I think we should belong to things. I know it's difficult for clubs and clothes and everything like that but I've belonged to an organisation for about twenty one years, nothing to do with mental health, but the two people I've come closest to there, over the years, I've found out they have been users of mental health services...*

It is interesting that the above participant had made friends with two people in particular at a non-mental health group that appear to coincidentally have had mental health problems. She stated that she did not know they had mental health problems but commented, "...you do gravitate together."

In addition, several sources of stress were associated with such friendships. Mostly, such stress was associated with friends becoming ill and becoming users of what were perceived as inadequate services, as the following comments demonstrate:

*P1: "...But I also think there's that stress of not knowing what to do to help. You know, you don't know what to do. You don't know how to help and haven't really got the resources to help anyway."*

*P2: "I was thinking about the stress also of knowing that they're going to go back into the mental health service and having an inadequate service. And if you knew that when somebody becomes unwell there was a service to meet their need, you know, they've fallen but then there's a net to catch them, then I think the stress and responsibility is taken away from you. But then there isn't that safety net to catch them so you know if they start going into free-fall there's nothing that's going to happen that's going to help at all."*

Therefore, for this participant, it wasn't illness per se that was stressful but her perceptions of the inadequate service that her friend was receiving. Furthermore, the responsibility felt towards friends' illness was not removed by use of services. However, another participant located the source of stress in his friend's illness:

*R2: "...I've got one friend who's a manic depressive like myself, who is very unstable. He's always drinking on his tablets so his tablets don't work and he's a bit of a strain because he'll phone me at different times of the day. He's constantly high or he's low. He won't get out of bed 'till three in the afternoon. And it is a*

*pressure. I don't want to lose him as a friend because I've known him twelve years. He's quite a worry that he could do something wrong. I've had to get services to get him in hospital before...It's a worry I could do without. But then he's seen me really ill and he's stayed by me. He's seen me saying stupid things, being as high as a kite, like he goes. And it's put him under stress. But then it's still a rewarding friendship. We've both got the same illness after all. So we help each other."*

It is clear from the participant's account that social networks comprised of fellow users might include stress associated with others' illness but also involve reciprocal or symmetrical relationships in receiving support as well as providing support through illness.

### **Partners**

Three participants stated that they had experienced rejection from partners and other participants expressed the view that they would feel more comfortable having a relationship with a service user than a non-user. They expressed the belief that they would not be accepted by a partner who did not have a mental health problem.

*S1: "...I don't think I'd like to go out with a guy now unless he was a user. I feel that they understand me better."*

Despite the following participant experiencing acceptance from pre-illness friends, such acceptance was not received from partners.

*J: "...I've managed to maintain friendships with people I knew in the sixties and seventies, before I was taken ill, and they always treated me the same, you know. They don't sort of turn against me when I have another breakdown or something but boyfriends have turned against me. They're all right when I'm well but if I'm taken ill they get almost cruel and violent you know. It's very difficult..."*

The following participant expressed the view that people with mental health problems expect rejection from potential partners that do not have a mental health problem and therefore that there is an active choice made to develop partnerships with other mental health service users or people with another disability.



G: *"The same sort of thing happens in relationships, you know, relationships with the opposite sex, you know. Most of the fellas that I know don't even consider trying to build up a relationship with somebody who hasn't had a problem because they'll be rejected. Just look at me, I'm thirty seven, single, I've got no kids, I haven't been able to hold down a steady relationship...I'd like to have a relationship, yes. But it's got to be basically a partner with some sort of understanding. Yeah, I wouldn't just sort of go out with somebody and in six months' time get married, you know, because I'd really have to get to know them, you know. Maybe in my personal situation I might have to consider marrying somebody with a different sort of disability...All I'm saying is it's very difficult to find somebody who would understand. Fair enough, it's not likely to happen because it would be a stigma against that person but you might find say a social worker or even a nurse who was interested. But you just don't know because that's stigma towards them that their husband or boyfriend has been in a mental health hospital. It's a stigmatisation around somebody else. Well that's how I see it anyway. That may be a narrow view but that's just from past experience. That's what happens. Yeah I know it happens."*

The participant summarised the general view held by participants that they wanted understanding and acceptance in interpersonal relationships. He also indicates the contamination of partners with the stigma that is attached to the person with a mental health problem. This provides an added dimension to the analysis of stigma in that rejection may result from a fear of stigma being attached to the partner or friend as well as a negative reaction to people with mental health problems per se. However, another participant indicated lack of choice in partners and friends, encapsulated in the comment, *"It's a very small world"*:

K: *"The stigmatisation, you know, like I'd like to meet a fella, a male partner, and although in theory you have this whole world open to you, all you really have is [service] users and anybody you knew well before your illness. It's a very small world."*

## **Family**

Some of the participants commented that they had experienced negative reactions from family members once their mental health problem became known within the family environment. Participants described mental illness as a taboo subject within the family whereby the participant's illness was either not discussed or the participant was excluded from family gatherings. One participant (S1) described the embarrassment that her daughter experiences when the participant's moods are either high or low, apparently due to awareness of the social visibility of her mother's behaviour. However, one participant (M) described his family as supportive throughout his illness but it is interesting to note that his mother had suffered from a mental health problem and thus the support he received from his family may have been due to their familiarity with, and acceptance of, mental health problems. This factor may have increased the level of comprehension or empathy for the participant throughout his illness. Nevertheless, participants described exclusion from family gatherings following psychiatric diagnosis, indicating variability in experiences of acceptance or rejection within families.

### **Summary**

Participants generally expressed a desire to develop social networks but found several barriers impeded their access to a broad range of social contacts. Such impediments were related to rejection and stigma against people with mental health problems. Disclosure was generally avoided or expected to lead to rejection, although one participant utilised disclosure to challenge public ignorance of mental health problems. Most participants preferred to socialise with other service users and experienced such friendships as supportive. Commonality of experience appeared to be the key factor in determining preference for service users as friends. However, such friendships were also associated with stress from various sources. Partnerships with other service users were regarded as either inevitable due to rejection from non-users or preferable due to greater commonality and understanding from fellow users.

Some participants experienced mental illness as a taboo within their families but the one exception noted was in relation to a participant whose mother had also experienced mental health problems.

The position of participants within society was summarised in the following statement:

*A: "...but it makes no difference whether you're like that or whether you're totally incompetent and totally overwhelmed by your mental illness. It doesn't matter whether you're anywhere between those two extremes. It seems that you won't be taken in by the community, you won't be integrated into the community except to meet other members of the mental health circuit who you might meet."*

Nevertheless, participants were not passive victims of rejection by non-users because they demonstrated an active choice to develop friendships with other mental health service users. However, participants also discussed structural impediments to socialising due to low income.

## **Public Attitudes**

A number of questions occurred to me in relation to public attitudes towards people with mental health problems. I wanted to examine how participants perceived public attitudes in relation to people with mental health problems. I also wanted to investigate the factors that are likely to influence public attitudes and the impact of public attitudes on community integration. Finally, I was interested to hear participants' views on what can be done to improve public attitudes towards this population.

### **Are public attitudes predominantly positive or negative?**

The majority of participants regarded public attitudes towards people with mental health problems as primarily negative. However, three participants felt that public attitudes are not necessarily negative. One participant regarded the attitudes of professionals to mental illness as more likely to be negative than the attitudes held by the general public.

*T: "I actually think that a lot of ordinary people are actually more open minded than a lot of mental health professionals and other people in positions of authority, you know, like employers, landlords and what have you. Journalists are very prejudiced against people with mental health problems but I think a lot of ordinary people, people without influence or whatever you want to call them, a lot of ordinary people realise that mental patients are basically ordinary themselves. When you hear the psychiatric profession going on about trying to fight the stigma attached to mental illness and yet it's the psychiatric profession that creates the stigma in the first place. I mean, they – it's like butchers promoting vegetarianism. Yeah, because they have this concept of mental illness, they have this concept of insanity and yet there's no agreed definition of mental illness."*

The participant makes the distinction between the attitudes of ordinary members of the public and the attitudes of people who play a significant role in determining the inclusion of people with mental health problems into society. For instance, the attitudes of employers and landlords would be expected to exert a critical influence on social participation. This view appears to refute the notion that increased contact with people with a psychiatric diagnosis produces increased tolerance of this group, as propounded

by Brockington et al. (1993). The participant also blames the biomedical model of psychiatry in producing stigma (“...it’s the psychiatric profession that creates the stigma in the first place”).

One participant (M) indicated that public attitudes may be improving but also indicated a lack of comprehension of mental health problems by both the public and by medical professionals. Another participant commented:

*S1: “Well I had that so much. Up until a few years ago, people would say ‘you haven’t got a housing problem, you haven’t got this, you haven’t got a money problem, you do this, you do that.’ And that’s just so ridiculous to say that. It means that everybody who’s poor should be ill then, you know. And that’s not the way life is. You shouldn’t be ill, you shouldn’t do this, you shouldn’t be depressed and you’ve got nothing to make you. You’ve got a child, you’ve got a mother, you’ve got a daughter, you’ve got – and I did. I had all those things but I still didn’t waste twelve years of my life to have a little bit of whatsername. You wouldn’t waste all those years would you? Losing a flat, losing everything. No one’s gonna go that far.”*

The participant refers to the view that people can somehow snap out of their illness or shouldn’t be ill because they should be grateful for what they’ve got. Johnstone (2000) referred to as this the ‘pull yourself together approach’. The participant’s comments demonstrate the public’s lack of comprehension of mental health problems. The following participant describes the fear with which the public view people with mental illness and the isolation that this produces:

*D2: “...I think an awful lot of them, because of ignorance and fear and prejudice and stigma view it like the first one you said, as something to be feared. And I think that for the majority of people of the public, that’s how they view it. Which is very sad because that’s what, to me, creates worse problems because the more society views mental illness as that, the more it will be kept under covers and the more it will get worse and the more isolated people will be and the whole spiral continues, you know. It’s like locking the skeletons in the cupboard, it will come out one day.”*

This concurs with the view that fear is the most likely reaction to people with mental health problems (Penn and Martin, 1998). Fear is likely to be generated by perceived characteristics of people with mental health problems. There was a consensus amongst participants that the predominant public stereotype of mental illness, and schizophrenia in particular, involves the indication of an association between mental illness and dangerousness to others. The following participant identifies a distinction in the minds of the public between mental illness involving psychosis and depression in that the latter is regarded as much less taboo. A number of participants made a distinction between different types of mental health problems in order to demonstrate the greater acceptability of depression over illnesses such as schizophrenia and mania. As one participant commented '*mania means mad, you see*' (P1).

*M: "If anything, it's [public attitudes] got worse, like people with personality defects. Dangerous schizophrenics wandering around at any minute liable to kill someone...So if something's going to be an epidemic and at the moment mental illness, oh God not one of those nasty – schizophrenics come in for such a raw deal. Schizophrenics you're gonna turn into someone else with an axe or something or – I just hate that stereotype of someone walking round in a world of their own sort of talking to themselves and – I don't know, doing bizarre things. Oh yeah I've seen that sort of thing but the majority of people it's just depression. It's out and out depression. My mum's had it, my younger brother gets it, I've had friends – just so many people have it yet there's the stereotype. That's a mental illness, ooh no, that's depression, that's not a mental illness...Oh yeah, depression is being embraced at the moment. People like 'oh a bit down,' everybody's talking about it. It's not like it used to be like 'oh cheer up, why are you depressed?' It's become much more acceptable now but I don't think mental illness is though."*

Therefore, the participant argued that even though depression is very common, the predominant public stereotype of mental illness involves psychotic phenomena and an attitude of differentiation towards the person. It also involves the image of the dangerous psychotic roaming in the community ready to commit random acts of violence on strangers. He also reiterated the distinction between depression, which is 'embraced', and psychotic illness, which elicits rejection. Other researchers have found that participants describe a hierarchy of diagnoses whereby some diagnoses are

considered to be more stigmatising than others, especially schizophrenia and borderline personality disorder (MHF, 2000). Another participant (A) argued that such a stereotype ignores the statistics that demonstrate that someone with a mental health problem is far more likely to harm him or herself than to harm others. Meanwhile, M argued that people with schizophrenia are far more likely to be afraid of other people and to withdraw from social contact as a result. However, the hierarchy of stigmatised diagnoses appears to negate negative responses to depression, such as the 'pull yourself together' approach described by S1 earlier.

Participants also asserted that negative public attitudes towards mental illness are conveyed in the derogatory language used to describe people with mental health problems. Participants referred to terms such as 'loony', 'nutter' and 'schizo'.

*D2: "I think people who have come into contact in any way, whether it's professionally or through families or personal experience, being educated, through the media or whatever, I think their views have definitely changed and they've had to have a better, realistic view. But there are some people who are very prejudiced still, whose automatic response to somebody with a problem like that is that they are dangerous, they are going to hurt them or are bad people, they should be locked up. And you just experience it in everyday language, in every word used. In slang, insulting words. One of the worst ones I've heard was 'rabbit boiler' and I had to get someone to explain it to me. I couldn't understand what that was."*

The term 'rabbit boiler' appears to have derived from the film 'Fatal Attraction' in which a rejected lover seeks her revenge by placing a former lover's family rabbit in a pan of boiling water. The rejected lover is portrayed as mentally unstable in the film. Nevertheless, the participant argued that contact and familiarity with people with mental health problems is likely to reduce negative attitudes but that negative attitudes persist among people with little knowledge of mental health issues. In addition, one participant compared derogatory language to racial abuse, arguing that the offensive language is more often tolerated in relation to mental illness than it is to ethnicity.

*M: "Yeah I suppose it would be like racial abuse, everyone's hot on that all the time...one's seen as highly offensive even though the other one is offensive to someone who's been 'look, you're a nutter, you're a bloody schizo,' or whatever."*

*That's offensive to that person but I think it is generally seen by society that well for the majority of people it's not really offensive is it?"*

The lack of objections to such language also indicates the outsider status of people with mental health problems because tolerance of derogatory language indicates lack of acknowledgement of psychiatric discrimination as equivalent to, for example, racial discrimination. The participant's comments also reiterate the comparison between people with mental health problems and other marginalised groups, with the suggestion being that former occupy even lower status than other social groups. This is known as the 'hierarchy of oppression' (Keating, 1997) and is critiqued in the discussion following this chapter.

### **The Impact of Public Attitudes on Community Integration**

One participant (D2) has already referred to the impact of negative public attitudes as producing isolation of people with mental health problems. She also suggested that the emphasis of public attitudes is on containing people commonly regarded as 'mad axe murderers'. She also referred to the impact of negative attitudes on the willingness of people with mental health problems to seek help. Importantly, she reiterated the view that people with mental health problems are less socially integrated than other marginalised groups.

*D2: "I used to do a lot of work with Mencap and the physically handicapped. Twenty years ago Mencap had this very good structured programme where they would try to change things and get people more integrated into the community. But in those days, years ago, was not really seen, you didn't see people out in the community. You didn't see them. Certainly didn't give them jobs and people had an attitude that they might catch it almost. And a lot of work was done, publicly, definitely. I think the stigma of mental handicap has changed considerably. And it's more acceptable to have a mental handicap than to have a mental illness. So they managed to achieve it and I just don't see why that mental illness be xxx as well. And I think one of the things is the Government could help through anti-discrimination."*



Perhaps mental health service users may be less accepted in the community than people with learning disabilities due to an expectation of violence and dangerousness of the former but not the latter. Alternatively, perhaps an assumed irrationality of people with mental health problems renders them less readily understood than people with learning disabilities. However, it is questionable whether people with learning disabilities are fully accepted as members of the community.

The threat of containment was reiterated by another participant who expressed concern that negative public attitudes and, specifically, biased news reporting, would lead to infringements of individuals' civil liberties.

*M: "Yeah. Do you remember [murder case]? They picked up someone that had been loitering around there. He had mental health problems and he was sectioned and held for weeks and weeks to see if it was him. And he was the person mentioned in all the papers because at the time when they found him, he was ill and so they sectioned him and interviewed him and he was the first suspect. He was the most likely suspect. All the papers had it down as him..."*

Therefore, the equation of mental ill health with violence and dangerousness could have dire implications for the civil liberties of people with mental health problems. The participant discussed the Michael Stone case that preceded the introduction of the 'Dangerous Personality Disorder Order' (Laurance, 2003; Moncrieff, 2003). The section examining New Labour mental health policy will examine in greater detail the influence of public attitudes towards the mentally ill on national mental health policy.

### **Factors that Influence Public Attitudes**

By far the most frequently cited factor influencing public attitudes was media portrayals of people with mental health problems. This included portrayals of mental illness in films, on television and in tabloid newspapers. The participant who mentioned the derogatory term of 'rabbit boiler' proceeded to examine the content of media representations of mental illness.

*D2: "...and I think what society doesn't realise is probably the media, I think especially films and newspapers, they depict a dramatic angle on mental illness,*

*usually violent, usually dangerous to other people. And they blow it all out of proportion and that is what the public actually think of mental illness...*"

*M: "I think out of everyone, of all the illnesses, schizophrenics get an absolutely raw deal. No one understands the illness at all and it's – I don't know. A lot of films, you have schizophrenics in films. You won't have 'oh there's that mad manic depressive that's likely to swap into a different person.' Schizophrenics, they're open to literally open season. There's always a film, some sort of slasher film with some sort of mentally deranged person. It's usually schizophrenia... God, all people ever get to see about it from the news and it's always in a bad way. It will be – I don't know, 'care in the community patient butchers nanny' or something. It's never seen in a positive light ever. Say you had something like the Para-Olympics, everyone says 'that's brilliant. People have got through adversity to do that sort of thing.' I've never ever seen anything to do with mental illnesses put in a positive light. No one's ever gone and said 'look, oh this person's really depressed but now look what they've done.' You never see that ever."*

Therefore, the two participants concur that media representations contain sensationalist and dramatic depictions of mental illness. The second participant suggests that physical disability is more acceptable to the public than mental illness. However, one could argue that coverage of events such as the Para-Olympics is marginalised and possibly patronising towards disabled people, in accordance with the 'personal tragedy' model of disability (Priestley, 1999). Nevertheless, the two participants above were clear in their view that the general public is influenced by media representations of mental illness and internalise the negative stereotypes depicted in films, television programmes and in the printed media. The following participant expressed concerns about tabloid reporting of a notorious offender with a diagnosed personality disorder.

*M: "I can't really imagine looking at The Sun or The Daily Mail, right-wing newspaper. I bet they mention that. I'm certain that they'll say about this appeal. That will be brought up... It's certain things although they should be offensive, aren't and that – just like that. In papers like The Sun, they probably describe Michael Stone as 'nutter'. That they would have no problem using that sort of language and it's – I doubt if anyone's going to write in and complain, 'I find your description of Michael Stone as a nutter offensive.' It just wouldn't happen."*

The participant's views of the use of derogatory language in tabloid newspapers was realised in relation to The Sun's depiction of Frank Bruno's compulsory admission to psychiatric hospital. The Sun's early headline of 'Bonkers Bruno Locked Up' was modified to more moderate language. However, Richardson (2003) claims that such headlines would elicit objections due to Frank Bruno being a well-liked celebrity and perceived as being unlike other mental health service users. Therefore, the Sun's change of headline does not appear to have been a response to improving public attitudes towards people who use mental health services. Moreover, the public's lack of objection to such derogatory language suggested by the participant further indicates the low status of mental health service users in contemporary British society.

Finally, two participants indicated the possible influence of internalised socialisation on their own attitudes towards mental illness, thus indicating the importance of socialisation in the development of public attitudes. One participant described her family as prejudiced against mental illness:

*P1: "But I carry those stereotypes and those things inside me and I notice them coming up and feel horrified by them, but I have to check that maybe that isn't what I believe and do I think that? You know, inside me is a deep-seated fear of people who are out of control."*

Another participant (G) stated that he referred to psychiatric hospitals as 'the funny farm' during his childhood and that had caused him confusion when he realised that he was affected by mental illness, thus suggesting that negative public attitudes are likely to influence self-concept or personal identity of people with mental health problems and suggesting that negative public attitudes are likely to influence internalised identities of those with mental health problems.

### **Improving Public Attitudes**

A number of participants commented that people with previous contact with people with mental illness might hold more positive attitudes than people with less contact. Of those participants who spoke about improving public attitudes towards mental illness, the consensus was to advocate proactive anti-stigma education to combat prejudice and

to challenge the stereotypes that have already been identified by participants. One participant had been directly involved in the delivery of anti-stigma education to school children, journalists and nurses and uses her personal experience of providing public education to provide an interesting insight into the delivery of such programmes.

*D2: "...Basically, it's about informing people about mental illness to reduce the stigma. So there's bits about famous people with mental health problems, talking about whether they themselves know people in their family, et cetera, talking about the stigma against it, the nicknames and all this, derogatory, how it makes you feel, giving them sessions where they have a tape of voices saying really horrid things, they're trying to make a conversation. I give them a session on my experience of mental illness and the impact. We also discuss other symptoms and other illnesses and I think there's a question and answer session after mine, which usually takes ages because they have loads of questions to ask...I've got mental health problems so I hope I say to them 'actually you can still function.' So all the feedback we've had and all the questionnaires that we've had written out have all supported the session I do as being the best impact on them of what it's like to have that sort of an illness. And the last bit they always find quite difficult to do but we do adults as well."*

However, the participant described the difficulties involved in public education training:

*D2: "We've done media groups, journalists. They were awful. Well no, they weren't awful because it was my first one and I was terrified because they were quite antagonistic because I was really making them face up to the fact that a lot of what they do is actually causing the stigma and we know that they are out to get headline catchers and sell papers but what they do to people's lives, you know. So they didn't really like that but it did have them go away and think...I do talks at the university as well and trainee nursing students or mental health students and sometimes when we talk about the negative parts, they get really upset and say 'you're being very negative' and I say 'well that's what it's like, go out there and change it'."*

The message from the participant appears to be that education programmes are more likely to be successful if they are targeted at children and adolescents in order to prevent negative views of mental illness becoming entrenched in the individual at an early age

and thus more difficult to challenge later in life. However, it is interesting to note that none of the participants specifically discussed challenging stigma by campaigning against negative or stereotypical media representations, despite a broad consensus that such representations significantly influence public attitudes towards people with mental illness.

### **Summary**

There was a lack of an absolute consensus but participants described public attitudes as predominantly negative, involving lack of comprehension of the nature of mental health problems and as characterised by ignorance and fear. The fear of the public of people with mental health problems was associated with a public perception of the dangerousness of the mentally ill. Participants described how the nature of public attitudes towards mental illness is indicated in the derogatory discourse surrounding mental illness. The status of people who use mental health services is indicated in the assumed acceptability of such language appearing in the tabloid media.

The impact of negative public attitudes was thought to cause people to avoid services, to avoid disclosure, to threaten civil liberties and to influence national mental health policy.

Participants overwhelmingly blamed biased media portrayals of mental illness for the negativity of public attitudes. There was a consensus that the media portray the mentally ill as violent to others, particularly in relation to schizophrenia. Two participants also indicated the impact of socialisation on the development of negative attitudes towards mental health service users.

The consensus amongst participants who expressed an opinion on the matter was that public education programmes are the most effective way of changing public attitudes. Interestingly, none of the participants suggested directly challenging media coverage of mental health issues, although one participant was involved in the education of journalists, in addition to mental health professionals.

## **Mental Health Services**

This section refers to community mental health services. Participants' views on inpatient psychiatric services will be presented in a later section. It was interesting to note that participants engaged in extensive discussions of their perceptions and experiences of mental health services. This may have been due to the recruitment of some participants from a user group involved in action to improve local services. It was clear from participants' responses that experience of community services and psychiatric hospitalisation impacted negatively on community participation and social inclusion.

Firstly, participants made comments that were categorised as an evaluation of community care. Secondly, I examined participants' ideas on the components of effective mental health care. Thirdly, I compared participants' views on what they wanted from mental health services with actual mental health care provision. I also examined the nature of professional power in the mental health system and the use of medical hegemony to maintain such power.

### **Community Care**

Participants made comments about the overall organisation of mental health services and indicated numerous failings of community care. Key issues raised were problems in accessing appropriate mental health services, due to being offered services that did not meet their needs, bed shortages, high case loads and overall lack of funding. More specifically, there was a general view of an over-emphasis placed on crisis intervention at the expense of preventative approaches, as the following participants describe:

*P1: "But there seems to be very little resources on preventative care that either you're well enough or you need to be in hospital."*

*P2: " My aim would always be to have a preventative medicine other than crisis because it's just so damaging, you know. The damage on that person and within the family unit can be unbearable. But they won't respond until somebody has either made an attempt on their life or made an attempt on someone else's life. Then they'll respond. That can't be right."*

Similarly, Rose (2001) found a lack of alternatives to inpatient admission during a mental health crisis. Another participant (G), located in a different part of the country, complained that services are difficult to access out-of-hours even in a crisis situation. He stated that crises are often left for the police to deal with and commented that the police are not always the best personnel to deal with mental health crises due to lack of sensitivity (cf. Rose, 2001). Another participant (R2) cited the case of his friend who committed suicide as a result of delays in accessing services.

Lack of support was also described following discharge from hospital. The following participant described lack of support at a time when she appears to have presented a significant degree of risk to herself:

*S1: "...Because I used to be sent home and just go and lay on my floor for months and never go anywhere. I never had any support. Nothing at all. That is important, support and all that I think. Even if you turn around and say I don't want it, which I probably did, I don't know. I can't believe they went nine years and didn't offer me anything...I mean, twice I went to the Tube and tried to throw myself under the Tube after leaving the [hospital] after three months."*

However, one participant did identify the availability of support as necessary and useful in terms that appear to support the biomedical view of mental health problems:

*G: "Well the good thing I suppose is the fact that they're there. People have got to accept the fact that there's a natural ailment, mental disturbance, which has to be treated in some way because there are people that need help and I'm not saying that medication is always the answer..."*

The longer-term consequences of negation of a preventative approach were identified by one participant in terms of lack of recovery. She referred to specific preventative strategies that are identified as missing from current mental health services. Interestingly, she identified information on preventative coping strategies as deriving from self-help books and groups and not from statutory mental health services:

*D2: "You know, they've been through the system, this happened to me and where does it take you in the end if you're never gonna get better and you're gonna keep coming back? Do you want to continue that life? And it took me fifteen years of being*

*in the system to get some help on looking at preventative measures and an alternative life. Mainly through myself actually going and looking up self-help books or joining groups. But I really believe that there needs to be much more work on strategies for living and living skills and coping strategies and work towards prevention of situations that can cause mental illness. Otherwise, I just think it's going to blow up into an epidemic in this country all over."*

This view concurs with the recommendation of the Mental Health Foundation that mental health services should adopt a holistic approach to mental health in which emotional, physical and spiritual needs are addressed and provide a broader range of services in accordance with such needs (MHF, 1997, 2000). In addition, the Mental Health Foundation reported similar lack of choice in services and lack of alternatives to conventional treatments, such as medication.

I would describe general problems of access to services as the 'paradox of availability' in which people who may not want a service may be coerced into accepting a service and others that do want a service experience difficulty accessing services. The following participant describes the paradox of availability:

*P1: "...Again, from the manic depression group, there are two categories of people. Those who've been admitted to the acute unit and those who haven't. And those who haven't always struggle to get the service they need. They're always struggling to get the right medication or to see their psychiatrist or to see their CPN or you know or whatever. And those who have been admitted to an acute unit are always struggling to get away from that. They're struggling to get the psychiatrist to lower their medication."*

Therefore, participants complained of significant gaps in services in the sense that either services are difficult to access or they adopt an approach that is not conducive to long-term recovery. I was interested to hear from participants the possible reasons for the inadequacies in services that they identified. A number of reasons for the failings of mental health services were postulated, including lack of talking treatments, an emphasis on medication, high caseloads, bed shortages and inadequate funding. In the following section, I will report that many participants expressed a desire to receive talking treatments. However, this was identified as a significant omission from services.



Talking therapies were regarded as being either inappropriate or not sufficiently available by many participants. Many participants complained of the emphasis placed on medication at the expense of other treatments and one participant commented “...*But they don't offer you any support for emotional issues at all.*” (P1)

One participant (R2) identified poor levels of support as being due to high caseloads of professionals, citing that his CPN had fifty-five people on his caseload. The participant described mental health workers as ‘overwhelmed’. Another participant (E) identified inadequate funding and bed shortages as problematic in the organisation of community care, although he did refer to the introduction of a home treatment service in his area as a progressive step. On a more specific issue, two participants expressed concern about the role of drug companies in the provision of community care. Both participants cited the priorities of drug companies as promoting their products to GPs and psychiatrists by offering incentives to attend conferences and meetings that involve the promotion of the product.

In summary, participants generally felt that the range of services available to them was limited and that there was too much emphasis on medication and on crisis intervention at the expense of talking treatments and preventative intervention. The following section will examine participants’ preferences for the services offered to people with mental health problems.

## **Treatments**

I asked participants to describe the mental health services they thought would be most useful in order to compare their proposals with the actual mental health services they described. Most participants described talking treatments or simply having someone sympathetic to talk to as assuming a prominent role in an improved mental health system (cf. MHF, 1997). However, many also complained that counselling, psychotherapy and psychological interventions fell below their expectations due to long waiting lists and the limited number of sessions offered. Furthermore, four participants described how they had been denied access to counselling or psychotherapy on the grounds that it would be “dangerous” (S) for them. A number of participants alluded to

more holistic approaches to mental health as being helpful, as the following participant explains:

*D2: "But to me, an ideal situation would be to see somebody who could prescribe you medication but can also give you therapy, talking therapies, et cetera and see you as very much a person in the community, your social environment, your – you know, everything about you, your lifestyle, and help look at that, the stress levels, your job, everything. It's not just your illness, it's what's led up to it, what's the future going to hold? And they don't address that."*

A number of participants were critical of the biomedical approach and one participant advocated a complete abandonment of this approach in an improved mental health system, with greater credence awarded to users' accounts of their experiences:

*T: "There would have to be an absolute sea change in attitudes towards people labelled mentally ill. I mean, they would be listened to and if they came out with stories of their being abused in whatever way, as children, sexually or physically abused or the mental abuse going on into the adulthood of the child, the authorities, they would take people seriously. They would embrace the theories put forward by R.D.Laing and they would reject this biopsychiatry approach, this emphasis on medication, on drugs. The whole targeting of the patient, you know. The way it is, a patient can't break wind without it being noted by a nurse as being evidence of mental ill health."*

Participants commonly expressed the view that service users are not listened to by mental health workers in relation to explanations of illness, backgrounds or views on treatment. One participant (P1) described her impression that mental health workers believe that service users should not challenge their specialist knowledge. A further participant wanted services to provide users with more information on illness and treatments in order to encourage greater autonomy and self-determination in managing their mental health problem:

*M: "Yeah I think tell people they have a problem. Not sort of speak down to them. Explain to someone. I wish someone had explained to me sort of four years ago. Said 'look we think you've got something, it's not a problem but it's something you can deal with. This is what you've got. This is how you can help yourself. Now with a little bit of knowledge, you'll be fine. You'll be able to – people wouldn't even know*

*sort of thing'. But no, it's – they have to approach it from a different angle rather than say 'look you're a mentally disordered criminal,' whatever it is. Thanks I feel really good now. People should be – the doctors should give the patients more trust to help themselves... ”*

It is interesting that the participant refers to the negative effects of labelling, for example, labelling someone as a mentally disordered offender. The participant also appears to refer to a need for greater emphasis on preventative approaches and greater emphasis placed on service users' potential for recovery. A commonly held view was that mental health professionals viewed users as essentially different whereby many participants referred to a 'them-and-us' attitude held by professionals, implying workers' attitudes of the inferiority of service users in relation to professionals. This is an example of 'dividing practices' in which the 'mad' are fundamentally differentiated from the 'sane' as a form of subjugation by one group (professionals) over another (patients) (Foucault, 2002). Finally, one participant (G) argued that mental health services should provide greater assistance to users wanting to return to employment (cf. MHF, 2000). This argument corresponds with the earlier assertion that mental health services should adopt a more holistic view of the person and their environment in order to treat mental health problems in an ecologically valid, broad context.

### **Psychiatrists**

I have already described participants as expressing concern that mental health services over-emphasise medication as the predominant form of treatment. This is exemplified in the operation of outpatient appointments with psychiatrists. Outpatient appointments were a common source of concern whereby the majority of participants to discuss this issue stated dissatisfaction with the standard of care they received at such appointments. The most common causes of dissatisfaction were the lack of time at appointments; lack of relationship with the psychiatrist; lack of consistency in terms of frequent changes of staff; the lack of accountability in decision-making by the psychiatrist; and explicit emphasis on medication as a method of risk management. In fact, psychiatrists were particularly unpopular amongst participants whereby three participants referred to psychiatrists as 'playing God', promulgating a sense of omnipotence and arrogance. In

relation to outpatient appointments, the following participant exemplifies the views expressed by many participants:

*P2: "No all there seems to be is the time pressure. Everything's rattled out so quickly that it's not like a relationship where someone's enquiring about how you are so they can assess the most appropriate treatment. It's like he's got five minutes to give you a prescription and in that five minutes you've somehow got to convince him of how you are so that you hopefully get some appropriate medication. But there's no comeback if you don't. Sometimes – I mean, in the beginning, when you were going on your own that it was like 'well what's he done that for?' ...And also it's not actually our experience but most people, they'll see one psychiatrist then for their next appointment they'll see another one so they don't build up any relationship with them. So they have no confidence in these people and so what happens is then that people begin to try to medicate themselves, to keep themselves well. So they learn about the medicines..."*

The participant was describing her experience as a carer of her partner so that her experience was as an onlooker in outpatient appointments. She even described an incident in which the psychiatrist spoke to her for a significant portion of an outpatient appointment, having mistaken her as his patient. The participant used this as an explicit example of how psychiatrists lack knowledge of their patients and relate to their patients so poorly that they may not even clarify the identity of their patient when an outpatient appointment is attended with a carer or friend. The participant's description of outpatient appointments underlines the emphasis placed on medication in these appointments and also indicates the lack of accountability of psychiatrists for their decisions. This was a frequent concern in relation to psychiatrists that will be explored in the following section. The following participant describes not lack of knowledge of the patient but lack of knowledge of a service. This might suggest that the psychiatrist lacked local knowledge, possibly indicating the problem of using locum staff. Two participants complained that psychiatrists appear to lack interest in their patients and this is described along with the function of risk management in prescribing treatment using psychiatric drugs:

*R2: "I just recently saw a psychiatrist on Thursday. The man was useless. Useless man. He knew nothing about the service I was talking about. He just – basically 'I'll see you in three months, keep taking the tablets.' I thought 'you just wasted my time*

*coming to see you.’ There was no proper interview...They don’t listen properly. All the time you’re taking them tablets and you’re not causing any trouble in the outside, they’ll leave you alone. Once every three months, come and see me. Yeah. They send you a letter to go and see them.”*

However, the same participant described a positive experience of an outpatient appointment whereby he discussed the elements that comprise useful contacts with psychiatrists. He explained that the helpful outpatient appointment involved visiting a psychiatrist who possessed knowledge of his patient by reading the medical notes, by showing a genuine interest in the patient, by spending time with the patient and by adjusting medication to suit the needs of the patient.

### **Accountability**

Three participants described psychiatrists as ‘playing God’. This appeared to be a reference to the power of psychiatrists to make far-reaching decisions that affect many areas of patients’ lives. It also appeared to refer to lack of accountability in decision-making and the power of psychiatrists to make decisions purportedly in the best interests of the patient. The following participant directed severe criticism at a particular psychiatrist who she accused of ‘playing God’:

*S: “Well I said to him [psychiatrist] because basically with my life, he was playing God in a sense because he’s not answerable to anybody. What he says goes. I was aware that each time he wrote a report on me and it went to case conferences or whatever to do with [son], it was down to him, down to him. He had the last say. He said whether or not it would be wise. And I was waiting, waiting for the day when he’d say it was okay and he eventually did...But to me, that is playing God. I mean, who is he to decide?...and the bit about medication. I mean, if you go to your GP, normally you should take what they give you because they know what is best for you. You think they do, well not all the time, but you think they know what’s best for you because they’ve trained to know what’s best for you. They’ve been to medical school. And so have psychiatrists, meant to have been, but really I think the only people that know what’s best for you is you. Me...but yeah, he was playing God, telling me to go on this medication, telling me to do that, telling me I had to stay in hospital, telling me I wasn’t allowed to see my son. He didn’t actually tell me that but because of*

*what he wrote that's what happened. Yeah he was. That's why I say he was trying to pay God."*

Many participants were troubled by the apparent lack of accountability of psychiatrists in their decision-making, particularly in relation to alleged malpractice. A number of participants expressed frustration at the lack of justice for victims of psychiatric malpractice. One participant (E) discussed malpractice in relation to the severe adverse side effects he experienced as a result of being prescribed Largactil. He described himself as a 'victim' of psychiatry and expressed concern about the psychiatric treatment of elderly patients and the potentially higher rates of iatrogenic death in this population. He espoused the strategy of adverse media publicity of cases like his own but cited collusion between psychiatric professionals as preventing justice being achieved in such cases:

*E: "...I think it's a situation that there is quite often a great collusion within their own profession to help one another and to protect one another if malpractice has happened."*

Lack of accountability was also thought to be related to the treatment of complaints by service users in which complaints of malpractice or poor treatment are regarded as lacking credence and thus users themselves are regarded as lacking credibility. When participants discussed making complaints against poor practice they expressed dissatisfaction that complaints are often attributed to illness or they expressed a fear of disbelief or a fear of withdrawal of services.

*D2: "...There are many frustrations and I do find sometimes at meetings I get very frustrated because there are still some people who think that a user should be seen and not heard. And when you do say your views, you're questioned and even made out to look as if perhaps you're ill because of what you're saying. But when I came out [of hospital], I was very traumatised and I wanted to complain and I just felt that nobody would believe me. It would be my word against theirs..."*

Another participant (E) explained the dilemma that some patients might experience in that he related an incident in which a service user wanted to complain about treatment but she was discouraged by fear that her services might be withdrawn. Indeed, another participant describes the actual withdrawal of a service following a complaint:

*T: "He stuck me off his list because I wrote a letter to his senior partner complaining about him, complaining about his performance as my GP..."*

Such action exemplifies the power imbalance between the patient and the medical practitioner. The issue of accountability was also examined in terms of a comparison with general medical services whereby lack of accountability was attributed to the subjectivity of psychiatric discourse as a medical science, as described by the following participant:

*S: "I suppose it's their insurance and their way of talking, their way of saying things. I mean, obviously if you were in the [general hospital] for instance, with a physical problem and they did something to your body that didn't really need to be done, then it's obvious isn't it? They can't dispute it because they weren't standing there saying 'in my opinion you need to have your breast off' or something. They'll say 'you need to have your breast off because you've got cancer' whatever. But with a psychiatrist, it's so complex anyway. But they can't – I mean, they're allowed to say whatever they like basically, aren't they? They are... But basically no doctor should be above the law but I would say psychiatrists are above the law because they are allowed to say whatever they like about a person and their opinions. Even though their opinions could change a person's life forever or maybe even kill them. They're allowed to do that but the doctors at the [general hospital] aren't allowed to do that. They aren't above the law. They are answerable. But who are psychiatrists answerable to? No one. I mean, I know there must be a governing body or something."*

The subjectivity of psychiatry has been indicated by a number of critics (e.g. Johnstone, 2000; Kutchins and Kirk, 1997), especially in relation to diagnosis (Parker et al., 1995). Foucault (2002) indicated the power inherent in a discipline parading as a scientific venture, thus enabling psychiatric service users to be subject to the control and subordination of those claiming to practice a scientific discipline. The participant's comments also describe the fundamental distinction between general medical patients and users of mental health services and particularly the subjectivity of psychiatry in the absence of somatic indicators of dysfunction. Indeed, Johnstone (2000) argues that psychiatry is unique in administering physical treatments in the absence of obvious physical pathology and in treating people against their will.

## **Professional Power**

Participants discussed power imbalances in relation to professionals with regard to issues of compliance, a statutory monopoly of services, dependency, the intrusiveness of home visits and difficulties participants experienced in extricating themselves from the mental health system. Three participants spoke directly about dependency deriving from mental health service use; the following was a fairly typical view:

*D2: "...And to a certain extent, I sadly think that an awful lot of the mental health professionals encourage that [dependency]. There's almost this – what's it called? Co-relationship? Co-dependency, whereby a mental health professional needs to be needed and the person who's ill, the patient, needs that and they fit their role so nicely that they get locked into it and neither one leaves so that this one never gets better and this one never really moves on. And that happens all the time and you can actually see it happening. So to a certain extent sometimes the system encourages that to happen, which is difficult."*

The sick role is a frequently cited consequence of mental health service use (Goffman, 1963; Johnstone, 2000). The following participant identified her community worker as helpful but regrets the dependency she experiences in relation to calling on a professional for assistance:

*J: "I find it paternalistic. I do. I'm sort of fighting all the time to maintain my individuality and my independence. And I feel I could just be taken over and changed into a sort of cabbage or something who, you know, just a vegetable. I really do and it does scare me...I'd like to get to the stage where I'm independent of support. I've asked you see, I've asked for a CPN for the last bout when I was having terrible problems and wanted to move and I was given a CPN for that situation. He did help me greatly...But at the same time, every time he comes round, I'm diminished as a person. He's a nice person. He's a helpful person but he's so nice and helpful I feel sort of as though I shouldn't – I'm a woman that's coming up to fifty-five, I ought to be able to handle these problems myself."*

There is an important question, therefore, concerning how mental health services propagate such dependency. One way might be to impede users' independence by



controlling the type of information users receive and the type of services that are available.

*P2: "I think you could easily become quite paranoid about this because you know, it's like they want the control of the information and I can feel myself thinking, you know, they really want the monopoly on all the services and all the information and all the medication and all that sort of thing but you know, from a support group of users I think that's true. Most of the good stuff comes from there. All the true information about how people experience manic depression and their episodes really does come from that place..."*

The way in which fellow users provide most useful information adds a further dimension to the reciprocity of relationships between fellow service users. This finding also concurs with the finding that most support is derived from outside of statutory mental health services (Rogers, Pilgrim and Lacey, 1993). An issue that is closely related to dependency is the difficulty numerous participants reported in managing to extricate themselves from the mental health system whereby the following participant describes how this is even acknowledged by mental health professionals:

*P1: "The CPN said to me some time ago – the one that we got rid of, she said to me once that you can – 'there'll be a time when you won't need to see me at all and I'll just be at the end of a phone for you but you won't get rid of having to see the psychiatrist.' It's like you have to see the psychiatrist for the rest of your life."*

Such comments from professionals indicate expectations of chronicity of illness, poor prognosis and lack of recovery. Indeed, the interviews revealed a common desire to be extricated from mental health services or participants commented that it is very difficult to achieve such extrication. Two participants who did manage to extricate themselves described their joy at being free from mental health services. Nevertheless, the difficulty in extricating oneself demonstrates the power of mental health professionals to demand compliance with a stated need for mental health services. The power of mental health professionals is also inherent in the system of visiting clients in their homes. One participant described such visits as intrusive and as an unwelcome infringement of personal privacy:

*J: "...But no, professionals visiting you, I mean, there are CPNs and people that do go round and it's rather intrusive. And it also advertises to everybody that you're a*

*mental patient if they're seen there often enough. It's either a social worker or a CPN."*

Therefore, participants complained of observing or of experiencing feelings of dependency as users of mental health services. Professionals were accused of wanting to control information and of seeking to monopolise service provision. This is evident in the section concerning user involvement in which participants complain that user groups and support groups are not promoted by professionals. The difficulty participants experienced in extricating themselves from the mental health system demonstrates the power of professionals to maintain some degree of control over service users' lives.

### **Medical Hegemony**

I employ the term 'medical hegemony' to refer to the power psychiatry derives from its construction of mental illness as a biological entity. Therefore, psychiatric professionals' power is derived from the medical model of mental illness and the language used to describe mental illness. A number of participants contested the medical model whereby the medical model was thought to be problematic in relation to the process of diagnosis; the notion of best interests; the concepts of insight and delusional thought processes and the discourse adopted by mental health professionals to describe mental illness. The following view was typical of the disapproval of the medical model:

*D2: "...I think one big flaw for me is that they see it purely as a medical model and I really believe that the whole system needs to change in this country and they need to look at you as a whole person and come at different angles, not just the medical model but the social model and the whole mix up of the person, what makes you who you are because you're not just a person who takes medication. You know, you need treatment in other forms."*

The participant makes two important points. Firstly, that the medical model dominates and construes the individual in a restricted way. The alternative social model is thought to construe the individual in a more holistic way. The social model is important to citizenship because it attributes disability to disabling environments that permit institutional discrimination, segregated services and exclusion from valued activities

(Oliver, 1996). Secondly, the dominance of the medical model restricts the availability of treatments to medication and neglects alternative forms of treatment. The concepts of insight and delusional thought processes undermine the credibility and competence of the patient. These concepts afford psychiatric professionals the power to define abnormal thought processes and to indicate that a patient is unaware of their illness. The following participant cites the notion of 'lack of insight' as a discourse adopted by professionals to question the credibility of users' accounts of their experiences:

*T: "But this lack of insight thing has been thrown at me for years. You know, 'he is deluded, he lacks insight' and it's all complete bollocks...The more you argue the madder they think you are or the more potentially aggressive or dangerous or sinister they think you are...And it was written down that I was diagnosed as a paranoid schizophrenic as if that proves something in itself, as if that explains quotes 'everything'. You just have to write down that phrase and that's supposed to cut off any kind of debate or investigation, you see."*

In relation to diagnosis, a number of participants complained of lack of information about their diagnosis, commonly citing ignorance of their formal diagnosis. The state of knowledge of diagnosis confirms the previously cited complaint of lack of information provided by mental health professionals. Three participants disputed the validity of any diagnosis on the grounds that they have never experienced formal mental illness. One participant complained of having received a number of conflicting diagnoses, thus questioning the validity of the diagnostic system. I asked her if she had been given information on a diagnosis:

*S: "Well I wouldn't say they explained anything to me but there was a number of diagnoses over a period of time, erm. My psychiatrist said I was psychotic. One particular psychiatrist said I was schizophrenic and then I went to the Maudsley to see a top woman who said she's neither of the two, you know. Just a bit – reacted badly to [a tragic event] and then I've had 'she's got personality disorder,' 'she's got a behavioural disorder,' erm...Well they gave me several diagnoses. And I've still never had one proper diagnosis. And you know why that is don't you? Because there wasn't anything actually wrong with me. So it's a big bloody farce and it's a big joke..."*

Although Bentall (2003) argues that diagnoses that change over time do not indicate a lack of diagnostic validity because symptoms change over time, many others question the validity of psychiatric diagnosis (e.g. Kutchins and Kirk, 1997; Parker et al., 1995; Boyle, 2002). However, it could be argued that information on diagnosis is relatively meaningless because of the subjectivity of such information whereby awarding importance to information provided by professionals implies that such information is reliable and valid. However, lack of information on diagnosis suggests a professional view that users of mental health services have no need for information on treatment, thus indicating the fundamental power imbalance between practitioners and users of psychiatric services.

The concept of best interests is, arguably, inherently paternalistic in that it awards professionals the power to determine a patient's best interests and thus possibly negate the patient's wishes. Two participants argued that psychiatrists are not necessarily aware of the patient's best interests, indeed one participant (T) argued that psychiatrists act in the best interests of those who wish to oppress the patient and certainly not in the patient's best interests. Lukes (1974) argued that one form of power is through the determination of people's interests, although he also stated that someone who agrees that another individual or group acts in their best interests cannot be said to have power exerted over him/her. The majority of comments relating to best interests refuted the notion that psychiatrists act in patients' best interests, although one participant disagreed, stating:

*D2: "...you can't always be the best judge of how you are. You're not always that aware of how you are."*

In summary, the hegemonic nature of psychiatry can be detected in the medical model that participants identified as dominating mental health services. Participants regarded the medical model as espousing a narrow view of mental health problems, thus negating a holistic approach that acknowledges the impact of social factors on mental health. The dominance of the medical model was regarded as leading to an over-emphasis on the administration of medication in mental health services. Furthermore, psychiatric diagnosis was described as being unreliable, stigmatising and as lacking personal relevance. The notion of lack of insight was regarded as derogatory and as a way of negating users' views of their experiences. The notion of best interests was regarded as

inherently paternalistic and one participant questioned whether psychiatric services were really provided in users' best interests, citing the interests of carers as more influential.

### **Summary**

Participants expressed a consensus view that mental health services should place greater emphasis on providing support through talking, either with talking therapies or simply by staff being available to talk with users about their lives. Participants complained of an over-emphasis on treatment using medication and some participants identified the medical model as propagating a narrow view of mental health problems. Participants demanded a more holistic view of mental health problems and greater emphasis on preventative intervention and coping strategies.

Participants were generally dissatisfied with the intervention of psychiatrists, citing numerous concerns in relation to outpatient appointments. Participants regarded psychiatrists as lacking in accountability in relation to their practice, particularly in relation to malpractice. Some participants felt that psychiatrists exerted excessive power over their lives and this was encapsulated in the accusation that psychiatrists 'play God'. However, at least two participants were grateful for psychiatric intervention during a crisis yet both also expressed concerns in relation to the nature of intervention.

The issues of dependency and negation of users' complaints indicate the power of professionals relative to users of mental health services.

## **Inpatient Services**

This section examines participants' experiences of psychiatric hospitalisation. All of the participants who related experiences of inpatient psychiatric treatment described treatment received in the last five years. None of the participants referred to old-style, large-scale institutions when describing experiences of hospitalisation. However, one of the geographical areas in the study was of particular interest because a new unit attached to a district general hospital had been opened two years prior to the study and enabled a comparison between an older-style small-scale institution and the new inpatient unit. Many participants discussed the older-style institution, which is referred to as KG in the findings, but expressed the view that, although the new unit represented a more pleasant environment and greater privacy, the standard of care and lack of meaningful activity remained comparable with the old psychiatric hospital.

Participants discussed citizenship in terms of a comparison between the access to rights and opportunities afforded to general medical patients and psychiatric inpatients. If such rights and opportunities are not equivalent, then psychiatric patients may be considered to lack the status of citizens. In addition, the findings refute Marshall's (1992) claim that state welfare services facilitate the attainment of social citizenship.

I wanted to examine the rationale for hospitalisation and what this rationale indicates about the civil rights and community membership of psychiatric inpatients. Most participants engaged in extensive discussions of inpatient care, mostly as a result of having been admitted to psychiatric inpatient units. Two participants had not experienced such hospitalisation directly but had visited friends in hospital and made comments about their responses to such visits. The main themes to emerge from the interview data were as follows:

- **Ward environment:** This section will include a discussion of levels of activity on the ward, availability of staff, violence, safety and risk management on wards. The discussions of such issues are summarised in an analysis of whether psychiatric hospitals provide environments that are conducive to recovery.

- **Power:** Examined under this heading are discussions relating to the exercise of power over people with mental health problems in the processes of admission to psychiatric hospital and subsequent detention, including sectioning and the status of informal detention. The practice of seclusion and control and restraint and the rights available to patients whilst in hospital are also examined.

## **Ward Environment**

### **a) Staffing**

The availability and quality of care provided by staff will be examined in this section. An almost unanimous complaint made by participants was the lack of availability of nurses on wards. Staff were described as lacking interest in the patients and to be more concerned with completing paperwork than with interacting with patients.

*D1: "It was horrible though. People there left on their own for hours anyway, just smoking or sitting doing nothing and then when they pluck up the courage to go and ask someone for help and they're told to go away. I don't expect that in hospital at all. Especially if the staff aren't doing anything else. If they're just – they need to congregate in the offices all the time. Sitting there and smoking and eating and talking. I'm sure they got some work done but they were obviously badly organised if they couldn't take time out to sit with a patient. Because you have a primary nurse. I never saw my primary nurse. I saw my primary nurse both times when I first went in, when they did the care plan and that was it. I was there for three months both times and never had a conversation with my primary nurse after that."*

Another participant complained:

*S: "...If the nurses do actually come and sit in the lounge, they pick up a newspaper and start reading or watch the telly."*

In other words, when the nurses do move into the proximity of the patients, they continue to avoid interaction with patients. The avoidance of contact with patients appeared to persist even when a patient made a direct request to talk to a nurse. One participant (D1) described how nurses would typically deny such a request by stating

that they were too busy with their paperwork. One participant (P) described how she had been admitted with substantial wounds caused by self-harm and that such wounds remained undetected and untreated due to lack of attention from staff.

Ward rounds were a particular source of complaint whereby participants cited lack of time available for the ward round, lack of discussion with patients and the numbers of professionals attending as particular sources of dissatisfaction. The following participant summarises the attitudes of participants to ward rounds.

*E: "Because it can be a bit daunting sometimes when you've got say, ten, fifteen people sitting around, all professionals, nurses and social workers, junior doctors and other nursing staff and they're all debating about what's the next stage or about release and so on. So it just depends on the individual but I know in my past I've sat in quite a big room, there must have been about twenty people there. Fortunately for me, I wasn't frightened. But I can imagine somebody who would find that very intimidating."*

Another participant (S1) complained that the large number of professionals attending ward rounds represented an infringement of the patient's privacy. The discussion of ward rounds suggested that patients find them intrusive and possibly intimidating and the lack of time meant that there is a lack of opportunity for patients to represent their viewpoint on care and discharge. Participants' responses also suggested that ward rounds are organised to meet the needs of professionals rather than to benefit patients.

#### **b) Activity and Treatment**

Participants frequently reported a lack of treatment and activity in psychiatric inpatient units whereby this led many participants to question the rationale for psychiatric hospitalisation. The following participant summarised participants' dissatisfaction with this aspect of hospitalisation.

*D1: "You don't get any treatment, right. You get given tablets if the doctor says you've got to have them. You get a ward round which is five minutes a week. There's occupational therapy for two hours in the morning if you like doing colouring in. And other than that, you're left to get on with it. No counselling, which I thought you would get. You know, if you're in hospital you'd assume*



*you'd get some therapy of some sort. There's nothing. You just sit in the smoking room mucking about with the other patients."*

Despite the general criticism of over-reliance on medication on psychiatric wards, one participant (D1) indicated that the lack of treatment extended to lack of medication. Such lack of treatment caused the participant to compare her stay in psychiatric hospital to a hotel in that she spent most of her time away from the ward. This caused her to question not only the rationale of hospitalisation but also the effectiveness of psychiatric inpatient treatment.

*D1: "...So what psychiatric treatment there was in that I don't know, but that's exactly how it was...if I'd have been really ill, if I'd been suicidal or really depressed or something. I don't know what I would have done. I would have probably topped myself because there was no help in there. So it's a good job I wasn't ill really."*

Her comments indicate a perception of neglect in inpatient units. Moreover, a number of participants cited lack of activity and attributed this to the poor facilities in hospital whereby lack of activity meant that daily routines punctured the day and became the main sources of occupation.

*D1: "We made our own amusement because there was no structure to anything. Mealtimes was the highlight of the day because it was something different to do...most days there was a blackboard, they would prop it up against the pool table, the pool table didn't have any cues so you couldn't use it. And there was a piano which half the keys were missing from so you couldn't use that either and there would be a blackboard this big propped up against the pool table with the grid of a word search on it. And that was the occupational therapy. That was what was left to entertain you with. All the jigsaws – I think I tried to do all the jigsaws, all of them had pieces missing and the books were like really old, old shitty, uninteresting novels that were, I don't know, Jim Goes to Sea and stuff like that, you know."*

The participant's previous reference to occupational therapy involving colouring in and her references to jigsaws and word searches suggest an infantilisation of psychiatric patients and a negation of therapeutic interventions aimed at facilitating recovery. The

message conveyed by participants was that there were no beneficial therapeutic interventions in NHS psychiatric units.

### **c) The Non-Therapeutic Environment**

Participants mentioned a number of features of the ward environment that they considered to be detrimental and not conducive to recovery. Frequently cited features were the behaviour of other patients, weight gain, control and restraint, violence and deaths of other patients. The main complaints concerned the distress exhibited by other patients and the general air of disruption on the ward.

*S: "Well as I said to you before, I said erm somebody could be really depressed like myself and it's an awful way to say it but I'm going to say it again anyway, you've got someone on the left hand side slashing up their arms or whatever, sticking cigarettes in their hands erm and then you've got someone on the right hand side screaming or whatever, trying to smash the windows and get out and then you go upstairs and have your friend hanging from the pipe. I mean, I don't really call that therapeutic myself. And that's basically it. That's every day, every night. Even during the night you couldn't get a good night's sleep. I wouldn't anyway, but you couldn't because there was too much going on. You'd get someone that was so distressed the bloody alarms would go off and that meant crashing of feet, like loads of people and like decking that person, you know, because that's what they thought you had to do, you see."*

Another participant (M) found his time in an inpatient unit to be non-therapeutic due to the weight gain he experienced. The participant attributed the weight gain to the lack of opportunity to exercise by incarceration and the poor sporting facilities available. He also commented that the weight gain adversely affected his self-esteem and this is noteworthy because it associates poor facilities with a directly adverse impact on patients' mental health. Interestingly, he contrasted the poor facilities available in NHS units with the impressive facilities he had experienced whilst receiving treatment in a private psychiatric unit. A number of participants commented on the superior facilities and activities offered at private psychiatric inpatient facilities in comparison with NHS units. However, private hospitals were also described as administering excessive medication even within the context of concerns raised about over-medication in NHS psychiatric hospitals.

An additional way that psychiatric hospital admission was found to be counter-productive was that it removed the person from their family and home life. One participant (D1) was not only highly distressed by being separated from her four children but she also described how she lost her home whilst she was an inpatient due to eviction by her landlord.

The view of hospitalisation held by many participants contradicts the notion of the asylum purpose of hospitalisation in which the patient is allowed relief from their problems in order to recover their mental health. It is clear that stressful aspects of the ward environment and aspects of psychiatric inpatient care led participants to question the rationale for psychiatric hospital admission. This view was summarised by the following participant:

*S: "You know, it's very damaging. I'm sorry but like I say I've yet to meet a person that actually says 'yes being in KG or being in [new unit] has really helped me'...And I know loads of people from KG...either they're still going there as nutty as ever or they're even nuttier, like I was..."*

#### **d) Safety, Violence and Risk Management**

One of the non-therapeutic aspects of the ward environment has been identified as the behaviour of other patients. A more extreme example of this is found in incidents of violence perpetrated by patients on other patients. Two participants reported having been assaulted by other patients.

*R2: "One bloke belted me in the face for no reason. A woman slapped me so hard around the face, nearly knocked me out, for no reason. It was horrendous. I think it's worse than prison myself. I'd rather go to prison than have all those drugs and being kept in like they did in those days."*

The second way in which patients were the victims of violence was at the hands of staff using a technique known as control and restraint. One of the main complaints about control and restraint was simply that it involved the infliction of pain. One participant referred to the use of control and restraint as 'physical abuse' and the staff who perpetrated such abuse as sadistic.

*D2: "But I think the worst memories for me are really the physical abuse that actually went on by some of the staff, being hurt. I was controlled and restrained many times and injected and my memories of this are that the people who did it, you can sense, I think everybody can sense, I know I certainly did when it would happen to me, that they enjoyed what they were doing and they were doing it very firmly so that it hurt me. They were actually hurting me. They weren't trying to keep me safe. They were trying to hurt me and I actually had my wrist almost broken. It was the ligaments were torn by one man who controlled me to the extent that that's how far it went and wouldn't stop when I kept pleading. And I saw it done on other people as well. It wasn't just me, it was done on others as well...And the whole atmosphere was one of aggression and well there was a malevolent atmosphere. It was a very aggressive place."*

The appropriateness of control and restraint as a technique for controlling 'challenging' or 'difficult' behaviour is questionable when examined in relation to the environmental triggers for the behaviour that attracted the use of control and restraint. Participants described control and restraint being used following escape attempts or from throwing items such as furniture around the ward. Participants attributed such behaviour to anger and frustration at being incarcerated and by the behaviour of staff on the ward. One participant (D2) referred to the claustrophobia of being incarcerated, the lack of fresh air available to patients, frustration at lack of self-determination and of not being listened to when complaining about medication. The following participant described her response to frustration caused by incarceration:

*S: "Well if like I got erm really stressed out...upset or angry or anything or the way I was being treated – like once I picked up a table and lobbed it across the room and erm the alarms went off and they all came running from God knows where. They just seemed to come out of the woodwork and they drag you upstairs, arms bent behind your back like a policeman does, head down...and erm you're sort of slung on your bed and injected basically, so you go to sleep."*

There are at least two elements of control exerted over the patient in the preceding description. Firstly, the participant describes being handled in the same way a police officer would handle someone who is being arrested and secondly, the use of

medication to manage 'disruptive' behaviour. The latter will be discussed in the section examining the use of power in psychiatric units.

Another form of ward violence that was described by participants was the witnessing of suicide attempts by other patients.

*T: "...actually I witnessed someone trying to hang themselves from a curtain rail...I was actually lying on my bed and this guy didn't say anything and then I heard this sound and it was the sound of the rail being pulled out of the wall and I saw this guy with whatever he had round his neck, tied up to the rail."*

A number of participants referred to friends who had committed suicide whilst in psychiatric hospital. This caused one participant to question the effectiveness of hospitalisation:

*S: "... So the bottom line is really how on earth did it help them? It helped them to die basically, leaving children behind who may grow up resenting their mother, father, whatever because they've killed themselves. They may become ill themselves...A mass of people all dying. It's like a war and it's not a war."*

The incidence of suicide and parasuicide on psychiatric wards led some participants to question the adequacy of supervision on psychiatric wards. A number of participants attributed high suicide rates in hospital to the side effects of treatment (e.g. R2) and the hopelessness caused by lack of recovery due to a narrow emphasis on medication at the expense of more holistic approaches to treatment (D2). However, one participant who had been involved in the consultation with users on the design of a new psychiatric unit criticised the unit as resembling a secure unit due to the emphasis on risk management at the expense of patient comfort and choice. The Health Trust was criticised for not listening to users at the consultation stage and decided to provide patients with plastic quilts and showers that ran for approximately seven seconds. I asked the participant why the Trust had taken such decisions.

*D2: "One was the fact that they wanted everybody to have plastic quilts and I said they'd sweat too much and they'd be awful...that was ignored and it's now been proved that I was right and they've had to spend a lot of money which was wasted...And the other issue was about the showers. And I was horrified to see that they were like sports centre showers, seven seconds, and I said this at the*

*time, I said 'I think that's disgusting,' I said. 'I wouldn't like that and I don't think you would. Would you have that in your home?' I said to the people on the panel. And I was told it was a safety issue...I think it's because of safety issues that they have to protect themselves and it's now very much a minimum risk environment. They can't afford to be sued so they have to make sure it's safe, as safe as you can make it, at all expense and at all costs to anybody else. I mean, even the freedom to choose whether you have a hot or cold shower. And I disagreed with this and to me what they were doing was turning it into a secure unit but not calling it that. So there were big frustrations for me at the time, and still are. Issues over the garden. You know, okay you have to have a fence so they can go out. And now it turns out that people can still get over the fence so they can't go out."*

## **Power**

### **a) Admission and Detention**

This section includes an examination of participants' experiences of admission to hospital and their rights whilst in hospital. A common theme in discussions of psychiatric hospital admissions was the use of police, ambulances and handcuffs, which some participants stated made them feel like a criminal. It struck me that some participants had been treated in a rather heavy-handed way during the process of sectioning. One participant described how the police had battered down her door in order to gain access while she was at home with her children:

*D1: "...They only had to press the doorbell. They just booted the door in, came running up the stairs, because I heard all this commotion. I wonder what's going on? As I went out there, there was bloody loads of them everywhere. There was only me."*

The way in which the participant felt overpowered in the situation is encapsulated in the comment "there was only me".

A number of participants commented that even when patients agree to enter hospital voluntarily, they are often coerced into remaining and accepting treatment, even as informal patients. One participant commented that voluntary admission is a misnomer. I asked her why she thought this.

*D2: "Well the door's locked for a start. You know, how can you be a voluntary patient if the door's locked? And if you do decide to go, you'll be more often than not the nurse will say 'can you just wait to see the doctor?' You can't just walk out the door. And then maybe they'll say 'well can you just wait until tomorrow to see the consultant?' And it isn't a question of just going when you want because sometimes they will be quite persistent about making you stay and I know a lot of people whereby if you leave the building you will be sectioned. Or if you don't take the medication you will be sectioned. I mean, that's another one. So you might be voluntary but you have to take the medication or you will be sectioned. So you're not really free."*

The information from participants was that voluntary patients are actively prevented from leaving the ward or are threatened with compulsory detention if they are not compliant with the wishes of the staff.

#### **b) Seclusion**

I was interested to learn whether participants had been the subject of seclusion and the possible rationale for the use of seclusion on psychiatric wards. Two participants spoke of their experience of seclusion. At the old psychiatric hospital referred to as KG, participants described the practice of placing patients on the 'landing' as a form of seclusion.

*S: "...At one point, when I was on the landing because I'd been 'difficult' –*

*MF: You were on the landing? What does that mean?*

*S: Well you're confined upstairs. Because – probably you've chucked a chair or shouted at someone or tried to smash a window. I did smash a few windows up there actually, I must admit. Once I was just standing in this room, pacing backwards and forwards because I was getting really, really angry, and the staff were there watching me and I just went like that, shoved my foot through this window and the alarm bells go off and you're confined upstairs. We were both actually confined upstairs at that particular time. She was in her bedroom and you were allowed to smoke up there...But she must have somehow got a lighter and erm she was sitting there, all of a sudden I saw these flames. I thought 'oh my God' and that was her...What I was trying to get at was she was punished for that. She wasn't like 'oh my God, are you all right? Oh come and talk to me,' and*

*you know. Oh no. She was ostracised. She was made to feel totally, totally – well that she had done something really wrong by trying to take her own life.”*

The incident refers to the response to a suicide attempt by the staff in a punitive way by placing the individual on the ‘landing’. The two participants who referred to seclusion both stated that it was used in a punitive way, usually in response to behaviour that was perceived as being disruptive or uncooperative.

### **c) Staff Attitudes**

An examination of staff attitudes might facilitate an understanding of why nursing staff appear reluctant to interact with patients. It may also help to explain why there is a paucity of activities available to patients. Negative staff attitudes may also be associated with the use of control and restraint and seclusion. All of the participants who discussed staff attitudes perceived them as being negative towards patients. Staff were even compared to prison warders or traffic wardens. Psychiatric ward staff were described as having an attitude of differentiation in that patients were regarded as inferior and different from staff. Staff were also described as punitive (“punished for being ill”, “made me feel like a criminal”), as the following participant explains:

*D2: “...Yeah, it’s the attitudes of the staff around. It’s how they deal with you...But quite often it’s – what I experience is a very punishing atmosphere. You’re being punished for being ill, that’s it. That’s exactly what it feels like. Most of my experiences – I think I’ve been in eight or nine times and very long stays, most of these experiences have made me feel punished for being ill, made me feel like a criminal, made me feel bad about myself, made me feel that I shouldn’t be mixing with society. They made me feel like that by their attitudes, by their silly laws and rules, which are totally ridiculous half the time... And somebody’s got their big hobnailed boot and they’re treading on you and an awful lot of staff in those sorts of places, I won’t say all, but some of them, have gone into that profession because they want to dominate people. They want to disempower people. They want the power. They want to crush people. They have an attitude that they obviously have an inferiority complex which is then made better by working with people who are less lucky than them. And you can see it in their eyes, the way they have such glee in their power and I’m talking about one particular person at the moment I know and it’s awful because to me they are the*



*type who would make prison officers or Gestapo or traffic wardens. What the hell are they doing in the mental health profession? To me, it's certainly not the type of person you should be employing. As I say, things are improving, but in the old days the places were full of people like that, looking after us. I won't say looking after us, controlling us. And (they got a kick out of it) and they were so disempowering...and then a lot of people came out of places like that totally disempowered and crushed. It took me years to recover. Years and years of trauma and therapy to get back any power in myself or belief in myself."*

A further attitude described by participants I refer to as 'behavioural attributions'. This category of attitudes relates to how patients' behaviour is attributed to illness and not to environmental factors or to reactions to being incarcerated. I examined descriptions of 'property damage' on the ward in order to establish participants' own interpretations of their behaviour. 'Property damage' was a term used by one of the participants (A) to describe damage to property on the ward. I have used this term to explore how patients vented their emotions whilst on the ward and to explore explanations of their actions. Property damage was attributed to frustration or distress caused by poor quality care, incarceration or over-medication on the ward. According to participants' views on the behavioural attributions made by staff, such property damage is either attributed to mental illness or to deviancy, without regard for the aspects of the ward regime that might trigger such behaviour.

The explanations adopted by ward staff differed from participants' explanations in that participants felt that ward staff were likely to attribute behaviour to mental illness rather than to environmental factors.

*S: "Because it goes back to what I was saying, if you show emotion, you know, you are given more drugs. If you sit there and cry, that means you're severely depressed and you're going to kill yourself in their eyes. If you sit there or stand up and start shouting or throwing things around, that means you're a danger to yourself and everybody else. It doesn't. It just means that you're stressed out or whatever, you know, because you're there. But you just get more and more drugs and as I just said, I was a zombie...I'm sorry but you couldn't do anything. You couldn't breathe without it being scrutinised and turned around...any emotion you had while you were in hospital would be used against you. It's like when you're*

*arrested and they say 'anything you say will be taken in evidence and used against you,' that's exactly what it's like in hospital. Anything. If you sit on the floor instead of on a chair, that's a sign that you're ill."*

#### **d) Medication**

The most common concerns about the use of medication on psychiatric wards concerned the emphasis on medication as the sole treatment available and the use of medication to control patients. Participants commonly referred to the use of 'acuphasing' following an incident of disruptive behaviour on the ward. Participants also complained of the administration of high doses of medication that produced sedation. The rationale for the use of medication was asserted to be the management of patients, as described by the following participant:

*M: "Most medication in places like KG and [forensic unit] is just tranquillisers. All the tranquillisers do is slow people down and put them half to sleep. They are a lot easier to deal with when they're half asleep...As I say, it's a bit like when you're outside and you've got a problem, what do you do? You talk to someone...and then you both discuss it and look into things and come up with solutions and that just seems a lot better way to me than here's your tablet, just sit down there and fall half asleep. Because how does that benefit anyone? All right, if someone's very manic and they're running round like Speedy Gonzales then yeah, it's a good thing. But they were literally just dishing them out like kids in a sweet shop."*

Participants used the term 'zombie' in relation to medication so frequently that I introduced the term 'zombification' to describe the effects of tranquillisers on psychiatric patients. The following participant represents the majority view on the function of tranquillisers on psychiatric wards.

*R2: "If you tried to commit suicide, you'd have that much medicine. You could sleep for three solid days after that. There's no way – you wouldn't do anything wrong for three days. The nurses could relax."*

#### **e) Regimentation**

Power differentials between patients and staff were epitomised in comments alluding to 'them and us' when discussing staff attitudes. Rules and regimentation represented

ways of enabling the staff to exert power over patients, as described by the following participant:

*D2: "Oh dreadful. Well okay, you have tea at certain hours of the day, you can have tea at ten or coffee at three, you know, that's it. And we need to have almost fights because of that. Because people would like to have a cup of tea or coffee when they want it, not you're told to have it then and if you come later it's cold and you don't even get it. I mean, it used to be horrific. So that's not very good. You can't make your own tea or coffee. You know, not being able to smoke here or there. Not being able – you know, having to go to bed when you're told to. 'You can't do this.' It's like a concentration camp the whole time..."*

#### **f) Comparisons with Prison**

A theme that runs through the entire discussion of psychiatric inpatient units is that they resemble prisons and staff members are comparable to prison officers in that patients feel that they are being punished. The comparison is not a simple one however, because some participants felt that prison is actually more legitimate and has better facilities and that the staff are actually friendlier in prisons in comparison with psychiatric nursing staff. One participant (A) described a 'prisoner mentality' in which the patient puts their head down, serves their time and endeavours to achieve an early discharge. The following participant exemplifies the 'prisoner mentality':

*D1: "Well the first time I was very resentful because I felt I was being held prisoner and I didn't know what to expect from day to day so it was all a learning curve...But the second time, I knew what the routine was and I knew that if you kept your mouth shut and cooperate, you get off your section quicker than if you argue. So you just learn to go along with it. It's like being in prison really. They say you keep your head down and just do your time and shut up and you'll get out quicker and that's what I did. I know people who have been there for eighteen months because they argue too much. You say to them 'shut up. Don't answer them back. Just do as you're told and you'll get out of here'."*

This view strongly implies that an inpatient is serving a sentence rather than being admitted to hospital to receive treatment. The lack of freedom of movement and the regimentation of the hospital routine also contributes to the notion of incarceration.

The following participant contrasted prison and psychiatric units on the basis of the latter's lack of legitimacy.

*T: "It's dreadful. It's worse than being remanded in prison custody, you know. At least if you're remanded in prison you know it's because you've done something. There's a reason for it...And I thought prison was really unpleasant because I was physically unwell and the standard of medical care was very poor. But I thought at least this place has legitimacy, you know. But I don't feel that about psychiatric facilities. I feel, you know, this isn't right. The whole set up isn't right, you know, people being sent to institutions that are called hospitals and they're called patients whereas they're really prisoners or detainees and they're forced to take medication. They are forced to have injections."*

### **Summary**

It is important to attempt to understand why psychiatric hospitals were experienced as punitive and as instilling a prisoner mentality rather than being perceived as places to receive treatment and achieve recovery. Participants described psychiatric hospital as failing to provide adequate treatment in the over-emphasis on medication and lack of alternatives. They also described lack of activity, poor facilities and lack of contact with staff. The limited treatment and lack of activity caused some participants to question the rationale of psychiatric hospitalisation. Psychiatric hospitals were also described as providing a non-therapeutic environment whereby the behaviour of other patients was disturbing, as was the witnessing of suicide attempts and violence directed towards patients either by staff in the form of control and restraint or by other patients. Separation from family and lack of exercise and fresh air were also discussed as indicative of the non-therapeutic environment of the psychiatric hospital.

The use of power by staff over patients was indicated by participants' discussions of the use of physical force in involuntary admission and the use of coercion in 'voluntary' informal admission. Seclusion and the use of medication were also indicative of attempts by staff to control and punish patients. Rules concerning access to ordinary opportunities on the ward (e.g. making tea, when to eat, when to retire to bed) also indicated the exertion of power over patients.

The fact that the 'prisoner mentality' was discussed by a number of participants and an even greater number compared psychiatric hospital with prison would strongly suggest that participants regarded hospitals as non-therapeutic.

In relation to Marshall's (1992) claim that state welfare enables the achievement of social citizenship, participants' experiences of NHS psychiatric inpatient treatment indicate that social citizenship was undermined through the provision of poor quality care and by differentiating not only patients from staff but also patients from the public, the latter not being subject to enforced incarceration.

One participant (D2) summarised the features of improved inpatient care as offering a place of safety with sensitive and understanding staff who are willing to spend time with patients, listening to their difficulties, minimum short-term medication, meaningful activities that are voluntarily engaged in and as encompassing a broad range of therapeutic and leisure activities and transitional support on discharge. The participant described such features as being present in a private inpatient unit she had attended.

## **Medication**

Medication is linked to citizenship because participants identified numerous ways in which medication impedes engagement in ordinary activities. For instance, participants described impediments to their ability to work, to parent and to engage in inter-personal relationships caused by medication. Therefore, medication was found to impede roles essential to the status of citizenship. Moreover, the role of medication in participants' lives indicates the way in which mental health problems are conceptualised in mental health services and how this suggests causality and directs treatment of mental health problems.

I wanted to explore the following questions in relation to psychiatric medication:

- What is the role of medication in psychiatric treatment?
- Had participants experienced side effects as a result of taking medication?
- What are the reasons for compliance and non-compliance with prescribed medication?

In addition to the questions above, participants raised concerns about issues relating to dependency and withdrawal. They also discussed the power of the user in relation to professionals in describing their attempts to negotiate on medication. Participants also referred to the use of coercion to enforce compliance with prescribed medication. Given that participants considered the psychiatric system to be dominated by medication, I wanted to discover whether participants perceived medication as useful. A number of participants reported that their medication was effective in stabilising their illness. Indeed, one participant indicated that her medication assists her to function in a healthy way.

*P: "I've been a voluntary patient but I've also been an involuntary patient. I just thought that – I'd got it into my head that I could control my condition myself without medication, everything. And I fast learned that I couldn't...And I realised – and now I have no problems taking my medication because the medication's*

*actually been done to suit me. I don't feel groggy. I can get on with different things. I can do my writing and it enables me to live. It doesn't seem to have any side effects that I can't deal with. And that's the big difference because some of these drugs are really potent but it's been done with a very fine balance."*

A second participant referred to his medication preventing him from becoming ill and reported no side effects:

*M: "...If it does something through chemicals or it does something because I believe it does something, I don't know. I really don't care. As long as I take it every day at nine and stay all right and it's got no side effects so I don't feel any different from before I became ill. Although supposedly – because when I went through my what's wrong with me phase, I went as far as to find out about the drugs. These are the side effects and I haven't had one side effect from it."*

However, the majority of participants who discussed medication complained of unpleasant side effects. The most commonly cited side effects were extreme thirst, weight gain, involuntary muscular movements (tremors) and emotional blunting. However, the most commonly cited side effect of all was sedation. A number of participants also discussed tardive dyskinesia and the embarrassment caused by involuntary movements such as uncontrollable facial movements.

*E: "One of the side effects was – severe side effects- was muscle cramps in the neck and in the tongue which made me feel like I'd swallowed my tongue. That's a really severe one. But also like the shaking leg. You know, that's quite common for a lot of people, But in certain high doses, which they tend to put you on when you go into hospital, that's one of the side effects that I was a bit concerned about..."*

Such comments prompt the question of the impact of medication on social networks through motivating social withdrawal due to the social embarrassment caused by medication-induced movement disorders (Estroff, 1981). One participant (M) referred to the psychological impact of weight gain as depressing and another participant's discussion of weight gain provides an interesting insight into the behavioural attributions of professionals in response to patients' complaints of side effects:

*G: "Well especially weight gain initially. I used to be a thirty-four waist, now I'm a forty-four. I used to be a forty-inch chest and now I'm a fifty-inch chest. So weight is the problem. The doctors are always accusing your diet, not enough exercise."*

The latter comment indicates the participant's perception that medical professionals fail to acknowledge the impact of side effects and instead blame the patient for not heeding their physical health needs. Such assumptions allude to the lack of credibility attributed to mental health service users who complain of physical health problems. Similarly, another criticism cited by participants was that mental health workers fail to recognise the impact of medication on daily functioning. The side effects of medication were reported to interfere with employment, parenting, emotional relationships and with cognitive functioning. The following participant exemplifies comments that were made in relation to the iatrogenic impact of medication on employment in impeding her usual occupation as a secretary:

*J: "If you're actually typing and your hands shake – I said the other week, I was shaking. I was sitting here shaking...Yeah, it's the side effects of lithium, plus an anti-depressant I took. Sitting down in front of a typewriter xxx letter at home, I couldn't hit the right keys. I've been typing all my life practically, you know. Had a good speed. And it's all completely gone because of the medication. What am I supposed to do? Give up the medication? You know, I mean, it's catch twenty-two."*

The participant's experiences illustrate the impact of medication on the ability to work and thus suggest a detrimental effect on citizenship. Furthermore, the sedative effect of medication was reported by two participants to reduce their ability to provide effective parenting and one participant regarded the demand for compliance with mental health services by the children and families social services department as somewhat ironic, given the impact of medication on her ability to parent:

*D1: "I can't look after my kids properly because I'm asleep all the time. I take the girls to school and, like today, because I'm up in the morning I'll have a sleep after you go but I'm not too bad today because my injection's tomorrow...Next week I can guarantee it, I'll take the girls to school, come home and sleep 'till three o'clock and then go and pick them up and then go and lay on the sofa. I*



*won't be able to move...Yeah, I've got to take this for the rest of my life and I can't have a life. It gets the kids down..."*

Personal relationships were reported to be affected by the emotional blunting attributed to medication. This meant that participants did not experience emotions so keenly and thus medication was reported to interfere with intimate emotional relationships.

I was interested to learn whether the side effects of medication were a motivation for non-compliance with a medication regime and, more generally, the reasons for complying or not complying with prescribed psychiatric medications. Participants produced more reasons for complying with medication than for not complying. However, the two main reasons cited for not complying with medication were rejection of illness and thus a belief that medication was not necessary and the unpleasant side effects of medications. The most frequently cited reasons for complying with prescribed medications encompassed the unpleasant effects of withdrawal from medication, physical and psychological dependency on medication, lack of information on side effects and coercion by professionals. Participants also discussed compliance as being due to fear of hospitalisation, fear of relapse in illness and the social unacceptability of illness. Therefore, compliance was not necessarily equated with positive appraisals of medication.

Participants described compliance with medication as being due to coercion by mental health professionals. A number of participants referred to the use of depot medications (intra-muscular injections) as a way of enforcing compliance with a medication regime.

*P: "I kept saying 'I want to come off it.' I kept saying 'no,' and they gave me it by injection because I refused to take it. And if I didn't turn up for the injection, they'd come to my home and find me, wherever I was and they made me take it. I lost seven years of my life through that."*

These comments suggest lack of autonomy to refuse treatment in the community, thus casting doubt on the voluntariness of compliance. The participant (G) whose psychiatrist denied the possible side effect of weight gain indicated a possible reluctance by professionals to acknowledge the side effects of medication. Another participant described the attitude of professionals towards non-compliance:

*S1: "Oh I think they're all for taking the medication and if you don't take it, it's irrational. I mean, I've had them come to my house and section me at my house. The actual consultant visited me in my house. J as well I think, because I didn't take my medication and I was very unwell."*

The latter comment implies that refusal to take medication caused the participant to become unwell. However, mental health professionals' attitudes towards compliance with medication indicate a commitment to the biomedical approach to mental health problems. Two participants described a sense of regret that they had not complied with their medication, attributing their ill health to absence of medication, although a number of participants attributed illness to withdrawal from medication. Therefore, it may be difficult to determine whether absence of medication causes a recurrence of illness or whether ill health is due to the adverse effects of withdrawal of medication. The following participant summarises the common attributions made by participants of non-compliance with prescribed medication:

*D2: "Yeah, many times I stopped taking my medication. A number of reasons. Sometimes because I felt I didn't need it. Sometimes I felt half my personality was lost with it and that was robbing me of that side of me. I felt very numb at times. Sometimes it was because I really didn't believe I actually needed medication because I was actually ill and I didn't think – I couldn't rationalise it at all. Other times, in the early days, I actually felt I should cure myself without medication and other times it was because I was trying to get pregnant and one of the worst things was I was put on medication that was actually making me infertile for many years and I didn't know it and it was only a blood test that showed it. And that happened three times because each time I went on a different medication, the same thing would happen. So that I was furious about, that I was being made infertile by the stuff they were giving me even though they knew I was trying to get pregnant. And they didn't tell me. They say now they didn't know but I think they should have known it's a side effect. But every time I stopped the medication, I became ill and ended up being sectioned and back in and then having to start all over again. It was a rough ride really. It was like a roller coaster for the last ten years. My view now on medication is that yes, it helps me. I don't try to let it control my life. I like to make sure it's monitored so I'm not over-medicated..."*

As stated previously, lack of information was cited as a possible reason for compliance with medication. I was interested more generally in whether professionals were forthcoming with information on specific medications and potential side effects. The question is also related to the willingness of professionals to negotiate with users on medication regimes. Generally, participants complained that professionals are reluctant to provide information on medication unprompted and a number of participants reported that they obtained information on medication from fellow service users. Two participants argued that professionals are unwilling to volunteer information on medication due to the expectation that such information would increase non-compliance. Another participant related lack of information on medication to users' decisions to self-medicate:

*P1: "Well you're not really given any information on medication, are you? ...We do this to a certain extent, we gather information so that if, for example, if I start to go high, then we can think well what we'll do then is we'll increase the mood stabiliser or something and decrease the anti-depressant. But we'll do that ourselves because it's so difficult to get that from the psychiatrist. By the time you've spoken to the CPN who then speaks to the psychiatrist, who then either has to see you or not, by the time all that's happened, your mood is out of control. So people end up self-medicating and the psychiatrists, quite understandably, hate that. They don't want their patients to self-medicate but they create that for themselves."*

Nevertheless, three participants cited examples of successful negotiation with their psychiatrists, although they attributed this to particular characteristics of individual psychiatrists and one participant made the point that his current psychiatrist, who he successfully negotiates with, may move on to a job elsewhere and be replaced by a less amenable psychiatrist.

*E: "But when you start to negotiate with them, it's like you're encroaching into the psychiatrist's area because they know best. You're not supposed to have the insight or knowledge, back then, to challenge or question what was being done."*

A further reason for compliance with medication was cited as a desire to avoid the unpleasant effects of withdrawal from medication, as the following participant explains:

*R2: "...Also I think to myself I would stop taking these tablets but the withdrawal is too bad. That's another reason why I have to keep taking them. I have diazepam, Valium. You try and get off that easily. There's no way. Otherwise, I'd stop taking them."*

One participant indicated the confusion some psychiatrists make between the effects of withdrawal from medication and relapse in illness. She also introduces the issue of physical dependency on medication.

*J: "Well because the thing is if you come off anything like lithium, sometimes you can have a breakdown through a rebound effect and I think that's probably what has happened to me in the last three times. I've had a rebound breakdown. But the psychiatrist takes it as a breakdown...Well stopping something like lithium and when it comes out of your system, you're so dependent on it, you get a rebound from that, so I've been told. And the Manic Depression Fellowship stand by this. They say you get rebound breakdowns. But he took it as a relapse and you know, they don't really care which it is, you're in hospital, you've got to have the medication and now I'm afraid to come off it in case I start going round the house and knocking on people's doors..."*

Finally, several participants expressed concern about the potentially adverse long-term effects of medication, as one participant (R2) stated, "you don't know what they're doing to your insides".

## **Summary**

Some participants stated that their medication is useful in stabilising their illness. However, participants complained of side effects, some of which severely impede everyday functioning and fulfilment of important citizenship roles. Participants also complained of lack of information on medication from professionals and reluctance of professionals to negotiate with users. Side effects were cited as a major reason for refusing prescribed medication. Participants also discussed dependency and the problems of withdrawal in relation to medication. The power differentials between service users and professionals were demonstrated by coercive responses to medication

refusal and reluctance by some medical professionals to negotiate with users over medication or to provide basic information on side effects.

## **Parenting**

At the time of the study, five of the participants were parents (including two in a same sex partnership), with eight children between them. Three of the five parents had been detained in hospital under the Mental Health Act 1983 and six of the children had been subject to care proceedings by the local authority children and families department.

Given Sayce's (1999) assertion that parenting is a citizenship right, I wanted to learn about participants' experiences of the impact of a mental health problem on parenting. It is important to examine parenting by people with mental health problems because research literature on such parenting is almost wholly negative, prompting the question of whether such a bias is reflected in professional practice. I also wanted to discover the impact of mental health services on parenting and family life. Finally, I asked participants about the type of intervention that would support parenting, if anything.

### **The impact of mental health problems on parenting**

Participants identified specific difficulties they had experienced in relation to parenting with a mental health problem. Participants discussed difficulties caused by mood swings, sleep deprivation and self-neglect. I have already examined the impact of medication on parenting in the chapter that discussed medication. Participants also discussed the stigma of having a mental health problem and the impact of stigma on the child, especially once the child attends school. Two participants were particularly concerned by the prospect of teachers' knowledge of the parent's mental health problem and the potential bullying of the child by classmates. However, of greater concern was the stigma and suspicion caused by teachers' knowledge of at risk registration of participants' children.

One participant (D2) identified the sleep deprivation associated with having a small baby as being a potential trigger for poor mental health. She also identified mood swings as possibly causing confusion in her child. Two participants identified the problem of the child blaming themselves for the mother's poor mental health, as described by the following participant:

*D2: "...I think I suppose the difference for me would be the actual changes in the person of me, the moods, that he might find difficult to live with or understand. And children often blame themselves and that's what would worry me is that he might end up thinking that it was because of him that I was like that and I hope when he's older to actually make it clear to him that it's not. I hope to explain things so that he understands..."*

Four of the parents expressed fear that stigma might be experienced by the child as a result of having a parent with a mental health problem. One participant mused on how she would explain their stay in a mother and baby unit to her child and commented:

*D2: "...I find it strange that you have to think like this because, as I said, if it was physical, people wouldn't have this guilt or this monster behind them about what do I say?..."*

It is interesting that the participant reiterates the frequently cited distinction between physical and mental ill health in her concern about how to explain her illness to her child. This is another aspect of the differentiation of people who use mental health services in that mental illness is experienced as stigmatising and as difficult to explain to others, the implication being that this is not the case in relation to physical illness.

However, participants made a greater number of comments concerning the positive impact of parenting on mental health. Participants discussed the motivation to recover from an episode of illness, the structure and distraction provided by parenting and the engagement of problem-solving abilities.

*D1: "...when you've got kids, you've got something to pick yourself up for and make an effort but without children, I would imagine it's much easier to give up really."*

*D2: "...It always puts more pressure on as well because it's very tiring but on the one hand, it's actually something for me to live for and to keep going for and something else to think of all the time."*

Participants also regarded mental health problems as performing an educative role in facilitating greater emotional awareness in their children:

*S: "...it can have a little bit of a positive effect because I think there's boys especially, a big thing, men don't hardly show their emotions. It's all like 'I'm a man, I don't do that sort of thing, that's woman's stuff'. But I think in some sort of way, it can have a positive effect by making them understand a bit more like if it's not so threatening as it's taking the person you love away from you. I think it can help in the sense that life isn't rosy is it? Life isn't rosy...and I don't think we should shut our feelings away in the closet."*

### **The impact of intervention on parenting**

Three of the five parents in the study (the same three as had been detained under the Mental Health Act 1983) had experienced the intervention of the Local Authority Children and Families Department in care proceedings made in relation to their children. Participants spoke of how they were expected by both statutory mental health services and children and families departments to prove the adequacy of their parenting. However, such participants were wholly critical of the conduct of social workers in conducting investigations and performing their duties in relation to the children involved. Participants spoke of the stress associated with the threat of removal of their child(ren) and of the scrutiny involved in proving their ability to provide adequate parenting. Social services' intervention was perceived as aggressive and threatening and thus was experienced very negatively. Personal emotional responses were described as encompassing anger, fear, depression and thoughts of escape from the process:

*D2: "They just assumed that because I had manic depression that I couldn't cope being a mother...The heavy-handedness of being on an at-risk register is like making me into a criminal..."*

One participant (D1) described how her children were removed from school, without warning, during a child protection investigation and another participant (S) described how children and families social workers coerced her husband into divorcing her following an assessment that she might have posed a threat to her child. A third parent (D2), who had no other children, experienced her child being placed on the child protection register before he was even born, suggesting that such decisions may be made without tangible evidence of harm. Moreover, the children and families social services department suggested that the participant's husband relinquish his employment



in order to demonstrate his commitment to parenting, indicating unrealistic expectations held by professionals. As just mentioned, the husband of another participant was reportedly persuaded to divorce his wife in order to distance himself from her. Therefore, fathers were also disadvantaged by social services involvement. The parents in the study emphasised the lack of evidence to suggest that they would harm their children and described these instances to convey the overwhelming power exerted over families by social service departments.

Furthermore, the participants who had come to the attention of the social services department complained that assessments of parenting were conducted out of context and were pre-judged on the basis of assumptions that parents with a mental health problem are incapable of providing adequate parenting to their children. Participants felt that judgements were made in the absence of tangible evidence of parenting and that there was a lack of a balanced view of the abilities of people with mental health problems to parent, as exemplified in the following comments:

*D2: "...So there is a very negative view of it [mental ill health] and it's very much looking at the bad things and what they failed I felt to do was look at the amount of people out there with mental illness who do succeed in bringing up babies and children and do a fair job. And you can do a bad job even without suffering mental illness, you know, and that's what's shocking is that, you know, it used to make me quite angry because I knew that if I had MS or diabetes or cancer, I'd be given all the support social services could give and you know, it would all be very understanding. But because it's a mental illness, it's 'ooh, the damage you're going to do'..."*

The participant illustrates two sources of concern expressed by parents in the study; firstly the view that parents with mental health problems attract a disproportionate amount of attention, especially in relation to people who pose a threat to their children or harm their children without action being taken to protect those children. The case of Victoria Climbié was frequently cited. This observation strongly suggests that childcare professionals discriminate against parents with mental health problems by demanding higher standards of care than those applied to parents without mental health problems (cf. Sayce, 1999). Secondly, the comments represent a commonly held view that mental health discrimination is evident when comparisons with physical illness are made.

A further source of dissatisfaction expressed by the parents in the study involved the impact of mental health services in causing separation of the parent from their children. Two participants explained how crisis intervention involved removing the parent with the mental health problem from the home and that this would have increased the stress of the situation and would have elicited feelings of failure in the parent in response to possible perceptions that the parent could not cope at home, thus suggesting the negation of the needs of parents in mental health services (Parker, 1999). For another participant, the impact of hospitalisation meant significant periods of time separated from her child and husband. It meant that she missed several of her child's formative years.

*S: "I can't figure it out at all. Sometimes now I think I can't handle it because my son was six years old when I went away. All right, I saw him practically every day, I mean, you can't call a twenty minute visit and I'm sat there like a zombie but – so basically I might as well not seen him at all, because it didn't really sink in. But he was six and when he came back, he'd been here a year and a couple of months, so it's not very long, and he was eleven when he came back. That's five years later and I've changed, he's definitely changed. I mean, he was a six year-old boy. Totally different. I don't dislike him being twelve as he is now, but he was my little boy. And I've missed five years of that and he's missed five years of me..."*

The participant's comments indicate a fundamental impact of mental health service intervention in that it denies the individual the role of parent. Numerous participants who cited access to family life as a primary defining characteristic of citizenship, including the opportunity to parent, indicated the importance of the parenting role. The expectations of mental health professionals exerted a significant impact on parenting because attitudes determine the type of intervention offered to parents. One participant was hospitalised in a mother and baby unit and encountered both pessimistic and deterministic attitudes from unit staff:

*D2: "Even at the mother and baby unit, the majority of staff came from that line, that most of us suffering from long-term mental health problems would never be able to cope and even at the end of it, because they said when I left there that they were concerned about my ability to cope long-term. Even though I was better and*

*happy coping, they still had to put that in at the end. They didn't think I could cope. And there were certain ones like the mothers with schizophrenia that would definitely not be allowed to take their child home unless they had a partner. And there were other people who were assessed, passed the assessment and still not allowed to take the child home because they'd had a bad upbringing and they did say because of my upbringing I wouldn't be a suitable mother."*

The picture that emerged from this participant was that single mothers ran a high risk of losing their babies altogether. However, the participant acknowledged that being a single parent is objectively more difficult if the parent has a mental health problem and therefore that such attitudes may not simply reflect negative attitudes towards single parents. Nevertheless, one participant (D1) indicated that children and families social workers were judgemental about the fact that different men had fathered her children.

The participant (D2) who experienced a mother and baby unit also described an incident of control and restraint being used against her and also being so heavily medicated that she was even unable to carry her baby. Mental health services also exerted a negative impact on her parenting ability by prescribing medication that prevented conception. The participant also described professionals' attitudes towards her attempting to conceive:

*D2: "Oh well, my CPN at the time was not supportive and said ' why don't you get a dog instead?' And after that I didn't want to work with him. Yes, he was not understanding. And in fact, I think a lot of them didn't dare voice their opinion...Because I think they would admit that that's not their right to say I can and can't have a child. But I think they would have felt that because of the difficulties involved that it would actually not be advisable."*

Such attitudes indicate the importance of considering whether parenting is a citizenship right that should be upheld with other fundamental rights. Other participants complained of professionals' attitudes to parenting that reflect attitudes of the broader population. A same sex couple experienced homophobic attitudes from professionals that were manifested by the lack of recognition of them as parents in a legitimate family unit.

*P2: "And they're not interested. I mean, I'm sure you know different families do things in different ways and they're not in the least bit interested in finding out what – how you manage your family life because they will not see us as a family. So they needn't find out whether [partner] has equal parenting rights as I do or whether the children want her to parent them. Because actually that was their choice. So – but nobody's ever asked those questions or found that out so they never have to look at that."*

The participants explained that such attitudes are driven by the way in which professional practice is informed by social norms, such as assumptions concerning legitimate family structures, and rejection of alternative family structures. The participants felt that professionals pathologised their lesbian relationship by attributing it as a cause of one partner's mental health problems. Mental health professionals also failed to recognise the legitimacy of the participants' relationship by failing to disclose information to the patient's partner; the participants found that heterosexual couples did not share this experience, as verified by speaking to heterosexual service users. In addition, mental health workers subjected the participants to intrusive questioning about their sexuality; again, heterosexual couples did not share this experience. Homophobic professional attitudes illustrate the importance of the broader issue of whether citizenship should be a universalistic or particularistic concept, the latter involving rights that uphold the citizenship status of marginalised groups (Young, 1995).

In summary, participants described professionals' attitudes that clearly demonstrate a reluctance to acknowledge that people with mental health problems might have a right to parent and are able to fulfil the parental role very successfully. Participants reported pessimistic and deterministic attitudes towards parenting with a mental health problem. In addition, professionals were reported to express negative attitudes that were possibly influenced by homophobic prejudice and judgemental attitudes towards single parents. Moreover, services that separate the parent from their child may be counterproductive and certainly all of the parents in the study stated that separation from their families was or would have been extremely damaging.

Participants' experiences of parenting were characterised as involving loss (cf. Phillips and Hugman, 1990). For instance, one participant (S) described her loss of authority as

a parent whilst her child was subject to substitute care. She also described loss due to separation from her child during psychiatric hospitalisation. Loss was also described in terms of impediments to parenting caused by medication-induced sedation (e.g. D1).

### **What kind of intervention would facilitate parenting?**

I asked participants what kind of support would have helped them parent during their mental health difficulties. The consensus view was that practical support at home would have been the most useful form of intervention whereby participants' main dissatisfaction in this respect was that services do not endeavour to support people within the family unit. In addition, one participant stated that the recognition of the impact of social circumstances on mental health would have facilitated a more useful view of the parent's difficulties. The participant (D1) argued that help in preventing the loss of her home and the provision of day care for her children so she could concentrate on her social circumstances would have been particularly helpful. However, the participant was hospitalised and lost both her home and residence of her children in part as a result of mental health service intervention. Another participant (D2) reiterated the usefulness of practical help such as brief respite from her parenting responsibilities during the day in order to enable her to rest. She also emphasised the need for assistance to be non-coercive. Participants experienced the intervention of the children and families department to be coercive and as undermining parents' ability to parent. Participants also argued that mental health intervention that focuses on preventing mental illness would have been useful.

In summary, participants preferred intervention that enabled them to remain at home and within the family unit and they valued strategies that emphasise the prevention of the escalation of problems that can exert an adverse effect on mental health and ability to parent.

### **Summary**

The findings demonstrate that parents with mental health problems are confronted with difficulties but this is quite distinct from claiming that poor mental health inevitably undermines parenting, as suggested by much of the research literature on this subject.

## **Part Two: Civil Citizenship**

Civil citizenship, in Marshall's (1992) model, encompasses freedom of speech and thought, ownership of property and the right to justice. The research findings examine civil citizenship with specific reference to the right to justice following hospital detention under the Mental Health Act 1983 through the operation of hospital managers' hearings and mental health review tribunals. Under civil citizenship, the individual is entitled to protection from arbitrary intervention by the state (Held, 1991). Due process is particularly important in relation to people detained under the Mental Health Act 1983 because detention is based arguably on subjective judgements of mental dysfunction and dangerousness and thus such judgements may be erroneous or subject to abuse (see racism in the mental health system: Keating, 2004).

I examined participants' experiences of the Mental Health Act 1983 in relation to knowledge of their rights under the Act whilst detained patients. Therefore, civil citizenship is examined bearing the following questions in mind:

- Are mental health review tribunals an effective route to due process?<sup>4</sup>
- Did participants understand their rights under the Mental Health Act 1983?

The fundamental question in relation to the civil citizenship of people who use mental health services is whether they enjoy equal access to legal systems and an equality of representation in relation to legal institutions and processes.

### **Mental Health Review Tribunals**

Although one participant stated that mental health review tribunals are an important attempt to protect the civil rights of detained patients, a number of participants indicated lack of confidence in the current tribunal system. Three participants regarded the tribunal process as futile in that the panel appeared to have made their decision prior to

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<sup>4</sup> Due process refers to a fair hearing in a formal legal context.

meeting the patient. I asked the following participant if she had ever appealed against her hospital detentions:

*D1: "I did the first time. When I went in the first time, I appealed and I learned that was a complete waste of time. I did the Managers' appeal and the hospital, the Board, and they'd made their minds up anyway. They weren't going to back down. So the second time I went in, I didn't bother...The third time, I didn't bother appealing because I know what to do. If I went back in there now I wouldn't argue with them. I would just let them do what they've got to do and get out of there again."*

Participants indicated the problem of low discharge rates (cf. Spencer, 1989) and their consequent lack of confidence in the tribunal system. I asked the following participant about the degree of knowledge a detained patient has about their rights:

*D2: "Well in the past, I didn't. I didn't know anything and consequently I remember once having a tribunal and the first time it happened I actually sort of refused to go in at the last minute because I thought there was no point. I thought they think I'm mad so I didn't go in. And another time I did have a tribunal and I thought I presented a very good case but they still didn't agree with me. So what's the point of these tribunals? In fact I've heard of only about two people ever get off a tribunal but I certainly now know my rights much more and would call an advocate just like that. Just because of having an advocate there means they have to do it by the book and they have to make sure and it does change their attitudes when they know you have an advocate in your ward round. It's like oh boy, no messing with me."*

Participants described independent mental health advocacy in positive terms as enabling service users to realise their rights by providing assistance in representing the user's views to mental health professionals.

Participants identified a number of barriers to due process. One participant (D2) felt that discharge rates from tribunals may be low due to the emphasis on the risk the patient might pose to themselves or others and the resultant desire of professionals to avoid litigation. She also felt that the composition of panels discourages comprehension of the

patient's situation whereby she felt that a user on tribunal panels would provide greater balance in panel decision-making. On further probing, the participant commented:

*D2: "Ooh I think without them [tribunals] would be worse. I think we definitely need something like that. But what I would like to see is a user on them, on the panel. I would like to see that. Somebody who sees it from their side because you're talking to people who are a) they're all professionals, b) mainly retired, c) law-abiding, et cetera. So they all come from that angle but nobody is there on that tribunal seeing it from your side. You know, when you have a jury, at least you have twelve people from different..."*

The participant's assumption is that the presence of people with mental health problems on tribunal panels would introduce a greater balance in comparison with the relatively homogenous composition of panels, as they are currently constituted. It is interesting that the participant compares the mental health review tribunal with trial by jury, thus indicating the importance of the concept of due process. Another participant (T) expressed dissatisfaction with the influence of professionals' reports on decision-making and the inability of the patient to respond to such reports because reports in his case had not been made available to him. His comments indicated the power imbalance between professionals and patients in the tribunal process and in the mental health system in general. They also reiterate Peay's (1989) finding that tribunals endorse mental health professionals' recommendations in a large majority of cases.

Another barrier to the realisation of due process in tribunals was the perceived inadequacy of legal representation available to detained patients. Two participants commented that they had never met their legal representatives prior to the hearing and therefore the solicitors had minimal knowledge of their clients. Two additional participants expressed concern about their suspicion that a particular legal firm held a monopoly over legal representation at mental health review tribunals and the comments made by a fifth participant appeared to suggest that detained patients are steered in the direction of a specific legal firm. She also confirmed the complaint that legal representatives are not always familiar with their clients' cases. I asked her if she had legal representation at a hearing.



*D1: "I did at the – whichever one they did in the hospital, I did. It was the solicitor that they recommend for all the patients in there. So I didn't know him from Adam."*

Finally, practical obstacles to due process were cited in that the impact of illness and medication impair the patient's ability to follow the procedures required for making an appeal against one's detention and appearing in front of a tribunal.

*R2: "It was hard for me because I was so unwell really, actually to take it in. For a start, I had to be helped to write a letter to them by a nurse because I was too drugged up to write I think. She wrote it and I signed it. And there they were talking to me, it was sort of going over me. I wasn't sort of taking it in that well..."*

The participant's comments confirm the finding that obstacles such as the impact of medication and lack of access to writing materials impede appeals under Section 2 of the Mental Health Act 1983 (Bradley, Marshall and Gath, 1995), although at least the participant was assisted by staff in making an appeal, indicating recognition by staff of the basic right to appeal against compulsory detention under the Act.

### **The Mental Health Act 1983**

A number of participants commented that they lacked knowledge of their rights under the Mental Health Act 1983 during their hospital detentions. The consensus view was that patients are provided with cursory written details of the Mental Health Act 1983 and the implications of their detention are not explained. Therefore, it appeared that the provision of such information was merely a paper exercise that held little meaning for participants. The ability to comprehend the information provided may have been impaired by illness or medication, as the following participant indicates.

*S: "Well I didn't really understand it [being sectioned] at the time. I mean, I was given a leaflet and it said 'you're being held against your will,' whatever it said, for a certain amount of time. 'If you want to appeal, blah, blah, blah.' So I didn't. Where I was so drugged up I didn't really take too much notice of it. But then I suppose, later on, when it became apparent that I wasn't actually getting out of the place, because I'd been sectioned, that was awful. That I'd had everything*

*taken away from me, you know. My freedom, because when I was voluntary – that makes me laugh as well because you're either voluntary or you're sectioned and when you're voluntary, to me it says that you can ask to leave or whatever but then they still stop you and then if you persist, they section you so you can't be one or the other, you're practically both mixed together."*

Therefore, the participant reiterated the cynicism expressed towards informal status that was explored in the section on hospital treatment. In addition, numerous participants related very similar views on lack of information provided and the impact of compulsory detention, thus reiterating the importance of due process as a fundamental civil right.

### **Summary**

Mental health review tribunals were generally regarded as a futile exercise, given the low discharge rate. Such low levels of discharge were attributed to the composition of tribunal panels, the influence of professionals' recommendations, poor legal representation and conservative approaches to risk management. The low discharge rates reported in the current research are confirmed by the Mental Health Act Commission (2005) which found a discharge rate of only 10% in the period 2000-04, although it was even lower in a study reported by Perkins (2003a), with only 5 out of 61 tribunals ordering a discharge.

In addition, two participants described practical obstacles to the appeal process, specifically in relation to the effects of illness or medication. Participants were generally dissatisfied with their legal representation, citing the monopoly of a legal firm and lack of knowledge of the patient. Participants also commented on their lack of knowledge of their rights under the Mental Health Act 1983 and did not find the patient literature particularly helpful in reaching an appropriate level of understanding of their status as detained patients. A number of participants indicated the usefulness of an independent advocacy service in ensuring effective representation in meetings and tribunal hearings.

Finally, several participants indicated their opposition to the proposed changes to the current Mental Health Act in the belief that such changes will further erode service users' civil liberties. Such views will be examined in the following section.

## **Part Three: Political Citizenship**

### **Mental Health Policy**

Political citizenship refers to political participation and influence over political decision-making. Participation is not restricted to formal participation such as standing for public office or voting because political citizenship has been examined in terms of user involvement as an act of political citizenship (Lister, 1998). However, user involvement is examined in the section that explores social citizenship because participants primarily discussed user involvement in relation to service participation rather than political participation. More specifically, political citizenship of mental health service users was examined in relation to their influence on mental health policy.

A number of key questions arose in relation to mental health policy under the current Labour government.

- How did participants respond to New Labour mental health policies?
- What are the factors that influence mental health policy?
- Do users of mental health services have the opportunity to wield political power?
- What is the Labour government doing to tackle stigma and discrimination?

#### **How did participants respond to New Labour mental health policies?**

Three major New Labour initiatives are examined in this section, encompassing community treatment orders (DoH, 1999b)<sup>5</sup>, assertive outreach (DoH, 1998) and the control of 'dangerous' people with personality disorders (DoH, 1999b). I was interested to examine whether participants welcomed such initiatives as a way of dealing with risk in the community or whether they regarded the initiatives as unacceptable infringements of individuals' liberties. Generally, participants possessed little knowledge of

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<sup>5</sup> The text refers to community treatment orders because this was the title of the proposals at the time of the research; they were later re-titled mental health orders.

community treatment orders. However, these were a new initiative at the time of the study and it was obvious that information about them had not spread to all areas involved in the study. In general, participants outside of the south east of England held greater knowledge of mental health policies than participants located in the southeast. Nevertheless, some participants had sufficient knowledge to express opinions on community treatment orders. The consensus expressed by participants was that community treatment orders represented an unacceptable threat to service users' civil liberties and participants expressed strong disapproval of them. Only two participants were willing to express positive appraisals of the policy, although they expressed ambivalence rather than outright approval.

*A: "So yeah, I mean, I think what people don't want and I think professionals and users don't want the riot squad to be going round houses sort of pinning people down and injecting them and then moving on to the next one, you know. But if the community treatment order is going to mean that kind of thing then I don't think anyone would expect it to work. But if it's going to be something that might possibly save someone from a worse history and it might bring them to their senses, I think it's worth trying..."*

One participant discussed community treatment orders in relation to perceptions of, or actual risk posed by mental health service users in the community.

*P1: "Well I think that's a very difficult one really. You know, part of me thinks everyone has a right to say whether they want to be treated or not. That should be a basic human right. But then if you look at it from their effect on other people, then that's something quite different isn't it? Because as we've said, for many people the result of the withdrawal of their drugs is aggressive behaviour. And for some, that's more aggressive than others. Some people could be quite a danger without their treatment. So it's like in one way I don't agree with it but then if there was a schizophrenic living next door to me and our two children and they then refused to take their drugs and they became very violent and abusive, I wouldn't want them living next door to me."*

The participant's comments prompt the question of whether aggressive behaviour is due to illness or due to the effects of withdrawal from medication in the process of refusal to

take medication. However, the participant's partner disagreed by emphasising the coercive nature of the orders.

*P2: "I feel terrified by the whole prospect. I just hate the idea of it. It's almost like the mind police. You know, strolling the streets, looking for somebody misbehaving and whipping them into a clinic, jabbing them full of stuff and then sending them out again. It's terrible."*

Several participants objected to the emphasis on medication in the proposed community treatment orders. The following participant made such an objection primarily on the grounds of the ineffectiveness of medication:

*T: "I think it's abominable, I really do, because I mean, this idea that drugs are some kind of magic bullet, like some kind of panacea. I mean, if the Government thinks that people will stop acting aggressively and disruptively if they are made to have an injection, it's completely untrue because people will just get angry. And you can be medicated and you can still be angry. You can still be disturbed. I mean, if there's a reason for it – because social workers and professionals, they try to say that I've been angry and disruptive because I haven't been taking my medication regularly but the thing is, people can take their medication regularly and they can still be disturbed and they can still be angry. And people are going to be angry because if they think that they're in the community and they're going to be forced by law to have an injection, it won't work."*

Moreover, one participant (E) argued that community treatment orders are based on a belief in psychiatry that service users should take medication for the rest of their lives and on the assumption that non-compliance with medication is irrational. This demonstrates the influence of medical hegemony on Government policy (see also Pilgrim and Waldron, 1998; Mulvany, 2000). On the contrary, E asserted that non-compliance is rational due to some particularly unpleasant side effects and due to the adverse impact of medication on everyday functioning.

Many participants expressed the view that community treatment orders would be unworkable, cited as a less frequently discussed aspect of legislative reform (Beresford and Croft, 2001). The main reasons postulated for the difficulty in enforcing the orders were professional reluctance and insufficient numbers of professionals to enforce the

orders. However, many participants also thought that the orders would cause people to avoid services in order to avoid the coercion inherent in the orders. This is suggested to be a likely response of users to new mental health legislation (Beresford and Croft, 2001). The following participant represents the views of many participants:

*D2: "Where are they going to provide the staff for this? That'll need a doctor, a social worker and somebody else to do that. I mean, you would have to go constantly out and do that...I think it's going to make matters worse and I think it's unworkable, yeah. I think it is because sadly it can put people against the health service when people try so hard and to work alongside instead of working against. It's the total opposite of what people want who are in the service and it's the total opposite to what I think a lot of professionals want. I don't think it will work. I think it's going to create a nightmare and headaches, I suppose if they said if you don't take your medication we will section you and bring you in, that may have a difference if that's what they intend. But if they just intend to grab you and jab you and throw you back at your home, I don't know. Who can tell?"*

Another participant (M) expressed the view that community treatment orders would be unworkable because of the sheer physical difficulty of medicating a person against their will given that the orders would not be enforced in an environment as secure as a psychiatric inpatient unit. Many participants objected to community treatment orders on the grounds that they involve the removal of the right to refuse medication in the community. This prospect was thought to be sufficiently dire by one participant that it would drive service users to adopting a nomadic lifestyle in order to evade capture by mental health services:

*D2: "Yes, I thought they couldn't make me swallow the tablets because I'm renowned for stopping them but they did put me on injections for a long time and you know, I thought you know, with compulsory orders I thought this would be awful because again, it's a right that's taken away, your right to refuse it if you're in the community. I don't see how they're going to be able to do it because do you know what would happen? I can see this happening actually ((laughs)), it's not funny, it's actually very serious. If they pursued people okay, say schizophrenics, with injections in the community, what are they going to do? Run away. Leave. They are not going to stay in one place. They'll up and off they go. They'll be homeless. (Running) homeless people. Moving on, moving on, never receiving the*

*right treatment and they'll just get ill. So instead of having what a lot of people around here I know are trying to do, is give continuity to people with schizophrenia so they have continuous care by people they know in the community and the right medication, constantly looked after in that sense and kept well, it will drive people – I can't believe they haven't thought of that. I mean, how will they stop that? How can they stop it? You can't. What will you do? Go and find them, send all the police out? The police are going to be ever so busy in this country."*

In summary, all but two of the participants who felt sufficiently confident to express an opinion were cynical about the proposed community treatment orders. Many participants felt that their introduction would be impeded by practical difficulties and would cause users to avoid services. Some participants also objected to the implication of the orders for users' civil liberties because they remove the right to refuse treatment outside of inpatient settings.

Assertive outreach was a similarly contentious Government initiative and similar objections were raised against it. Participants felt that assertive outreach services were based on coercion and would similarly drive users to avoid services. One participant (D2) questioned the relevance of assertive outreach to her area, stating that it may be more appropriate for large urban areas such as London in which service users may live more disrupted and disadvantaged lifestyles. The participant also indicated the difficulty in enforcing engagement:

*D2: "...So I don't know about this assertive outreach. Sadly, I think it's made up by somebody who hasn't a bloody clue as to what goes on all around or what it's like to be severely mentally ill. Either that, or they haven't listened because I think the people I know who've been like that I don't think they'd respond in the way they'd want them to. I think they're gonna make tracks and run away and be obscure and go to different towns...But if they are going to be threatened by compulsory medication or treatment orders or whatever and they'll have assertive outreach chasing after them, it's going to ruin everything that's been built up. It really is. And it just seems stupid to waste resources when what they really should be doing is building stronger community services...So I don't think assertive*



*outreach is going to work. I'm certainly not sure about this community treatment. I'm glad I'm not in the service. I wouldn't like to have to do it."*

In relation to the legislation introduced to deal with reputedly dangerous people with personality disorder in the community, participants expressed concern over the civil liberties implications of preventative detention. Objections were also similar to the objections to community treatment orders and assertive outreach in that individuals affected by the legislation were anticipated to avoid services and there would be professional reluctance to enforce the legislation. The following participant summarises this view but also indicated the influence of populism on the construction of mental health policy and the civil liberties implications of the notion of treatability:

*D2: "...I mean, its [the Government] happy to keep the general public happy but we'll just pay token to service users to keep them happy too. I mean, there has been an outcry about all these secure units because they're going to have to lock people up before they've even done anything. And do you know what that's going to do? It's going to drive people underground. People aren't going to want help. They wouldn't dare go for help in case they get branded as personality disorder. If they get branded they'll probably be thrown in with the key thrown away. So what is going to happen is no one will go to their GP, their psychiatrist, anyone, for help..."*

The same participant raised objections to the civil liberties implications of the notion of treatability in relation to personality disorder:

*D2: "...Because if you've not treated them and they're not treatable, how can you ever release them because you can never say they're well again? Well yeah, I mean, there's two things about that I think are really quite sad in a way is the fact that he [Michael Stone] was turned away. Now I don't believe anything's not treatable anyway. I don't believe that. I believe that you just perhaps treat people with personality disorders in a different way. And maybe they don't respond to drugs, maybe that's true...I would suspect that quite a few professionals will be wary of diagnosing them because once you've diagnosed them, that's it, they're done for life...I wouldn't like to be a professional because you can't win either way because if you don't label them and get them locked up and something happens, you're sued and if you do, you could be committing somebody who's not*

*– may never do anything, to a prison for the rest of their lives. It may be on your conscience for that. I don't know.”*

A number of participants questioned the validity of the diagnosis 'personality disorder'. One participant (D2) argued that it is an 'umbrella term' that captures a broad range of impaired functioning (cf. Pilgrim, 2001). However, she did appear to regard the disorder as existing in that she stated “...an awfully high percentage of people have personality disorders. Small bits of their personality might be disordered and it could be anything from a dependency on alcohol or going upwards.” However, other participants were more cynical about the validity of the diagnosis:

*M: “...I still don't really understand what it's supposed to be. And just the title 'personality defect', does that mean that you're walking around in Wellingtons with custard in the bottom? Is that a personality defect? I just don't really understand the terminology, the symptoms, the by-product of the symptoms. I really don't understand what it means.”*

### **Factors that influence mental health policy**

The majority of participants blamed concern with public safety and 'knee-jerk reactions' to homicides perpetrated by mentally ill people as propelling mental health policy. The following participant expressed concern that the actions of a small minority of the mentally ill serve to stigmatise all mental health service users. She also indicated the reluctance of professionals to enforce coercive policy proposals and represents the view of many participants that homicides committed by the mentally ill are the main driving force of current mental health policy:

*J: “But no, I feel all the time I'm fighting to maintain my individuality. I don't believe you should have to hide anything. People should accept us but every time somebody goes out and stabs somebody, it puts a bad (picture) on the service user or a schizophrenic or whatever the person might be. And that's causing more and more stigma...You know, it's going to mean more of a void between the world and us, you know...Well it's because of the fuss that's been made about people stabbing, being stabbed...there's a very low percentage of mental health users that will kill and usually they've been misusing drugs as well as not taking their medication. And it's happening more and more, people going stabbing people*

*with swords and in a hospital and in a church and obviously it's mental illness but we're not all going to start doing things like that. Most of us just want to live our lives and be part of the world, the community. And I think it's becoming an increasing battle. Service users will need each other more and more and we'll have more ideas of being ghettoised and being a closed community within ourselves. And I think that's very frightening really."*

A number of participants identified populism and public pressure for greater containment as a factor underlying the construction of current mental health policy and in the expenditure of funds. Lister (2001) describes populism as involving the 'wooing' of the wider electorate that allows the tabloid media to set the parameters of political debate and leads to exclusionary policies (see also Beresford and Croft, 2001) and is part of the demonisation of mental health service users whereby Pilgrim (1999) states:

"Us and them, sane and insane, public and patients, most voters and few – so much for social inclusion." (p.2)

Populist mental health policy appears to be an example of the 'dividing practices' described by Foucault (2002) in which the powerful construct a dichotomy between the 'sane' and the 'insane'. Such populism is based the stereotypes of dangerousness described by participants (see also Beresford and Croft, 2001).

The following participant refers to the type of facilities Frank Dobson's 'extra' £700million is being spent on and the re-institutionalisation this involves:

*D2: "...I've been trying to get the MP here to see if they'd put forwards suggestions and questions in Parliament. So if somebody did, they'd be putting their neck out because the majority of the population would just be quite happy if they are locked up and that is why – do you know where a lot of this new money has gone? Into secure units around the country. They've put masses of money into secure units just to lock people away and that is it. And so sadly, do you know what is so sad is that they closed the asylums and chucked everybody out. They didn't give any community care. Things have backfired and now they've rebuilt smaller asylums and they're going to lock them up and throw away the key. And that's the cycle. And that's happened in fifteen years."*

**To what extent do mental health service users have the opportunity to wield political power?**

In relation to the construction of mental health policy, one participant (E) contrasted the considerable power the professional lobby exert on the construction of policy with service users' relative lack of power to influence policy. However, a second participant spoke of a lack of formal political power due to the stigma of mental health problems:

*D2: "...I mean, I've often thought about campaigning a bit more but I'm scared because I'm scared that someone will see my name or picture in the paper and say send in a thing saying this person is a mad woman. So it doesn't really give you much confidence to go out there and be political when you've got that little skeleton in the cupboard. Because I was thinking, I could never stand for Parliament...I'm surprised we're allowed to vote ((laughs))...The last election I know because I have actually missed elections because I was sectioned or whatever. Yes, if you're sectioned, yeah. Prisoners can vote can't they?"*

**To what extent is the Government tackling stigma and discrimination against mental health service users?**

Standard One of the National Service Framework for mental health (DoH, 1999a) states that the Government will introduce policies that tackle the stigma and discrimination associated with mental health problems. I asked participants whether they thought the Government was honouring its promise. A number of participants welcomed the National Service Framework as facilitating greater user involvement and as giving users 'almost legal status' (D2) in having a right to be consulted in the provision of mental health services. However, the following participant indicated the problem of professional resistance to greater user involvement:

*P1: "...I think they have to accept [user group] because of the National Service Framework. So they have to accept [user group] and they have to listen to them and some people in the service are very supportive of that and want to encourage that but there are quite a lot who aren't and who don't have the same belief that users should be involved in the development of mental health services. And that*

*belief that we said 'we've trained several years for this so I know what I'm doing and you don't'. They sort of want to keep hold of it."*

Another obstacle to the realisation of the more emancipatory aims of mental health policy is the lack of appropriate funding, as suggested by the following participant:

*D2: "...Yeah, I mean, I think if the NSF was really serious then it should have been backed with the appropriate funding for development of services but because that hasn't really happened, it's just a laugh isn't it? But the general population don't know that. I can't believe why people don't get out from the television and the radio and say this to the country and say well this is what is really happening..."*

The lack of appropriate funding to realise the more emancipatory aims of the National Service Framework can be contrasted with the participant's previous comments explaining the funding of the more coercive elements of current mental health policy. The contradictions between the progressiveness and authoritarianism inherent in New Labour welfare policies (Lister, 2001) seems most explicit in the Government's approach to mental health policy. In addition, the way in which most participants who expressed a view objected to community treatment orders as coercive and discriminatory indicates that the Government was not regarded as honouring its promise to tackle stigma and discrimination against mental health service users. Indeed, many participants indicated that current mental health policy serves to increase the stigma of mental health service use.

### **Summary**

Participants objected to all of the three New Labour mental health policy initiatives. Community treatment orders in particular were regarded as unworkable, likely to cause people to avoid services and as posing an unacceptable threat to service users' civil liberties. The same objections were raised in relation the preventive detention of 'dangerous' people with 'severe personality disorder'. Assertive outreach had not been implemented in at least one of the study areas and thus provoked less comment. However, it was viewed as unworkable on the grounds that engagement cannot be

coerced and would cause people to avoid services in order to avoid coercion and threats to individual autonomy.

Participants who provided a view were unanimous in blaming high profile homicides committed by persons with mental health problems as driving coercive mental health policy. The Government's concern with populism was regarded as driving an emphasis on public protection and as causing even greater stigmatisation of people with mental health problems.

Stigma was identified as a barrier to political involvement and the relative power of the professional lobby to direct mental health policy was seen as indicative of service users' lack of political power. Therefore, participants appeared to suggest that mental health service users lack political influence. The following section examines the influence of users of mental health services on those services.

## **User Involvement**

Having questioned participants about their experiences of mental health services, I wanted to examine the extent of user involvement in relation to statutory mental health services. User involvement is an active form of political citizenship (Lister, 1998). User involvement is also relevant to citizenship because citizenship is described as involving participation in democratic decision-making, including in relation to welfare services (Croft and Beresford, 1992; Beresford and Campbell, 1994). This is referred to as participatory democracy (Beresford and Campbell, 1994) whereas participants described user involvement that fell significantly short of such participation. A number of questions were constructed to question participants about their experiences and views of user involvement:

- How are users involved in statutory mental health services?
- How would participants like to be involved with services?
- Do users exert an influence over services?
- Are there specific barriers to user involvement?
- What is the response of mental health professionals to user involvement?
- What has been the personal impact of user involvement on participants?

### **How are users involved? How would users like to be involved?**

The most commonly reported type of involvement was consultation in which representatives from services sought users' views on the development of services. In one of the study locations a new inpatient psychiatric unit was built and users were consulted on the design of the new unit. However, one participant complained that several of her own suggestions for the unit were ignored by the project co-ordinators. The experience appeared to demonstrate that users exerted questionable influence over the final decisions for the unit. The participant has already been reported as complaining that the new unit was designed with greater emphasis placed on risk management than on patient comfort (e.g. plastic bed sheets and showers that ran as sports centre showers). This is her view of the consultation process:

*D2: "... Again you know, if there's any ideas to change a service, they need to be consulted, the users. And very much listened to. And if they [users] say no they*

*don't want that changed, there must be a good reason to go against that decision. Because what I don't like is if users are just asked and their views are not listened to and they're not taken into account and then that's just not on. It's not appropriate. To me, the success is when you are actually listened to and change is because of what you've said."*

Participants referred to information sharing as an additional form of involvement. One participant criticised the view that services pay lip service to users views in that he found the information sharing aspect of involvement enlightening and as "a learning process in itself" (E). He referred to the value of attending health trust meetings and Community Health Council meetings in order to keep abreast of developments in his local area.

Another type of involvement was the monitoring of services, referred to as 'voice' by Peck, Gulliver and Towel (2002). One participant (D2) described monitoring as a way of indicating to the local health trust the problems arising in relation to services and described the local user group as a 'watchdog'. Users in one of the study areas were involved in establishing a patients' council in a new inpatient unit. This was presented as one way in which services could be monitored and as a way of modifying the balance of power between psychiatric professionals and service users.

Networking was also seen as a further means of user involvement. A small number of participants discussed attendance at conferences and other events in which they were able to meet with other service users from across the country, as described by the following participant:

*E: "Well I'm certainly not academic in the sense that I can articulate a lot of factual information and give you a big summary but what I feel for myself is that by being involved with the various groups I am involved in, I get a better picture of how other service users find their involvement. Certainly with the National Voices Forum and for a while with Mindlink, when I was involved. You see people from other parts of the country that otherwise you wouldn't see. And certainly for the conference where I met you about your research, I think it's good networking. It's important. The only thing I can say with those professionals who have their own professional network but are not service users, they have a vested interest not*



*to promote service user involvement because it's too challenging for them sometimes or they might not like to have to change the way they do things."*

It is interesting that the participant contrasted service user networks and professional networks in a comment that identified two possible barriers to user involvement: professional resistance due to being challenged or not wanting to change. The participant's distinction between professional and service user networks might suggest that professionals benefit from stronger networks whereas user networks may be less well established and less powerful than professional networks. The implication appears to be that professional networks may serve the purpose of maintaining the power imbalances that exist between professionals and service users.

Participants also identified individual ways in which they could become involved in changing services. A number of participants were involved in writing about their experiences. One participant (E) submitted articles to a magazine distributed to service users and another participant (A) had published his own research involving ex-patients' views on the local psychiatric asylum and members of the discussion group had participated in user-led research. Writing about individual experiences was explained as an attempt to challenge the stigma of mental health service use. An additional method of involvement was to respond to Government policy proposals, such as the Green Paper on the reform of the Mental Health Act.

### **To what extent do users influence services?**

There were distinctly mixed views on the extent that users influence statutory mental health services, although many participants expressed frustration at the pace of progress. One participant (D2) has already been described as being dissatisfied with her experience of consultation on the design of a new psychiatric unit. However, participants in the discussion group argued that the greater involvement of users in services had changed the behaviour of professionals involved in their care. Other participants argued that the presence of a user group did influence the organisation of local services, as described by the following participant:

*P1: "I think that [user group] is far more influential now than its ever been and certainly, from what I understand, things have come a long way in the last ten*

*years but they're still a long, long way behind many other areas in terms of involvement and recognition of the user group. I mean, some people go up to conferences where different user groups are involved and when they do that, they come back with stories of how these groups are and how the Trust supports the user group in a very real way. Because you can sit at home and think we're actually doing a really good job and this isn't too bad at all, but when you go out and see what other areas are doing and they're doing that because they have the full backing of the Trust that they're under."*

It became apparent when speaking to users in different parts of the country that the participants in the Midlands and East Anglia were more likely to comment on user involvement in relation to national mental health policy and were more likely to refer to national user events such as conferences whereas the users in the south east of England expressed opinions more relevant to local user involvement. This could have been an effect of some of the participants located in the South East being recruited from the local user group and thus the activities of the group became salient in the research. Furthermore, the participants located outside of the south east of England were recruited through a national conference and therefore might have been more likely to be involved in national user involvement activities and therefore might have been more aware of national policy. In addition, at least two members of the user group in the South East cited social contact as the prime reason for attendance at group meetings, rather than commitment to user involvement as a political activity.

Certainly, a large amount of interview material was generated as a result of participants' discussions of the local user group located in the south east of England. Interview data on the influence of user groups was also generated as a result of the local circumstances in the southeastern area. For instance, a number of services had been threatened with closure shortly preceding the study period and this presented an opportunity to discuss participants' views on how influential the user group had been in persuading the authorities to abandon the threatened closures. Participants held mixed views about the influence of the user group on preventing the closure of some services. One participant, who was not a member of the user group in the South East, expressed doubt over the influence of user groups:

*M: "That's sounds a good idea but it goes back to how much say do these groups actually get and how far they can influence policy and what goes on? I don't know. I'm unsure as to how much they can actually get done or challenge really."*

Nevertheless, one participant reported having received positive feedback from a representative of the local health trust following the user group's involvement in campaigning on the threatened closure of local services:

*D2: "...We had the mental health director wrote to us and said – not director, I don't know the terms actually but one of the – I don't know who she is, she actually wrote to us and said that it was really very influenced by our concerns and reason as to why it needed to stay open and actually thanked us very much and hoped we continued to support the services, like we have been doing basically. I mean, as I said it's not just because of [user group]."*

Certainly there was doubt in relation to whether users influence central Government policy. I asked the following participant if he thought the local user group (of which he was a member) exerted influence:

*T: "I'm not sure. I'm not in a position to say but all I know is that service users don't have much impact on the Government with the Government bringing in CTOs and detention, preventive detention for psychopaths, so I don't think service users have that much impact on the Government."*

This comment is relevant to the question of whether service users are able to wield political power. The answer according to this participant is that Government mental health policy suggests that users lack political power. This is an important aspect of user involvement and illustrates two levels at which user involvement operates: the local level in relation to local services and at the national level in relation to national policies. An additional level is individual involvement in care planning whereby participants' reports of changes in behaviour of individual professionals as a result of user involvement suggests greater satisfaction with individual involvement in comparison with local or national user involvement.

However, one participant (E) was optimistic about the influence of users over services in his area, the Midlands, but when he described consultation he described the sharing

of information rather than influence over service development (“they’ll probably tell us when it will be implemented”). It is interesting that his account of the development of a new psychiatric unit in the Midlands concurs with the account of the new unit built in the south east of England:

*E: “They haven’t started locked wards yet but I think at the next patients’ forum meeting it will be – they’ll probably tell us when it will be implemented. I think they’ve noted the objections and the reasons why but because of patient safety I think really you have to take that into account. And in a sense, I can see why, it’s whether they do a survey of the patients on the ward at the time, whether they would be happy to have that. I think some would and some wouldn’t. But because the staff at [user group] are quite busy in other areas, they visit other day centres relating to the Trust around the area, I think really it would be expecting them to do too much and do quite an involved consultation on that. So we’ll have to see when it starts and basically monitor it if it goes ahead.”*

The final comment might suggest a problem with user involvement occurs in relation to the relatively small number of service users involved who are confronted with the enormous task of changing the balance of power within mental health services.

### **What is the response of professionals to user involvement?**

Only two participants described professionals as holding positive views towards user involvement and this was with reference to specific individuals rather than to professionals in general. All other comments in relation to professionals’ responses to user involvement identified negative views held by professionals. Reasons for professionals’ resistance to user involvement encompassed perceptions of threats to professional power, fear for their own jobs and not wanting to change. Another relevant factor mentioned was the influence of the National Service Framework for mental health on professionals’ behaviour. The NSF was regarded by participants as coercing professionals into accepting user involvement whereby professionals were thought to recognise the demands of the NSF for greater user involvement but lack commitment to involving users in their care or in the delivery of services. The following participant

discusses the impact of the NSF but also highlights the need of users to be encouraged to become involved in user initiatives:

*P1: "Well as I said, some consultants and CPNs just sort of – they'll do it because they have to but they don't really encourage it. If you're unwell, you're very vulnerable and you need encouragement to be involved in those things. One CPN actually brought someone to [user group]. They really encouraged them to come along, brought them in and were with them. But people need that sort of encouragement, to know that they might have something valuable to say and if the CPNs aren't doing that, if the CPNs are very reticent about user involvement and in some cases very discouraging, then people won't get involved. People won't know that they can get involved or that they have any sort of validity."*

Nevertheless, one participant (D2) did report having been encouraged to attend her local user group as part of a rehabilitation programme, thus suggesting that some professionals might be supportive of user involvement. A number of participants referred to professional reticence to accept user involvement as being due to perceived threats to professional power and as not wanting to change. Therefore, overall, professionals were described as being reluctant to accept user involvement although a small number of individual professionals were found to be more encouraging of involvement than others.

### **Barriers to user involvement**

Participants identified a large number of barriers to user involvement. Professional resistance was examined in the previous section. Other barriers included lack of invitations to meetings and networking opportunities; lack of financial remuneration for involvement; lack of commonality with other users; obstructive health trusts; lack of funding; the complexity of policy documents; illness; reminders of patienthood; lack of confidence; lack of influence and lack of credibility of users. Lack of financial remuneration referred in part to inequities in the payment of travel expenses between users and health trust staff, as discussed by the following participant:

*P1: "We get invited to some things. And then when you are invited to something, you're not – they pay something like five or ten pence a mile, ten pence a mile petrol. That's what the Trust pay, which is an insult really because these people,*

*like myself, we're all on benefits. We can't afford to keep going to different places."*

Lack of invites to meetings referred to the lack of invites from the local health trust. The behaviour of health trust staff was also highlighted as indicating the lack of value placed on user involvement by the health trust. The participant above described how representatives from the health trust either cancelled scheduled meetings or arrived too late to conduct a fully attended meeting. These incidents conveyed a lack of commitment of health trust staff to user involvement. In addition to lack of financial remuneration, one participant (G) argued that user involvement is not attractive to users because of the voluntary nature of participation because participation does not attract payment.

Other participants indicated that local user groups were funded by the health trust and therefore that they were not totally independent of the health trust. One participant indicated that user group workers were employed by the health trust, although they were users of mental health services. Lack of influence over health trust policy was also cited as a barrier to user involvement:

*E: "...I don't think they can rock the boat if they wanted to, make objections if it's a majority decisions but at the end of the day, if the Trust wants to do something because it's important then they do it. Then there's not much that the user group can do apart from object or at least once the change is implemented, monitor it and report back to the patients' forum."*

The participant's comments indicate a lack of participation in democratic decision-making whereby decisions are made in the absence of service users, then related post hoc.

Not all of the participants were members of a user group and one participant (M) commented that he had not joined a user group due to a lack of commonality with other users. Another participant (S) who was not an active member of the local user group commented that she felt unable to participate fully in user initiatives because it reminded her of her negative experiences of having contact with mental health services. She described her unease at attending a patients' council meeting in the local psychiatric

inpatient unit because it reminded her of her experiences as a psychiatric inpatient. Therefore, there should be respect for non-involvement of users in an inherently oppressive mental health system (Williamson, 2004). The participant also referred to the use of jargon in inhibiting her involvement in a patients' council meeting. Therefore, users themselves may be responsible for excluding participants by their use of jargon that may not be familiar to new members of user initiatives. Finally, illness was attributed as a barrier to user involvement:

*D1: "Well maybe perhaps it's the nature of the illness that people have, it breeds apathy so it's hard to get people motivated."*

### **The personal impact of user involvement for users**

Amongst participants who discussed the issue, there was a consensus that user involvement exerts a positive personal effect whereby some participants described increased self-esteem, greater access to information, greater motivation and the use of experience to help others. One participant (K) referred to user involvement as providing her with 'a meaningful life' and another participant (E) referred to greater access to information on local services and as a way of remaining occupied and less isolated. The following participant summarised the positive personal impact of user involvement:

*D2: "There are times when it certainly feels tokenistic and I get very angry. But on the whole, I'd say it's far more positive, so that's for me personally. To me, apart from that, to me as a person, it's actually helped me get out and about, integrate and have motivation and have some hope that things will improve. It's given me a driving force and an aim in life to try and improve on the mental health service. It's given me self-esteem, confidence. It's given me so much. You know, I've written a paper about it and said how much it's given me. So that's actually very important to me."*

She proceeded to describe the level of user involvement she would like to see develop: that users should be involved in staff recruitment, professional training, management of budgets, campaigning for increased resources for services and anti-stigma campaigns. However, she also suggested that users require support and training to be effectively involved in mental health services and policy.

## **Summary**

Participants appraised user involvement as being greatly beneficial both on an individual level and as a collective group. Consultation was the most frequently cited means of involvement but some participants expressed dissatisfaction with their influence over service provision. Nevertheless, participants did express satisfaction with greater opportunities to receive information about service developments and appreciated the shift in power inherent in user involvement.

Members of the discussion group felt that professional practice had changed as a result of their involvement in user initiatives. However, other participants were cynical of professionals' motives and regarded them as resistant to change and as wanting to retain their power in relation to service users. The overall view held by participants appeared to be that user involvement represents a significant progression but that the balance of power has not swung sufficiently towards service users.

Participants identified a broad range of barriers to user involvement. These included personal factors but mostly involved barriers placed by health trusts. Similarly, professionals were cited as demonstrating resistance to user involvement, although individual exceptions were also mentioned.



## **Feedback from Participants**

Following completion of the analysis of the interview data, participants were contacted by letter in order to establish whether they wished to receive a copy of the findings chapter (see Appendix 7). Twelve of the eighteen participants were written to whereby two of the letters were returned due to the participants no longer residing at the address. Nine of the participants replied by requesting a copy of the findings but one participant responded by stating that she would agree to provide feedback on the findings “for a fee”. It was not possible to pay a fee in return for feedback due to lack of funds but it was agreed with the participant that she would receive the findings without an obligation to provide feedback. Indeed, the letters sent to the participants emphasised that there was no obligation to provide feedback.

Of the nine participants who received a copy of the findings, only three provided feedback, two in face-to-face meetings and one by email. All three participants commented that they had been struck by the similarity of others’ experiences to their own. It appeared that the research had been useful to the participants in that many had explained the rationale of their participation as wanting to share their experiences with others and publicise their experiences to a wider audience. Therefore, the usefulness of this research depends on its dissemination both to influence policy and service provision but also to share experiences with other service users.

The remaining participants might have been discouraged from providing feedback by the sheer length of the findings chapter, amounting to approximately 50,000 words. In retrospect, I should have offered a shorter summary of the findings in order to facilitate reading and encourage feedback, especially given that Ward and Flynn (1994) recommend avoidance of lengthy documents in the dissemination of research findings. However, I offered the full version of the findings to enable participants to read their own contributions in order to ensure accuracy of interpretation.

## **Chapter Seven: Discussion**

The concept of citizenship was introduced at the beginning of this thesis by reference to Marshall's (1992) tripartite model that encompasses civil, political and social citizenship. The primary aim of the research described in this thesis was to attempt to answer the difficult question of whether people who use mental health services enjoy the opportunities and rights associated with citizenship or whether, as a social group, they occupy a disadvantaged position in society in relation to people who do not use mental health services. I hope to argue convincingly that Marshall's (1992, 1981) conceptualisations of citizenship were flawed due to the negation of the role of power in defining non-citizens and excluding marginalised groups from participation in society.

However, if people who use mental health services are socially excluded as a social group, the problem emerges of whether exclusion is caused by mental health status or by structural factors such as poverty or unemployment. In order to resolve this problem, the findings must be examined to identify the particular aspects of mental health status that increase vulnerability to social inequality.

Read and Baker (1996) conducted a quantitative survey of users' experiences of discrimination. Their findings on employment and parenting were replicated in my own study in that respondents reported harassment from work colleagues, dismissal, rejection in job applications and concealment of psychiatric history in job applications and at least two of the four parents in my study had their parenting unreasonably questioned. However, Read and Baker admitted that they questioned users on a narrow range of topics, acknowledging that they had failed to question users on their experiences of housing, income, education and training. Therefore, my own research covers a broader range of topics and examines topics in greater detail than is possible in a quantitative survey.

Wahl (1999) argued that stigmatised individuals enter social relationships in an inferior position and that 'mental illness' is a prime example of a stigmatised master status (Becker, 1963), defined as encompassing all social roles and as undermining alternative roles. The question arises of whether mental health service use is a master

status to the exclusion of alternative social roles. Participants' discussions were dominated by mental health service use, thus suggesting that they were particularly dissatisfied with such services (the majority of comments were negative), but also indicating the importance of mental health services in the lives of users of these services. The question remains, however, of whether participants primarily identified as someone with a mental health problem. The finding that many participants indicated lack of full enjoyment of citizenship indicates the lack of alternative roles to challenge the service user role. For instance, participants identified lack of employment as involving denial of the valued social role of the economically active citizen.

However, an examination of the advantages of mental health status identified by participants raises important questions about the nature of inclusion. A number of participants described the advantages of occupying the role of a mental health service user. Mental health status was described as enabling the avoidance of coercion into employment and the enjoyment of greater leisure time than the employed, although poverty curtailed leisure activities unless the individual was able to enjoy the concessionary prices offered to some users. The status also enables an escape from the obligations of employment, including an obligation to attend regularly and to remain well. Therefore, some aspects of exclusion from employment appeared to be beneficial.

Moreover, employment has been described as detrimental to health due to lack of exercise and lack of time spent with family and friends and on leisure activities (Anon, 2003). Moreover, exclusion from paid employment often means exclusion from low paid employment. The Government's rhetoric of inclusion through paid employment ignores the prevalence of low paid work (Levitas, 1998) whereby the Social Exclusion Unit report on mental health (SEU, 2004) is accused of ignoring the impact of low benefit levels on social inclusion (O'Kelly, 2004). Instead of demanding inclusion in paid employment, economic inclusion (Perkins, 2003b) might involve an increase in benefit levels (O'Kelly, 2004) to enable choice of whether or not to work and graduated benefits to reduce the role of the benefit trap in discouraging participation in paid work. Flexibility in employment is also recommended to address the kinds of fears participants expressed in relation to the

stress of work exerting a negative impact on mental health (Perkins, 2003b; Sayce, 2003) and greater flexibility in the benefits system to enable people to claim benefits easily during periods in which they cannot work (Perkins, 2003b). However, the latter suggestion fails to address the increased likelihood of dismissal from work due to sickness absence and the way in which the individual's lifestyle would be determined by periods spent claiming welfare benefits while absent from work.

This raises the question of whether people with mental health problems want to be included in society dominated by sane people. New Labour discourse that advocates social inclusion through paid work is an example of the hegemonic nature of social inclusion discourse (cf. Faulks, 1998). Pete Shaughnessy (2000) comments:

I am excluded. I am in the tribe who no one in their right mind would want to be part of it [sic]. I don't want to be included. I don't want to be included in your narrow, moralistic, judgemental world. You all aspire to be at the top, I'm content to be at the bottom.

A meaningful social identity is defined by the dominant voices in society whereby marginalised groups are excluded from the norms of society determined by powerful social groups (Young, 1989). Jenkins (1996) describes social identity as consistent over time and as established through social relationships but also as organised through similarity and difference.

Participants' comments on social networks, user groups and self-help groups indicated a preference for contact with fellow service users, thus suggesting identification of commonality according to mental health status. Participants also distinguished themselves from non-users in their discussions of poverty (being poor in relation to others), social relationships (preferring user friendships, avoiding friendships and partnerships with non-users), employment (difficulty explaining unemployment to non-users), visibility in the neighbourhood and in public attitudes (identifying as the subject of negative public attitudes, implying differentiation between users and the public). However, dominant norms are not necessarily the most healthy to pursue and thus membership of a marginalised group can be appraised as valuable for both the group members and wider society. For example, consumerism and employment are valued by many but may undermine autonomy and creativity (Illich, 1978). Moreover, consumerism is associated with environmental damage

(Clayton, 2000). Nevertheless, participants did appear to desire inclusion in a society dominated by such values because they expressed normative aspirations. For instance, participants indicated not only that they felt disadvantaged in relation to other citizens but also that they held similar cultural values in that they desired property ownership, employment, sufficient income, family life and leisure opportunities. This appears to confirm the view that socially excluded groups share the same values as the socially included (Bauman, 1998).

Furthermore, inclusion was experienced in terms of group membership whereby participants expressed acceptance and commonality in groups comprised of fellow service users. The participants' explanations of their commonality with other mental health service users appears to be an example of identity politics in which marginalised groups find commonality through common experiences of disadvantage and oppression (Young, 1989). It is interesting to note that one participant commented on the disingenuous group membership of another individual who attended a user group but had not received an official psychiatric diagnosis, indicating the operation of a form of exclusion. The complexity of citizenship is exemplified in participants' conceptualisations of commonality in that oppressed groups are not simply excluded from the mainstream of society but construct their own inclusion through group membership according to characteristics such as mental health status or use of mental health services, although it is not the case that participants felt that inclusion in mainstream society is neither realistic nor desirable because participants made reference to 'normative aspirations' in demanding access to the same opportunities as non-disabled people.

Group membership was conveyed by some participants' comments in relation to other marginalised social groups. A number of participants compared users of mental health services with other groups of disabled people whereby people with a learning disability or physical disability were believed to experience less discrimination and stigma. Moreover, prisoners were perceived as being less stigmatised than mental health service users in that they were thought to be less likely to experience problems obtaining employment and to receive better treatment in prison than a psychiatric patient receives in hospital. One participant commented that conditions were better in prison than a psychiatric hospital and that prison involves some degree of legitimacy

in punishing criminals whereas psychiatric hospital was regarded as having no legitimate purpose.

Such comments appear to demonstrate the 'hierarchy of oppression' (Keating, 1997) whereby members of an oppressed group present their own oppression as more salient than the oppression of other marginalised groups, thus minimising others' experiences of oppression. Keating claims that the construction of a hierarchy of oppression perpetuates oppression by failing to recognise commonality of oppression amongst marginalised groups. It also fails to recognise multiple oppression whereby oppression based on specific characteristics is often experienced simultaneously (Keating, 1997). For example, a number of participants in the current study referred to the cumulative impact of mental health status, gender, sexuality, physical disability and age. Keating argues that commonalities between oppressed groups should be recognised in order to increase collective resistance to oppression. This appears to be the rationale underlying suggestions that the mental health user movement should combine forces with the disability movement in order to build resistance to oppression experienced by both groups (Beresford, 2000a).

Keating (1997) indicates the existence of three levels of oppression: socio-cultural in which language and cultural communication constructs representations of marginalised groups. This level is observed in the participants' concerns relating to media representations of the mental health issues and the use of derogatory language in public discourse. The second level, the socio-political level, is produced by social institutions, such as psychiatric hospitals, the psychiatric system and the government. The third level of oppression relates to the psychological impact of oppression, specifically in relation to internalised oppression. This level can be observed in participants' concerns surrounding stigma and difficulties surrounding self-disclosure.

It occurred to me that participants' lives were particularly vulnerable to scrutiny whereby private life becomes scrutinised in the public domain. Participants expressed concern over their visibility in their neighbourhood; their parenting was scrutinised by professionals; their disability was scrutinised by benefit officials (cf. O'Kelly, 2004); behaviour was scrutinised by ward staff during psychiatric inpatient treatment; professionals gained access to private information during the process of assessments

under CPA and gained access to their private life through home visits. Despite proposals by David Blunkett (and latterly Charles Clarke) to introduce national identity cards, members of the public are not exposed to such a high level of scrutiny as users of mental health services.

Participants referred to the stigma of having a psychiatric diagnosis and attributed stigma to predominant stereotypes held by the public and propagated by the mass media. Participants presented a hierarchy of diagnoses whereby schizophrenia and mania were thought to elicit the most negative public responses due to fear of unpredictable behaviour due to perceptions of an association with violence.

Participants in the study described avoidance of disclosure of mental health status across a broad range of experiences: in relation to job applications, visibility in the neighbourhood, within social networks and in relation to parenting. The fear of disclosure appears to represent a strategy for managing information about identity (see Goffman, 1963), in this instance, mental health status. Goffman (1963) defines stigma as unwanted differentiation that leads to expectations of rejection, avoidance of social interaction or behaviour being interpreted according to the individual's main identity. Another aspect of managing identity involves social avoidance and seeking contact with sympathetic others (Goffman, 1963), which was clearly illustrated by participants' preference for contact with other service users. This was predicated on the grounds of commonality of identity and greater likelihood of acceptance. However, the concept of stigma has received criticism due to its individual emphasis and thus the negation of the role of structural factors in the discrimination and exclusion of marginalised groups (Sayce, 1998). Therefore, an analysis of social identity should incorporate the role of power in the formation of identity.

Participants associated social rejection with negative public attitudes based on stereotypes of the unpredictability and dangerousness of mental health service users. Pickering (2001) argues that stereotypes support power imbalances in society whereby the powerful determine the nature and targets of stereotyping and the stereotyped are powerless to resist such mechanisms of social categorisation. Participants' comments on stereotypes suggest that people with mental health

problems occupy the status of 'other' (cf. Foucault, 2002) because stereotypes serve to define insiders and outsiders in society.

Participants were unequivocal in blaming the media for the propagation of damaging stereotypes. Research appears to present a consensus view that the mass media presents negative representations of mental health issues (Wahl, 1995; Philo, 1996b; Philo, McGlaughlin and Henderson, 1996) and that such representations influence public attitudes (Wahl, 1995). The problem confronting such research is how to determine cause-and-effect in that the media and the derogatory language employed by the media may exist within a context of pre-existing public attitudes whereby the media merely satisfies the demand for such representations rather than the media creating such attitudes. Henderson (1996) interviewed television producers who informed her that their remit in producing programmes is to entertain rather than to educate and that good stories are more important than the accurate presentation of social issues, thus suggesting public demand for entertainment rather than a balanced examination of social issues.

However, researchers have acknowledged the role of socialisation in the acquisition of negative public attitudes (Philo, 1996b). Moreover, comments from some of the participants indicated their own socialisation into negative attitudes towards people with mental health problems and the impact of such attitudes on their acceptance of their own mental health status. This finding appears to support the notion of the internalised negative identity that Becker (1963) and Goffman (1963) considered would confront the individual labelled with a deviant identity. It could, alternatively, represent internalised oppression in which the stigma of mental ill health influences individual self-identity (cf. Keating, 1997).

In addition, participants made an association between negative public attitudes, media representations of mental health problems and the emergence of coercive mental health policy. The suggestion that mental health policy has been driven by public concerns over a postulated (but erroneous) association between mental ill health and violence raises the question of whether the issue of homicides committed by people with a mental health problem has become the subject of a moral panic (Muijen, 1995). Cohen (2002) defines a moral panic as 'short term reactions to the immediate...and



long term reflections on the 'state-of-our-times'. Therefore, moral panics contain moral judgements (Thompson, 1998) and are transmitted primarily through the mass media (Cohen, 2002). Moral panics exaggerate the threat posed by the targets of the panic and serve to increase hostility to particular social groups (Cohen, 2002). Cohen argues that, like stereotypes, moral panics reveal sources of power in society since moral panics are targeted at those thought to pose a threat to the social order and involve demands for the imposition of social control on those threatening the status quo (Thompson, 1998). Moral panics are propelled by fear and perceptions of increased risk to the moral and social order (Thompson, 1998) and create folk devils in society (Cohen, 2002).

The suggestion of a moral panic involving homicides committed by people with mental ill health raises the question of whether users of mental health services are folk devils in society. Cohen (2002) describes folk devils as visible reminders of social roles to be avoided whereby such roles involve threat to social values and majority interests. The role of the media in creating folk devils and moral panics is simply to exaggerate the threat posed by the target group. This is achieved through the use of terms associated with derogation and violence, such as 'psycho', 'maniac' or 'sicko' (Philo, McGlaughlin and Henderson, 1996). Tabloid newspapers have been found to exaggerate the numbers involved in homicides associated with the mentally ill and call for greater control of the mentally ill (Crepaz Keay, 1996). Moreover, media representations do influence public attitudes (Philo, 1996a, 1996b) and serve to increase nimbyism and reduce help-seeking behaviour (Secker and Platt, 1996).

However, politicians also play a crucial role in the exaggeration of the risk posed by people with mental health problems. Participants argued that mental health policy, specifically the proposed compulsory community treatment and personality disorder legislation, serves to increase the stigma of having a psychiatric diagnosis. Participants also explained policy developments as a reaction to high profile homicides involving people with mental health problems. Interestingly, a number of participants adopted a 'community care has failed' discourse in attributing homicides to problems the perpetrators experienced in accessing mental health services. Therefore, the link participants made between homicides and policy suggests that policy development either contributes to or is informed by moral panics. Participants

believed that the overall effect of a moral panic involving mental health service users is to undermine the civil liberties and social participation of people with mental health problems. Participants also regarded mental health policy as discouraging help-seeking behaviour because use of mental health services was associated with stigma and threats to civil liberties.

Research suggests that mental health policy responds to public pressure for containment and colludes in predominant stereotypes of the dangerous mental health service user (Laurance, 2003). It appears that users of mental health services lack the power to influence public policy and that they are less influential than the public in the development of mental health policy. However, Morrall (2000) argues that moral panic theory has been misapplied to mental illness because, he asserts, notions of moral panic ignore the real suffering of both the victims of homicides and of the perpetrators of such homicides. Morrall argues that, although the number of homicides perpetrated by the mentally ill is small, the violence is real and that mental illness associated with violence is real. He argues that social constructionist analysis of the issue denies the suffering involved in such violence and claims that the blaming of the media represents a denial of responsibility by psychiatric professionals, resulting in increased public anxiety over the perceived threats people with mental illness pose to society. Morrall disputes research on media representations of mental health issues by claiming that the media do not exaggerate the threat posed by the mentally unwell.

Moreover, Pickering (2001) argues that moral panic theory is flawed because moral condemnation is not transient. This point relates to the subjects of moral panic theory in that Cohen's original research examined the media attention paid to the violence between the Mods and the Rockers in the Sixties (Cohen, 1972) and Thompson (1998) examined panics surrounding Ecstasy and the rave scene in the 1980s, high profile murder cases and AIDS. Pickering's argument could be adopted to posit that people with mental health problems have been the target of moral condemnation for a considerable period of time. However, media attention surrounding high profile homicides by people with mental health problems tends to blame community care for an increase in violence by this group (Crepaz Keay, 1996) and suggestions of such an increase are clearly erroneous due to an annual decrease of 3% in such homicides in

recent years (Taylor and Gunn, 1999). Nevertheless, in accordance with Cohen's definition of moral panics (Cohen, 2002), the identification of a moral panic in relation to high profile homicide cases involving the mentally unwell depends on how transience is defined. The era of community care spans almost twenty five years, thus suggesting that concerns about community mental patients being 'Freed to Kill' (Crepaz Keay, 1996) extends beyond a merely transient reaction. However, it could be argued that each high profile homicide triggers a resurgence of a familiar moral panic, with specific high profile cases leading to changes in government policy (Muijen, 1995).

Gramsci's (1971) notion of hegemony may be relevant (see Morrall, 2000) in that moral panics are hegemonic in obscuring social inequality by producing folk devils onto which frustration can be targeted. Hegemony is defined as ideology that obscures power relations in society (Desmoyers-Davis, 2003). Stereotyping and the creation of folk devils have been attributed to the powerlessness of people with mental health problems within society. I will argue that the powerless status of people who use mental health services is derived from 'psychiatric hegemony' (Davidson, 2003) that constructs mental health problems as rooted in biological dysfunction and prescribes biological intervention as the panacea to mental distress. The powerlessness of mental health service users derives from their subjugation to the psychiatric profession whereby the power of the latter is derived from its power to define irrationality and the power to privilege medical expertise over irrationality (Foucault, 1994). Foucault argues that the location of psychiatric expertise is the psychiatric institution (see also Shaughnessy, 2000).

Participants' discussions of inpatient psychiatric hospitalisation bore remarkable similarity to research on psychiatric inpatient care in that they described lack of activity, lack of therapeutic intervention, lack of staff-patient interaction, heterogeneous patient mix and poor physical environments (see SCMH, 1998; Walton, 2000). Participants' descriptions of inpatient care also bore similarities to Goffman's description of the 'total institution' (Goffman, 1961) in that participants complained about the rules and rigid regimentation of ward life. Goffman discussed regimentation and 'tyranisation' as involving 'curtailment of self', referring to suppression of individual autonomy. Goffman also referred to the 'mortifying'

experiences of ward life as involving lack of privacy, communal living, restricted movement and subordination to authority. Participants complained about all of these features of ward life. Goffman concluded that psychiatric hospitals have a custodial function due to the systematic oppression of patients and SCMh (1998) concluded that hospitals function merely to contain patients, given the lack of therapeutic intervention offered to patients. Participants' discussions of psychiatric hospitalisation confirmed the function of containment fulfilled by psychiatric hospitals in their descriptions of responses to ward life as involving a 'prisoner mentality' in which patients subordinate themselves to the authority of the psychiatric professions in order to achieve earlier discharge or greater freedom. The existence of the prisoner mentality strongly suggests that participants did not view psychiatric hospitalisation as therapeutic. Indeed, many participants described hospitalisation as counter-therapeutic in discussing lack of privacy, disruption caused by a heterogeneous mix of patients and suicide attempts, lack of fresh air and exercise, lack of freedom of movement and the stress associated with containment.

A number of participants referred to the high number of deaths amongst mental health service users, particularly in relation to suicides of inpatients. Mortality of those diagnosed with mental ill health is significantly higher than amongst the general population (Brown, Inskip and Barraclough, 2000), although it is claimed that suicide cannot explain high rates of excess mortality (Waddington, Youssef and Kinsella, 1998). However, other researchers have claimed that suicide is the largest cause of excess mortality amongst people with mental ill health (Brown, 1997) and unnatural deaths, including suicide and accidents, account for up to 50% of excess mortality (Mortensen and Juel, 1993). Other researchers attribute excess mortality to the effects of neuroleptic polypharmacy (Appleby, 2000; Waddington, Youssef and Kinsella, 1998) yet others indicate excessive rates of cardiovascular, circulatory and respiratory diseases amongst people with mental health problems and attribute such diseases to a combination of unhealthy lifestyles (such as cigarette smoking) and poor treatment of physical illness (Brown, Inskip and Barraclough, 2000). Participants' complaints of the negation of physical illness by both general medical and mental health professionals should be viewed within the context of excess mortality and the potentially fatal consequences of failing to investigate and treat physical illness in people who use mental health services.

The most striking example of the untherapeutic nature of psychiatric hospitalisation was conveyed by participants' discussions of abuse that occurred at the hands of ward staff. A number of participants commented on the prevalence of the use of 'control and restraint' and the use of medication to sedate patients following resistance to the ward regime. The former can be described as involving physical control and the latter as involving chemical control. Abuse was also in evidence, although not discussed to any great extent, in the use of seclusion following supposedly disruptive behaviour.

Power is thought to be central to abuse (Penhale, 1999) whereby abuse is defined as:

...use of power to serve self-interest (or group interest) when there are seriously damaging consequences for a person (or group) that is less powerful (Williams and Keating, 1999: 131)

Copperman and McNamara (1999) explicitly relate the types of experiences described by participants with abuse. For instance, they claim that abuse is inherent in seclusion, forced compliance with medication, limited contact with staff and lack of autonomy on the ward. Moreover, formal complaints of abuse are unlikely to be made (Alty, 1994) or to be addressed because the credibility of patients' accounts is undermined (Williams and Keating, 1999; Copperman and McNamara, 1999) and reflects the powerlessness of patients in relation to professionals (Penhale, 1999).

Lukes (1974) argued that institutions exert power through collective support that derives from consensual political or social relations. It is argued that the legitimacy of psychiatric hospitalisation derives from 'psychiatric hegemony' (Davidson, 2003) that not only defines mental illness as involving biological mechanisms but also prescribes professional dominance of intervention (Foucault, 1994). The power of psychiatric hegemony is apparent in the way some participants had internalised the biomedical perspective in describing their mental health problem as being due to a 'biochemical imbalance', although many participants explicitly rejected the medical model by attributing emotional distress to social problems.

Moreover, participants' experiences of psychiatric hospitalisation not only reveal locations of power in society, but also reveal the sheer damage caused by psychiatric intervention. Illich (1995) refers to iatrogenesis in describing the harm caused by

medical intervention. Iatrogenic medicine is described as that in which the costs outweigh the benefits, problems are individualised and recovery is undermined. Clinical iatrogenesis is clearly witnessed in relation to participants' experiences of medication in terms of unpleasant side effects and the restrictions placed by such effects on the ability to function in everyday life. A small number of participants described medication as stabilising their illness but a larger proportion of participants described side effects that restricted the ability to function in relation to employment, parenting and social relationships. The power of psychiatry was demonstrated in the greater number of reasons produced by participants to comply with a medication regime in comparison with reasons not to comply. For instance, participants attributed compliance to fear of hospitalisation and coercion from professionals, fear of illness and fear of withdrawal from medication. Professional power was demonstrated by professional resistance to self-medication (cf. Illich, 1995) and control of information on treatment (cf. Rose, 2001).

Illich (1995) also refers to social iatrogenesis in the way medicine removes individual responsibility for health. Illich indicates the problem of the medicalisation of everyday problems as contributing to social iatrogenesis. Similarly, Breggin and Cohen (1999) argue that psychiatry has increasingly medicalised everyday emotional responses. They argue this is inherently problematic because psychiatric medication is similar to alcohol and illicit drugs in merely obscuring problems. They argue that an increasing medicalisation of emotional problems reduces individuals' tolerance of painful emotions and undermines ability to harness resources to cope with such emotions. Social iatrogenesis appears to bear resemblance to the final category of iatrogenesis, cultural iatrogenesis (Illich, 1995) in which healthy responses to problems are paralysed by the over-intervention of medicine. Social and cultural iatrogenesis relate to the dependency that was identified by participants as problematic in relation to mental health services.

The problem of dependency in mental health services was referred to by numerous participants and has been identified with the propagation of sick role behaviour in mental health service users (see Johnstone, 2000). Johnstone argues that the medical model in psychiatry removes responsibility from the patient for their recovery whereby psychiatric professionals collude in the sick role by playing the 'rescue

game' in which professionals place individuals in a dependent position. The sick role bestows certain advantages in that illness implies lack of responsibility and lack of rationality and thus enables escape from the demands of healthy functioning (Goffman, 1963).

Similarly, Coleman (1999) accuses the mental health system of colluding with patients to undermine recovery, particularly in relation to the role of medication in removing the individual's capacity to relinquish dependency on others. Dependency in the mental health system is inherent in the notion of imputed needs (Illich, 1977) in which professionals determine individual needs, such as in the care planning process (Baldwin, 1998; Stainton, 1998). McKnight (1977) indicates how professional intervention in the name of 'care' is disabling by locating deficiencies within the individual, thus warranting individual intervention; it fragments the client into discrete problems, therefore warranting inter-disciplinary intervention; and results in professionals monopolising solutions to problems they have prescribed in the first place. McKnight argues:

When the capacity to define a problem becomes a professional prerogative, citizens no longer exist. The prerogative removes the citizen as problem-definer, much less the problem-solver. (McKnight, 1977: 85)

Furthermore, Illich (1978) argues that modern life is dominated by professional intervention and that the effect of this is to undermine individual autonomy in developing creative solutions to problems.

User involvement is described as an active form of citizenship (Lister, 1997). The findings suggest that user involvement was largely restricted to consultation and there appeared to be regional variations in the nature of user involvement. A fundamental question that arises in relation to user involvement in mainstream statutory and voluntary services is whether users would want to be involved in a mental health system that is fundamentally flawed (Williamson, 2004). Moreover, the dominance of the medical model remains, despite the ascendancy of user involvement in mental health services. The construction of mental distress as an illness is fundamentally damaging due to the implication of dysfunction and abnormality for perceptions of people with mental health problems as inferior to the well majority, note one

participant's comment concerning the difficulty in participating in an able-bodied society. This is also noted in relation to the hegemonic nature of social inclusion discourse (Faulks, 1998).

Moreover, the dominance of the medical model is rendered explicit in discourse adopted by the current Labour government. Labour discourse equates mental and physical illness in describing mental health problems as being as 'common as asthma' (Dobson, 1998); in employing a professor of psychiatry as the mental health czar (Louis Appleby) and, most explicitly, in demanding compliance with medication in its proposals for compulsory community treatment (DoH, 1999b, 2004). Despite the Government's attempt to emphasise normality of mental health problems in their prevalence, Labour mental health policy serves to increase the stigma of mental health service use and increases the oppressive aspects of mental health care. The Government's approach to mental health lacks coherence, veering between claiming to challenge prejudice in the National Framework for mental health (DoH, 1999a) and simultaneously threatening the civil liberties of mental health service users in the draft Mental Health Bill (DoH, 1999b, 2004).

The medical model assumes that mental distress deprives patients of insight into their illness and impairs rationality, thus justifying doctors' decision-making in patients' best interests (Cavadino, 1989). The paternalism inherent in *parens patriae*<sup>6</sup> constitutes discrimination because it is only applied to people with mental health problems (Bean, 1986) whereby non-discrimination would involve the detention of all members of the public who engage in potentially self-injurious behaviour (Pols, 1989). Participants made frequent references to the fundamental distinction between psychiatric and general medical patients on the issue of the ability of general medical patients to refuse treatment. It would appear that the civil liberties of people with mental health problems are significantly more easily removed in the name of state protection than for any other group in the community. This is particularly the case in relation to removal to a place of safety by the police under Section 136 of the Mental Health Act 1983 and the removal of individuals' freedom of movement under, for instance, Sections 2 and 3 of the Mental Health Act 1983. The increased use of

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<sup>6</sup> *Parens patriae* is defined as the justification of compulsory detention in the patient's best interests (Cavadino, 1989).



Sections 2 and 3 of the Mental Health Act 1983 (Hotopft et al., 2000), the increased Government expenditure on secure inpatient beds (DoH, 1998a) and proposals for compulsory treatment and care plans (DoH, 1999b, 2004) indicates the creeping onslaught on mental health service users' civil liberties. It would appear that such developments might indicate an increasing tenuousness of community residence since the advent of community care twenty-five years ago. Participants' descriptions of their visibility in their community in the process of 'sectioning' and the relative ease of removal from the community within the sectioning process suggested the tenuousness of community membership.

An important question that arises from T.H.Marshall's conception of citizenship is whether it is a neutral concept. Marshall failed to examine differences in citizenship status in relation to gender, ethnicity or sexuality, primarily due to reflecting the attitudes prevalent at the time of his writing. An updated analysis of citizenship eschews the postulated neutrality of the concept by examining the citizenship status of certain social groups. Citizenship is not a neutral concept because certain social groups appear to be more vulnerable to social inequalities than other social groups. The thesis of my research is that people with mental health problems are particularly vulnerable to experiencing social inequality but this argument must be presented within the context of an interaction between numerous structural factors to present a complex picture of social exclusion.

In relation to gender, there was no significant difference between the importance of employment for male and female participants. Employment appeared to be equally important to both sexes, except that people who were carers either of children or partners appeared less interested in securing employment. However, research on employment and poverty suggests that women are disadvantaged in the labour market due to the competing demands of caring or parenting and in the benefits system due to the assumption of women's financial dependence on men; women are also more likely to be poor, especially single parents (Flaherty, Veit-Wilson and Dornan, 2004). All four of the parents in the study were women and only one male (M) discussed parenting but in a hypothetical sense about future parenting. One participant (D2) discussed how single parents are more likely to lose residence of their children due to the absence of the perceived stability provided by a male partner. Interestingly, two

participants discussed the professional attitudes they had encountered in a rejection of their same-sex parenting; they felt that their family was not regarded as valid by professionals. The same participants described the impact of crisis mental health services on removing the individual from the family unit as very unhelpful and female participants exclusively referred to the impact of psychiatric inpatient treatment on their family life in terms of separating the parent from their children. Women exclusively described the negative impact of medication on parenting and personal relationships, particularly in relation to sedation and emotional blunting.

One participant (T) made explicit reference to the interaction between mental health, male gender and social inequality. He expressed concern that male mental health service users are more likely to be deemed dangerous. He also made reference to the prevalence in abuse in the histories of people who use mental health services and a number of participants made reference to abuse in their own histories. However, the research produced no data to suggest whether gender differences exist in the prevalence of abuse in the backgrounds of people with mental health problems because investigation of aetiology was not an aim of the research. Interestingly, there did appear to be a gender difference in illness discourse adopted in that men were more likely to adopt a biochemical explanation of their illness whereas women were slightly more likely to explain their mental health problem in terms of social stressors such as housing or income problems. The reasons for this are not apparent in the findings. However, participants, regardless of gender, were more likely to attribute mental health problems to social rather than biomedical factors: explanations encompassed family dynamics, family dysfunction, abuse and an accumulation of social stressors. Two participants (P1, D2) did refer to family disposition that might suggest genetic factors in the causation of mental health problems. In addition, one participant (S) suggested that males are disadvantaged in relation to mental health issues due to gendered cultural beliefs surrounding emotional expression in that males are expected to inhibit their emotions, although she did not discuss the finding from research that this factor might cause men to be more likely to engage in substance misuse and suicide as a way of dealing with emotions rather than expressing and sharing negative emotions in a cathartic way (Johnstone, 2000). Furthermore, participants expressed the belief that schizophrenia and mania are more likely to lead to social rejection due to public perceptions of dangerousness and unpredictability.

Such perceptions suggest that public attitudes are, perhaps unsurprisingly, more concerned with threats to the public rather than threats to people with mental health problems posed by social inequality, self-injurious behaviour or violent victimisation.

Read and Baker (1996) found that 50% of the respondents to their survey had experienced harassment in the workplace and in the community. Participants in my study also reported harassment at work and, to a lesser extent, in the community. However, Berzins, Petch and Atkinson (2003) found that workplace harassment was less common amongst people with mental health problems due to lower levels of employment. Nevertheless, they found that 41% of respondents reported harassment in the community in comparison with 15% of the general population. Verbal abuse, particularly derogatory name-calling, was the most common form of harassment, yet people with mental health problems were significantly less likely to report victimisation to the police due to a fear of not being believed and mistrust of the police due to their association with detentions under the Mental Health Act. A study of urban violence directed at people with mental health problems found that 16% reported having been a victim of violence in the previous year compared with 7.1% of the general population living in urban areas and reported in the British Crime Survey (Walsh et al., 2003).

The reported experiences of two participants (P1, P2) reiterated the findings of a small body of research on the experiences of lesbian, gay and bisexual mental health service users. The participants' comments reiterate the concept of multiple oppressions in indicating the cumulative impact of discrimination based on mental health, sexuality and physical disability. McFarlane (1998) argues that the primary form of discrimination is ambiguous in cases of multiple oppression. Moreover, the participants in my own study reported heterosexism of mental health workers. Rankow (1996: cited in McFarlane, 1998) defines heterosexism as:

The institutional and individual assumption that everyone is heterosexual and that heterosexuality is inherently superior to, and preferable to, homosexuality or bisexuality.

Both McFarlane and the participants in the current study indicate that mental health workers view homosexuality and lesbianism as pathological and caused by or is the cause of mental ill health (cf. Golding, 1997). Voyeurism and inappropriate

questioning was reported in McFarlane's study and my own findings. Similarly, mental health workers failed to recognise same-sex partnerships by failing to provide information on treatment and services to partners. Furthermore, Golding (1997) indicates that homophobia from mental health workers and users add to the stigma of same-sex sexuality but also isolate lesbian and gay mental health service users from other users. Golding argues that rather than displaying homophobic behaviour, mental health workers should affirm sexuality and challenge internalised oppression rather than reproduce the homophobia and heterosexism of wider society.

In relation to class, two participants referred to a system of social stratification in which people with mental health problems are located at the bottom of such a system. One participant (T) described social drift whereby he failed to replicate the success of his parents in employment and explained this in terms of the stigma of mental health service use. It is interesting to note that many of the participants held advanced qualifications and yet many complained of difficulty in obtaining or maintaining paid and unpaid work due to the stigma and discrimination associated with mental health status. Data was not collected on the class backgrounds of participants' families but high levels of unemployment within the context of high levels of educational attainment indicate disproportionate disadvantage experienced by participants.

As mentioned previously, a major omission from my research is an analysis of the interaction between mental health, ethnicity and social inequality. Only one participant (K) was a member of an ethnic 'minority' and made some comments about her African-Caribbean background but did not extrapolate possibly because the ethnic composition of the small group discussion (two white females and one African-Caribbean female) precluded an in-depth discussion of ethnicity.

The criticism of neutrality aimed at T.H.Marshall's (1992) analysis of citizenship raises the question of whether the concept of citizenship is a useful vehicle for the analysis of social inequality in relation to people who use mental health services. The usefulness of the citizenship framework is that it examines the status of people who use mental health services beyond the status of service users because it demands fulfilment of a broad range of social roles. The citizenship framework also offers an alternative to the biomedical model that continues to dominate the analysis of the

experiences of people with mental health problems. The citizenship framework also enables an examination of normative social values in defining valued opportunities available to citizens and the type of membership demanded by citizens and also an examination of the power dynamics inherent in the question of who defines such values.

The originality of the present study lies in the application of T.H.Marshall's tripartite model of citizenship to people who use mental health services. The tripartite model provides a conceptual framework for the analysis of the social participation and membership of people who use mental health services. This has not been achieved before in a qualitative study. For instance, although Barham and Hayward (1995) made explicit reference to employing a conceptual framework of citizenship, they failed to examine the theoretical basis of their conceptual framework. Barham and Hayward's sample comprised of twenty male and four female ex-patients with a diagnosis of schizophrenia. The sample of participants in my study is broader in that it included eight males and ten females and did not restrict inclusion in the research to people diagnosed with schizophrenia. Barham and Hayward's participants hailed from a northern town with high rates of social deprivation, as evidenced by high rates of supplementary benefit receipt. The participants in the current study were mostly recruited from a seaside town in the south of England that nevertheless also featured high rates on measures of social deprivation such as unemployment, poor housing, suicide rates and teenage pregnancies (ODPM, 1998).

However, my study is comparable with Barham and Hayward's study in omitting an analysis of ethnicity due to an absence of non-white participants, although Barham and Hayward's sample did not feature any non-white individuals whereas the current study included one female from an African-Caribbean background. Nevertheless, the Barham and Hayward study was seminal in linking the social exclusion of ex-mental patients with membership inherent in definitions of citizenship and thus is highly influential to my own research. However, the current research examined service users' conceptions of citizenship in an analysis that enables a comparison to be made between participants' descriptions of their own status and how they perceive themselves in relation to others. The research also examined the impact of service use on citizenship, arguing that mental health service use undermines the citizenship of

people who use mental health services by distinguishing them from non-mental health service users by presenting mental ill health as involving incapacity, irrationality and dangerousness. Marshall (1981) propounded the concept of welfare capitalism to suggest that state welfare mitigates the effects of capitalism on social inequality. The findings suggest that state welfare in the form of the benefits system and mental health services not only fails to mitigate the effects of social inequality but also serves to institute social inequality. Nevertheless, citizenship is useful in that it is a broader concept than social exclusion. However, like social exclusion, the concept can be hegemonic in serving a variety of political agendas.

Dunn (1999) conducted an inquiry into the social exclusion of people who use mental health services. However, although the data was qualitative, evidence was gleaned from professionals as well as users and it is not clear how in-depth the discussions of discrimination actually were. However, the inquiry encompassed a broad range of topics, including a discussion of the tenuousness of community membership caused by the use of the Mental Health Act 1983 in detaining individuals in psychiatric inpatient units. The advantage of Dunn's study in comparison with my own is that it examined the opinions of a broad range of 'stakeholders', including those of mental health workers. My study might have benefited from obtaining the views of mental health professionals on the findings of the research as an opportunity to respond to the criticisms participants levelled at mental health services. However, the explicit aim of the study was to examine the views and experiences of citizenship by mental health service users, therefore the views of professionals were not sought.

In summary, power is central to an analysis of the citizenship status of people who use mental health services. I contend that citizenship status is undermined by the power of psychiatry to define the mentally unwell as irrational, incompetent in decision-making and as deviant in relation to behavioural norms. Lack of political citizenship is demonstrated in the lack of influence of mental health service users over public policy, particularly in relation to the influence of psychiatric hegemony on current mental health policy. The relative lack of power held by service users is also evident in the way media representations are able to present the mentally unwell as outsiders and deviants. In addition, stereotypical public attitudes surrounding people with mental health problems demonstrate service users' powerlessness to resist negative

stereotypes (see Pickering, 2001). However, participants cited user involvement as enabling the development of a meaningful social identity in the absence of conventional social roles, such as the economically active citizen. User involvement is also depicted as an active form of citizenship (Lister, 1997) and appears to be engaged in as a recognition of the failure of passive citizenship to guarantee equal rights and opportunities to mental health service users and represents resistance to professional dominance in users' lives that bestows the discredited status of patienthood (see Barham and Hayward, 1995).

Social identity is also central to an understanding of citizenship in that participants described differential citizenship in recognition of commonality with other users of mental health services and lack of commonality with those outside of their social group. Young (1989) argued that differential citizenship should lead to special rights for marginalised groups. The nature of such rights will be examined in the following chapter that examines the implications of the research for research, policy and practice.

# **Chapter Eight: Implications for Research, Policy and Practice**

## **Implications for Research**

Participants' references to a hierarchy of oppression (see Keating, 1997) indicate the relevance of an examination of other marginalised groups within a citizenship framework in order to identify commonalities and differences between such groups and the social group identified with mental health service use. Participants believed that they were more oppressed than other groups of disabled people. This belief could be examined by conducting in-depth interviews investigating the citizenship status of members of other marginalised groups, namely people with physical or learning disabilities, unemployed people, welfare benefit recipients, asylum seekers or ex-prisoners. Such interviews might elucidate on the similarities oppressed groups share and the experiences unique to mental health service users.

In addition, interviews might be conducted comparing the experiences of people who use secondary mental health services and people with mental health problems who do not become ensconced in the mental health system in order to test my intuition that mental health service use serves to undermine the citizenship of people with mental health problems rather than poor mental health per se. This would enable a direct test of the labelling theory of mental ill health.

Furthermore, the suggestion by one participant that people who live in mental health residential care or long-stay hospitals are particularly socially excluded should be investigated by qualitative research that examines their experiences of social participation and community membership. In addition, the finding that homelessness is more prevalent in urban areas (Burrows, 1997) raises the issue of the representativeness of the current sample of participants. Therefore, further research could compare the experiences of citizenship of mental health service users between urban, rural and semi-urban areas. It may be the case that even greater disadvantage would have been found if the participants were mostly recruited from large urban areas in Britain.



An analysis of citizenship could also be rendered more sophisticated by examining citizenship status of mental health service users according to gender, ethnicity, age or sexuality in order to examine in greater depth the impact of multiple oppression.

Finally, descriptions of citizenship are predicated on the notion that citizenship involves rights and opportunities available to members of a community. However, perhaps a more stringent examination of the citizenship status of mental health service users would involve establishing a baseline of rights and opportunities available to ordinary citizens by examining the citizenship of people who do not use mental health services and comparing their experiences with those of mental health service users. Nevertheless, the heterogeneity of experiences and circumstances of people who do not use mental health services might render broad conclusions somewhat problematic, although the experiences and circumstances of people who do use mental health services are also heterogeneous but are still worthy of examination. Moreover, qualitative research endeavours to capture the complexity of human experience.

The overall implication of the research is that mental health service users hold credible views and are able to express those views in a clear and articulate way in relation to the complex concept of citizenship. The sheer quality of the interview data collected demonstrates the value of conducting qualitative research on issues that affect users of mental health services.

### **Implications for Policy**

The Government has emphasised inclusion through paid work (Levitas, 1998). However, many participants expressed unwillingness to engage in paid work for a variety of reasons. Therefore, the Government should re-evaluate its welfare-to-work policy in relation to people who use mental health services. Given that all of the participants were long-term unemployed and were, therefore, reliant on welfare benefits for significant periods of time, the Government should review the levels of welfare benefits for disabled people in acknowledgement of the way in which inclusion through paid work is not always feasible or desirable. The feasibility of engagement in paid work would presumably be increased by more realistic wages in

the economy overall. The findings on participants' views of employment also indicate the importance of avoiding the imposition of dominant social norms on political analysis of social inclusion and citizenship.

Furthermore, participants expressed concerns about the complexity of the application process in relation to disability benefits and their seeming greater applicability to people with physical disabilities. Therefore, the findings suggest that the application process for disability benefits should be simplified and made more relevant to people with mental health problems.

Many participants expressed an expectation of rejection in employment applications following disclosure of mental health status. Therefore, perhaps the Government should direct employers to omit questions on health in job applications. However, one participant (A) expressed doubts of the appropriateness of this suggestion due to duties currently placed on employers to support employees with long-term health problems. In addition, public education programmes should particularly target employers and those in influential positions in relation to determining the social participation of mental health service users in order to reduce discriminatory behaviour of employers, landlords, ect.

An additional way in which the Government could contribute to the social inclusion of mental health service users is to regulate the media more stringently in order to reduce the amount of derogatory language used and sensationalistic reporting that participants' attributed to the stigma of mental ill health. However, the Government does address this in proposing a greater role for Ofcom in monitoring media representation of mental health issues (SEU, 2004). Nevertheless, the Government also needs to examine its own contribution to the stigma of mental health problems due to the way in which it emphasises the threat posed by people with mental health problems in the community. Government policy should also be more coherent; less concerned with populism; place greater emphasis on social equality rather than hegemonic rhetoric on social inclusion; abandon proposals for coercive mental health legislation and abandon the psychiatric hegemony peddled by the psychiatric establishment.

Participants in the study expressed a consensus opposition to the Government's proposed compulsory community treatment orders. The most obvious implication of the research for policy is an abandonment of the notion of compulsory treatment or care plans in the community on the grounds that citizens should be free to choose whether or not to accept intervention from a mental health service. Nonetheless, two participants indicated that they were, in retrospect, grateful for intervention in recognition of the impact of their illness on their well-being. Therefore, it is realistic to conclude that some people might require intervention against their wishes but participants' experiences of inpatient treatment cast doubt on the adequacy of that intervention. Moreover, participants complained that mental health services over-emphasise crisis intervention at the expense of preventative and rehabilitative intervention, the implication for policy being that there should be greater expenditure on preventative services rather than the acute services described in *Modernising Mental Health Services* (DoH, 1998a). Users of mental health services should also be more influential in the formulation of mental health policy in order to redress the imbalance participants identified between users, professionals and the public in the formulation of mental health policy.

Young (1989) discussed differential citizenship as involving special rights for marginalised groups. Such special rights possibly indicate the need for anti-discrimination legislation specifically intended to assist people with mental health problems. Criticism has been directed towards the Disability Discrimination Act 1995 for its greater relevance to people with physical and sensory disabilities (Sayce, 2000) and thus anti-discrimination legislation should address the needs of mental health service users more specifically and ensure proper implementation of such legislation.

### **Implications for Practice**

The main implication of the citizenship paradigm for practice is the recognition of service users as citizens beyond their service use and the acknowledgement of the importance of meaningful roles beyond that of mental health service user.

One way of conceptualising individuals beyond the 'patienthood' role (see Barham and Hayward, 1995) is to abandon the biomedical conceptualisation of mental distress

in an abandonment of notions surrounding incapacity in decision-making, irrationality and irresponsibility. Rather, people who use mental health services should be treated as competent in decision-making and autonomy should be respected, exception in only the most extreme of cases.

Mental health services should also recognise the disadvantages service users experience in relation to a range of indicators of social exclusion and should seek to address such disadvantage with proactive approaches to community participation. Services should also recognise the ways in which services impede realisation of full citizenship status. For example, services should acknowledge impediments caused by the side effects of medication in relation to employment, social networks, education and parenting, as outlined in the findings of the current research. In relation to parenting, services should provide practical support for parents and listen to users' experiences of parenting in an abandonment of the assumption that mental health problems preclude good parenting.

Moreover, the 'reciprocity principle' (Eastman, 1994) should be invoked whereby deprivation of liberty should be met with an obligation to provide adequate treatment. Participants supported previous research (e.g. SCMH, 1998; Walton, 2000) which indicated lack of rehabilitation, activity and staff-patient interaction on psychiatric inpatient wards. Therefore, compulsory psychiatric inpatient treatment should be met with rehabilitation and holistic treatment that extends beyond medication and activities that infantilise patients. Moreover, the abusive nature of control and restraint should be recognised by the abolition of this abusive, dehumanising and potentially fatal intervention (see the Rocky Bennett case: Guardian, 6<sup>th</sup> February 2004). The greater civil citizenship of mental health service users would encompass greater respect for rights under the Mental Health Act 1983, specifically in relation to the right to leave hospital and refuse medication if categorised as an informal patient. It also means access to independent advocacy and a user on tribunal panels to balance professional decision-making.

User involvement in services should extend beyond mere consultation to encompass involvement in genuine decision-making and the development of user-led services. The development of self-help groups should be supported by mental health

professionals in recognition of the commonality and mutual support reported between members of such groups. User involvement should also extend to the provision of training to staff by users, given the dichotomous, hierarchical attitudes that participants attributed to mental health workers. This would enable staff to achieve greater insight into the impact of good and poor mental health care on service users and the difference that this can make to users' lives. A "sea change in attitudes" (T) is demanded of mental health workers.

However, overall, user involvement should extend beyond service use into genuine participation in society, as defined by people who use mental health services.

Given the high mortality rates of mental health service users and some participants' concerns surrounding the poor treatment of physical health problems, mental health services should take seriously users' physical complaints and liaise with primary care services to provide testing, monitoring and advice on maintaining physical health. Users' reports of physical ailments should be awarded greater credence in order to ensure rapid and adequate treatment of physical health problems. Moreover, participants' demands for greater emphasis on mental health promotion in mental health services echo the recommendations made by MHF (1997, 2000). More specifically, MHF (2005) recommended the acknowledgement of the beneficial impact of physical exercise on mental health in the introduction of nation-wide exercise on prescription, thus enabling subsidised access to leisure facilities, especially given that participants identified low income as impeding access to such facilities. There is also a requirement of the opportunities to be available to exercise during inpatient treatment, given the inevitably adverse effect of lack of fresh air and exercise on physical health. Smoking in inpatient units and other mental health facilities should also be prohibited, given that psychiatric hospital is the only NHS inpatient environment to allow smoking (Mehta, 2002).

The most important implication for research, policy and practice, however, is that mental health service users' definitions of citizenship and social inclusion should inform policy, practice and future research.

## **Chapter Nine: Summary and Conclusions**

The findings of the study revealed that the citizenship status of mental health service users is undermined, as evidenced by disadvantage participants experienced in relation to employment applications, harassment in the workplace and constructive dismissal. None of the participants were engaged in paid employment at the time of the interviews; this meant that most, if not all, were in receipt of welfare benefits. Participants described the impact of low benefit levels on social participation and the scrutiny and vulnerability to withdrawal of benefits associated with receipt of disability benefits. Some participants referred to their own poverty in relation to a notional average income that would be required to participate in material consumption. Participants expressed aspirations towards such consumption and thus adopted social norms in this respect but described poverty as denying them the opportunity to participate in a property-owning, mortgage-earning society.

Housing was primarily discussed in terms of visibility in the neighbourhood caused by the presence of emergency vehicles at Mental Health Act detentions. Participants also referred to addresses known to house mental health service users as being targets of vandalism. Three participants described their experiences of homelessness but this was not a common experience possibly due to the fact that most participants lived in a small town rather than a large urban centre where homelessness is more likely to be experienced (Burrows, 1997).

Participants provided varying reports on the availability of acceptance and support for people with mental health problems in further and higher education but one participant described explicit discrimination in relation to his experience of further education.

Some participants described themselves as socially isolated and identified barriers to developing and maintaining social networks; these encompassed rejection, public fear of mental health problems, stigma, poor social skills and lack of opportunities to develop social networks. Expectations of rejection provoked avoidance of disclosure of mental health status to members of the public. However, participants expressed a

consensual preference for socialising with other mental health service users, conveying a sense of commonality and social identity as a coherent social group based on use of mental health services. Public attitudes were described as primarily negative, driven by fear and ignorance of people with mental health problems and informed by misrepresentations of such people in the media. The use of derogatory descriptors of people with mental health problems conveyed their lack of power to challenge such negative discourse.

Mental health service use dominated participants' discussions of citizenship, indicating the importance of services in users' lives. Participants described community mental health services as placing an over-emphasis on medication to the exclusion of talking treatments and holistic approaches to recovery and as over-emphasising crisis intervention at the expense of preventative intervention. Medication was primarily described according to the adverse impact of unpleasant side effects on everyday functioning, specifically in relation to impediments caused to employment, social relationships and parenting.

Psychiatric inpatient treatment was presented as fulfilling a function of containment due to lack of rehabilitation and activity on wards, poor facilities and lack of staff-patient interaction. Inpatient treatment was also described as non-therapeutic due to the distress of other patients and abuse inherent in over-medication and the use of control and restraint. Inpatient services were considered to be punitive whereby participants described a 'prisoner mentality' that conveyed their belief that they were "punished for being ill" (D2) rather than viewing psychiatric hospitals as places to receive rehabilitation and achieve recovery.

Participants' descriptions of psychiatric treatment and services refute Marshall's (1992) claim that welfare services mitigate the effects of social inequality. Rather, mental health services appear to contribute to inequality by removing the individual from their community in the form of compulsory detention, by attaching stigmatising labels to individuals, by constructing the status of patienthood, by impeding everyday functioning by the side effects of medication, through loss of housing, family relationships and parenting through hospitalisation and through the construction of the individual as irrational, incompetent and dangerous.

Moreover, the lack of political citizenship of mental health service users is conveyed by their lack of influence over mental health policy. Participants viewed current mental health policy as coercive, stigmatising and as undermining users' civil liberties. However, user involvement was interpreted as a form of active political citizenship whereby participants expressed their satisfaction with advances in involvement with mental health services but dissatisfaction with the rate of progress of involvement. Moreover, participants were more likely to be satisfied with individual involvement in care planning than with involvement in service planning, delivery and central government policy.

Service users' civil citizenship was doubtful due to the apparent lack of due process experienced in relation to detentions under the Mental Health Act 1983. Specifically, mental health review tribunals were described as having low discharge rates, being influenced by conservative approaches to risk management and as indicating the power of mental health professionals to influence the judgements of tribunal panels.

It is concluded that users of mental health services experience significant disadvantage in relation to aspects of social, political and civil citizenship and thus can be described as lacking the opportunities for social participation and community membership that may be available to less marginalised social groups. However, participants in the study failed to indicate commonality with other marginalised groups, preferring to invoke a 'hierarchy of oppression' (Keating, 1997) to describe how people who use mental health services are located at the bottom of a hierarchy of oppressed social groups. Nevertheless, participants constructed their own inclusion through involvement in social relationships with other users, participation in self-help groups and engagement in user involvement in mental health services. Participants demonstrated resistance to the patienthood role by developing meaningful alternatives to conventional social participation in the form of inclusion in formal and informal networks with other mental health service users. Moreover, participants indicated advantages associated with mental health status, namely exemption from obligations to engage in paid work and to adhere to ordinary norms of behaviour. Therefore, theories of citizenship must avoid assumptions determining the basis of inclusion and



membership because such membership does not ascribe to the simplistic conceptualisation of the included-excluded dichotomy.

## References

- Abberley, P. (1997) The concept of oppression and the development of a social theory of disability. In L. Barnes and M. Oliver (eds) *Disability Studies: Past, Present and Future*. Leeds: The Disability Press.
- Adams, R. (1996) (2<sup>nd</sup> Edition) *Social Work and Empowerment*. Basingstoke: Macmillan Press.
- Adcock, M. (1996) A legal framework for child protection: Children Act 1989 (UK) (p.312-324) In M. Gopfert, J. Webster and M.V. Seeman (eds) *Parental Psychiatric Disorder: Distressed Parents and their Families*. Cambridge: Cambridge University Press.
- Albert, M., Becker, T., McCrone, P. and Thornicroft, G. (1998) Social networks and mental service utilisation-A literature review. *International Journal of Social Psychiatry*, 44, 4, 248-266.
- Alcock, P. (1997) *Understanding Poverty* (2<sup>nd</sup> Edition). Basingstoke: Macmillan Press.
- Altamura, A.C. and Malhi, G.S. (2000) Compliance in major psychoses. *International Journal of Psychiatry in Clinical Practice*, 4, 81-82.
- Altheide, D.L. and Johnson, J.M. (1998) Criteria for assessing interpretive validity in qualitative research. In N.K. Denzin and Y.S. Lincoln (eds) *Collecting and Interpreting Qualitative Materials*. London: Sage.
- Alty, A. (1994) Patients' views about seclusion (p.161-173) In A. Alty and T. Mason. *Seclusion and Mental Health: A Break with the Past*. London: Chapman and Hall.
- Anon (2003) Get a life: work can be bad for your mental health. *Mental Health Today*, May, p.10-11.
- Anthony, W.A., Rogers, E.S., Cohen, M. and Davies, R.R. (1995) Relationships between psychiatric symptomatology, work skills and future vocational performance. *Psychiatric Services*, 46, 4, 353-357.
- Appelbaum, P.S. and Griiso, T. (1995) The MacArthur Treatment Competence study 1: Mental illness and competence to consent to treatment. *Law and Behaviour*, 19, 105-126.
- Appleby, L. (2000) Safer services: conclusions from the report of the National Confidential Inquiry. *Advances in Psychiatric Treatment*, 6, 5-15.
- Appleby, L., Shaw, J., Amos, T. et al. (1999) *Safer Services: Report of the National Inquiry into Suicide and Homicide by People with Mental Illness*. London: Department of Health.

Appleby, L. Thomas, S., Ferrier, N., Lewis, G., Shaw, J. and Amos, T. (2000) Sudden unexplained death in psychiatric inpatients. *British Journal of Psychiatry*, 176, 405-406.

Aristotle (Translated W. Ellis) (1986) *The Politics*. New York: Prometheus Books.

Askonas, P. and Stewart, A. (2000) *Social Inclusion: Possibilities and Tensions*. Basingstoke: Palgrave.

Avriam, U. and Segal, S.P. (1973) Exclusion of the mentally ill: reflection on an old problem in a new context. *Archives of General Psychiatry*, 29, 126-131.

Baldwin, S. (1998) *Needs Assessment and Community Care: Clinical Practice and Policy Making*. Oxford: Butterworth and Heinemann.

Banister, P., Burman, E., Parker, I., Taylor, M. and Tindall, C. (1994) *Qualitative Methods in Psychology: A Research Guide*. Buckingham: Open University Press.

Barbalet, J.M. (1988) *Citizenship*. Milton Keynes: Open University Press.

Barham, P. (1997) *Closing the Asylum: The Mental Patient in Modern Society*. London: Penguin.

Barham, P. and Hayward, R. (1995) *Relocating Madness: From the Mental Patient to the Person*. London: Free Association Books.

Barnes, C. (1992a) Institutional discrimination against disabled people and the campaign for anti-discrimination legislation. *Critical Social Policy*, 12, 1, 5-21.

Barnes, C. (1992b) Qualitative research: Valuable or irrelevant? *Disability, Handicap and Society*, 7, 2, 115-124.

Barnes, C. (1996) Disability and the myth of the independent researcher. *Disability and Society*, 11, 1, 107-110.

Barnes, M. (1993) Introducing new stakeholders-User and researcher interests in evaluative research: A discussion of methods used to evaluate the Birmingham Community Care Special Action Project. *Policy and Politics*, 21, 1, 47-58.

Barnes, M. (1997) *Care, Communities and Citizens*. London: Longman.

Barnes, M. (1999) Users as citizens: Collective action and the local governance of welfare. *Social Policy and Administration*, 33, 1, 73-90.

Barnes, M., Bowl, R. and Fisher, M. (1990) *Sectioned: Social Services and the 1983 Mental Health Act*. London: Routledge.

Barnes, M. and Whistow, G. (1992) Research and user involvement: contributions to learning and methods. In M. Barnes and G. Whistow (eds) *Researching User Involvement*. Leeds: Nuffield Institute.

Barnes, M. and Wistow, G. (1994) Learning to hear voices: listening to users of mental health services. *Journal of Mental Health*, 3, 525-540.

Barratt Brown, M. and Coates, K. (1996) *The Blair Revelation: Deliverance for Whom?* Nottingham: Spokesman.

Barry, C.A. (1998) Choosing qualitative data analysis software: Atlas/ti and Nudist compared. *Sociological Research Online*, 3, 3:[www.socresonline.org.uk/socresonline/3/3/4.html](http://www.socresonline.org.uk/socresonline/3/3/4.html)

Bassuk, E.L., Rubin, L. and Lauriat, A. (1984) Is homelessness a mental health problem? *American Journal of Psychiatry*, 141, 12, 1546-1549.

Bauman, Z. (1997) *Postmodernity and its Discontents*. Cambridge: Polity Press.

Bauman, Z. (1998) *Work, Consumerism and the New Poor*. Buckingham: Open University Press.

Bauman, Z. (2000) What it means 'to be excluded': living to stay apart-or-together? In P. Askonas and A. Stewart (eds) *Social Inclusion: Possibilities and Tensions*. Basingstoke: Palgrave.

Bean, G.J., Stefl, M.E. and Howe, E. (1987) Mental health and homelessness: issues and findings. *Social Work*, 32, 5, 411-416.

Bean, P. (1986) *Mental Disorder and Legal Control*. Cambridge: Cambridge University Press.

Bebbington, P.E. (1995) The content and context of compliance. *International Clinical Psychopharmacology*, 9, 41-50.

Becker, H. (1963) *Outsiders: Studies in the Sociology of Deviance*. Glencoe: Free Press.

Becker, D.R., Drake, R.E., Bond, G.R., Xie, H. Dain, B.J. and Harrison, K. (1998) Job terminations among persons with severe mental illness participating in supported employment. *Community Mental Health Journal*, 34, 1, 71-82.

Beck-Sander, A. (1998) Is insight into psychosis meaningful? *Journal of Mental Health*, 7, 1, 25-34.

Beck-Sander, A. (1999) Working with parents with mental health problems: Management of the many risks. In A. Weir and A. Douglas (eds) *Child Protection and Adult Mental Health: Conflict of Interest?* Oxford: Butterworth Heinemann.

Bene-Kociemba, A., Cotton, P.G. and Frank, A. (1979) Predictions of community tenure of discharged state psychiatric patients. *American Journal of Psychiatry*, 136, 1556-1561.

- Bentall, R.P. (2003) *Madness Explained: Psychosis and Human Nature*. London: Penguin.
- Beresford, P. (1996) Poverty and disabled people: challenging dominant debates and policies. *Disability and Society*, 11, 4, 553-567.
- Beresford, P. (2000a) What have madness and the psychiatric system survivors got to do with disability and disability studies? *Disability and Society*, 15, 1, 167-172.
- Beresford, P. (2000b) Service users' knowledges and social work theory: conflict or collaboration? *British Journal of Social Work*, 30, 489-503
- Beresford, P. (2001) Service users, social policy and the future of welfare. *Critical Social Policy*, 21, 4, 494-511.
- Beresford, P. and Campbell, P. (1994) Disabled people, service users, user involvement and representation. *Disability and Society*, 9, 3, 315-325.
- Beresford, P. and Croft, S. (2001) Mental health policy: a suitable case for treatment? (p.11-22). In C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness Too*. Ross-on-Wye: PCCS Books.
- Beresford, P., Green, D., Lister, R. and Woodard, K. (1999) *Poverty First Hand: Poor People Speak for Themselves*. London: CPAG.
- Berzins, K.M., Petch, A. and Atkinson, J.M. (2003) Prevalence and experience of harassment of people with mental health problems living in the community. *British Journal of Psychiatry*, 183, 526-533.
- Bhugra, D. (1989) Attitudes towards mental illness: a review of the literature. *Acta Psychiatrica Scandinavica*, 80, 1-12.
- Bines, W. (1997) The health of single homeless people. In R. Burrows, N. Pleace and D. Quilgars (eds) *Homelessness and Social Policy*. London: Routledge.
- Bird, J. and Davies, M. (1996) *Supervision Registers: An Exploratory Study*. Social Work Monographs. University of East Anglia, Norwich.
- Bittner, E. (1967) Police discretion in apprehending the mentally ill. *Social Problems*, 14, 278-292.
- Blair, T. (1998) *The Third Way: New Politics for the New Century*. London: The Fabian Society.
- Boardman, J., Grove, B., Perkins, R. and Shepherd, G. (2003) Work and employment for people with psychiatric disabilities. *British Journal of Psychiatry*, 192, 467-468.
- Bogardus, E.S. (1925) Measuring Social Distances. *Journal of Applied Sociology*, 9, 299-308.

- Bohanon, C. (1991) The economic correlates of homelessness in sixty cities. *Social Science Quarterly*, 72, 4, 817-825.
- Bolzan, N., Smith, M., Mears, J. and Ansiewicz, R. (2001) Creating identities: Mental health consumer to citizen? *Journal of Social Work*, 1, 3, 317-328.
- Bord, R.J. (1971) Rejection of the mentally ill: continuities and further developments. *Social Problems*, 18, 496-509.
- Bowers, L. (2000) *The Social Nature of Mental Illness*. London: Routledge.
- Bowring, F. (2000) Social exclusion: limitations of the debate. *Critical Social Policy*, 20, 3, 307-330.
- Boyle, M. (1999) Diagnosis. In C. Newnes, G. Holmes and C. Dunn (eds.) *This is Madness*. Ross-on-Wye: PCCS Books.
- Boyle, M. (2002) *Schizophrenia: A Scientific Delusion*. (2<sup>nd</sup> Edition). London: Routledge.
- Bradley, C., Marshall, M. and Gath, D. (1995) Why do so few patients appeal against detention under Section 2 of the Mental Health Act? *British Medical Journal*, 310, 364-7.
- Breggin, P. (1993) *Toxic Psychiatry: Drugs and Electroconvulsive Therapy: The Truth and the Better Alternatives*. London: Harper Collins.
- Breggin, P.R. and Cohen, D. (1999) *Your Drug May Be Your Problem: How and Why to Stop Taking Psychiatric Medications*. Massachusetts: Perseus Books.
- Brockman, J., D'Arcy, C. and Edmonds, L. (1979) Facts or artefacts? Changing public attitudes toward the mentally ill. *Social Science Medical*, 13A, 673-682.
- Brockington, I.F., Hall, P., Levings, J. and Murphy, C. (1993) The community's tolerance of the mentally ill. *British Journal of Psychiatry*, 162, 93-99.
- Brown, S. (1997) Excess mortality of schizophrenia: a meta-analysis. *British Journal of Psychiatry*, 171, 502-508.
- Brown, S., Inskip, H. and Barraclough, B. (2000) Causes of excess mortality of schizophrenia. *British Journal of Psychiatry*, 177, 212-217.
- Browne, D. (1997) *Black People and Sectioning: The Black Experience of Detention Under the Civil Sections of the Mental Health Act*. London: Little Rock Publishing.
- Bryman, A. (1988) *Quantity and Quality in Social Research*. London: Unwin Hyman.

Bryman, A. (1996) Foreword. In M. Williams and T. May. Introduction to the Philosophy of Social Research. London: UCL Press.

Bulmer, M. and Rees, A.M. (1996) Conclusion: Citizenship in the twenty-first century. (p.269-283). In M. Bulmer and A.M. Rees (eds) Citizenship Today: The Contemporary Relevance of T.H. Marshall. London: UCL Press.

Burns, T., Goddard, K. and Bale, R. (1995) Community supervision orders for the mentally ill: Mental health professionals' attitudes. *Journal of Mental Health*, 4, 301-308.

Burrows, R. (1997) The social distribution of the experience of homelessness. In R. Burrows, N. Pleace and D. Quilgars (eds) Homelessness and Social Policy. London: Routledge.

Bury, M. (1996) Disability and the myth of the independent researcher: A reply. *Disability and Society*, 11, 1, 111-113.

Byrne, D. (1997) Social exclusion and capitalism: the reserve army of labour across time and space. *Critical Social Policy*, 17, 27-51.

Callinicos, A. (2000) Equality. Cambridge: Polity Press.

Campbell, J. (1997) 'Growing pains', disability politics-the journey explained and described (p. 78-89). In L. Barton and M. Oliver (eds) Disability Studies: Past, Present and Future. Leeds: The Disability Press.

Campbell, P. (1999) The service user/survivor movement (p.195-209) In C. Newnes, G. Holmes and C. Dunn (eds) This is Madness. Ross-on-Wye: PCCS Books.

Campbell, P. (2001) Surviving social inclusion (p.93-102) In C. Newnes, G. Holmes and C. Dunn (eds) This is Madness Too. Ross-on-Wye: PCCS Books.

Caton, C.L.M. and Goldstein, G. (1984) Housing change and chronic schizophrenic patients: A consequence of the revolving door. *Social Science Medical*, 19, 7, 759-764.

Cavadino, M. (1989) Mental Health Law in Context: Doctors' Orders. Dartmouth: Dartmouth.

Cavadino, M. (1991) Community control? *Journal of Social Welfare and Family Law*, 13, 1, 482-92.

Chamberlin, J. (1988) On Our Own: Patient-controlled Alternatives to the Mental Health System. London: Mind Publications.

Clayton, C. (2000) Dirty Planet: The Friends of the Earth Guide to Pollution and What You Can Do About It. London: The Women's Press.

Coffey, A., Holbrook, L.B. and Atkinson, P. (1996) Qualitative data analysis: Technologies and representations.

Social Research Online, 1,1. [www.socresonline.org.uk/socresonline/1/1/4.html](http://www.socresonline.org.uk/socresonline/1/1/4.html)

Cohen, C.I. and Thompson, K.S. (1992) Homeless mentally ill or mentally ill homeless? *American Journal of Psychiatry*, 149, 6, 816-823.

Cohen, S. (1972) *Folk Devils and Moral Panics*. MacGibbon and Kee.

Cohen, S. (2002) *Folk Devils and Moral Panics* (3<sup>rd</sup> Edition) London: Routledge.

Cohler, B.J., Stott, F.M. and Musick, J.S. (1996) Distressed Parents and Their Children: Interventions for Families at Risk (p.107-134) In M. Gopfert, J., Webster and M.V. Seeman (eds) *Parental Psychiatric Disorder: Distressed Parents and their Families*. Cambridge: Cambridge University Press.

Coleman, R. (1998) *The Politics of the Madhouse*. Gloucester: Handsell Publishing.

Coleman, R. (1999) *Recovery: An Alien Concept*. Gloucester: Handsell Publishing.

Copperman, J. and MacNamara, J. (1999) Institutional abuse in mental health settings (p.152-172) In N. Stanley, J. Manthorpe and B. Penhale (eds.) *Institutional Abuse: Perspectives Across the Life Course*. London: Routledge.

Cornwell, J. (1996) *The Power to Harm: Mind, Murder and Drugs on Trial*. London: Penguin Books.

Corrigan, P.W. and Penn, D. (1997) Disease and discrimination: two paradigms that describe severe mental illness. *Journal of Mental Health*, 6, 4, 355-366.

Crepaz Keay, D. (1996) A sense of perspective: the media and the Boyd Inquiry. In G. Philo (ed) *Media and Mental Distress*. London: Longman.

Crepaz Keay, D. (1999) Drugs. In C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness*. Ross-on-Wye: PCCS Books.

Crimlisk, H. and Phelan, M. (1996) Mental health review tribunals: time for a change? *British Journal of Psychiatry*, 169, 678-681.

Crocetti, G., Spiro, H.R. and Siassi, I. (1971) Are the ranks closed? Attitudinal social distance and mental illness. *American Journal of Psychiatry*, 127, 9, 1121-1127.

Croft, S. and Beresford, P. (1989) User involvement, citizenship and social policy. *Critical Social Policy*, 26, 9, (2), 5-18.

Croft, S. and Beresford, P. (2002) The politics of participation. *Critical Social Policy*, 12, 2, 20-44.

Cumming, E. and Cumming, J. (1957) *Closed Ranks: An Experiment in Mental Health*. Cambridge: Harvard University Press.



Dahrendorf, R. (1988) *The Modern Social Conflict: An Essay on the Politics of Liberty*. Los Angeles: University of California Press.

Davidson, L. (2003) *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York: New York University Press.

Davies, J., Thronicroft, G., Leese, M., Heginbotham, A. and Phelan, M. (1996) Ethnic differences in risk of compulsory psychiatric admission among representative cases of psychosis in London. *British Medical Journal*, 312, 533-537.

Davis, D. et al. (1980) Important issues in the drug treatment of schizophrenia. *Schizophrenia Bulletin*, 6, 70-87.

DeHaan, A. (1998) 'Social exclusion': An alternative concept for the study of deprivation? *IDS Bulletin*, 29, 1, 10-19.

Delanty, C. (2003) *Community*. London: Routledge.

Department of Health (1999a) *A National Service Framework for Mental Health*. London: TSO.

Department of Health (1999b) *Reform of the Mental Health Act 1983: Proposals for Consultation*. Cm. 4480. London: TSO.

Department of Health (1998a) *Modernising Mental Health Services: Safe, Sound and Supportive*. London: TSO.

Department of Health (1998b) *L v Bournewood Community and Mental Health NHS Trust*. [www.open.gov.uk/doh/coinh.html](http://www.open.gov.uk/doh/coinh.html)

Department of Health (2002) *Mental Health Bill: Consultation Document*. Norwich: HMSO.

Department of Health (2004) *Draft Mental Health Bill*. London: HMSO.

Department of Health (2005) *Government response to the report of the Joint Committee on the draft Mental Health Bill 2004*: [www.dh.gov.uk](http://www.dh.gov.uk)

Denzin, N.K. (1988) Qualitative analysis for social scientists. *Contemporary Sociology*, 17, 3, 430-432.

Denzin, N.K. (1998) The art and politics of interpretation. In N.K. Denzin and Y.S. Lincoln (eds.) *Collecting and Interpreting Qualitative Materials*. London: Sage.

Denzin, N.K. and Lincoln, Y.S. (1998) Introduction: Entering the field of qualitative research. In N.K. Denzin and Y.S. Lincoln (eds) *Collecting and Interpreting Qualitative Materials*. London: Sage.

- Desmoyers-Davis, T. (2003) *Citizenship in Modern Britain*. London: Cavendish Publishing.
- Dilks, S.E. (1995) Ethical issues in community housing. *Journal of Mental Health*, 4, 475-482.
- Dobson, F. (1998) Hansard: 8/12/98. Col: 145-157.
- Drewett, A. Y. (1999) Social rights and disability: the language of 'rights' in community care policies. *Disability and Society*, 14, 1, 115-128.
- Driver, S. and Martell, L. (1997) New Labour's communitarianisms. *Critical Social Policy*, 52, 27-46.
- Dunn, S. (1999) *Creating Accepting Communities: Report of the Mind Inquiry into Social Exclusion and Mental Health Problems*. London: Mind.
- Dworkin, R.J. (1992) *Researching Persons with Mental Illness*. London: Sage.
- Eastman, N. (1994) Mental health law: civil liberties and the principle of reciprocity. *British Medical Journal*, 308, 43-45.
- Ellis, A. and Davis Smith, J. (2004) A sense of purpose. *Mental Health Today*, February, p.20-23.
- Estroff, S.E. (1981) *Making It Crazy: An Ethnography of Psychiatric Clients in an American Community*. Berkeley: University of California Press.
- Etzioni, A. (1997) *The New Golden Rule: Community and Morality in a Democratic Society*. London: Profile Books.
- Evans, M. (1998) Behind the rhetoric: the institutional basis of social exclusion and poverty. *IDS Bulletin*, 29, 1, 42-49.
- Ezzy, D. (2002) *Qualitative Analysis: Practice and Innovation*. London: Routledge.
- Fairclough, N. (2000) *New Labour: New Language?* London: Routledge.
- Farina, A. and Felner, R.D. (1973) Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology*, 82, 2, 268-272.
- Faulks, K. (1998) *Citizenship in Modern Britain*. Edinburgh: Edinburgh University Press.
- Fennell, P. (1992) Balancing care and control: guardianship, community treatment orders and patient safeguards. *International Journal of Law and Psychiatry*, 15, 205-235.
- Fernando, S. (1991) *Mental Health, Race and Culture*. Basingstoke: Macmillan Education.

Fernando, S. (1998) Modern schizophrenia and racism. In S. Fernando, D. Ndegwa and M. Wilson. *Forensic Psychiatry, Race and Culture*. London: Routledge.

Fiander, M., Burns, T., McHugo, G.J. and Drake, R.E. (2003) Assertive community treatment across the Atlantic: comparison of model fidelity in the UK and USA. *British Journal of Psychiatry*, 182, 248-254.

Fielding, N.G. and Lee, R.M. (1998) *Computer Analysis and Qualitative Research*. London: Sage.

Finlayson, A. (2003) *Making Sense of New Labour*. London: Lawrence and Wishart.

Fisher, M. (1995) Desktop tools for the social scientist (p. 14-32). In R. Lee (ed) *Information Technology for the Social Scientist*. London: UCL Press.

Fisher, M. (1997) *Qualitative Computing: Using Software for Qualitative Data Analysis*. Aldershot: Ashgate Publishing.

Fisher, N., Turner, S.W., Pugh, R. and Taylor, C. (1994) Estimating numbers of homeless and homeless mentally ill people in north east Westminster by using capture-recapture analysis. *British Medical Journal*, 308, 27-30.

Flaherty, J., Veit-Wilson, J. and Dorman, P. (2004) *Poverty: The Facts*. London: CPAG.

Focus on Mental Health (2001). [www.ontheside.org./focus/fpovdel.html](http://www.ontheside.org./focus/fpovdel.html)

Fontana, A. and Frey, J.H. (1998) Interviewing: The art of science. In N.K. Denzin and Y.S. Lincoln (eds) *Collecting and Interpreting Qualitative Materials*. London: Sage.

Foucault, M. (1994) *Ethics: Essential Works by Foucault 1954-1984, Vol. 1*. London: Penguin.

Foucault, M. (2002) *Power: Essential Works of Foucault 1954-1984, Vol. 3*. London: Penguin.

Freire, P. (1970) *Pedagogy of the Oppressed*. London: Penguin.

Frey, J.H. and Fontana, A. (1993) The group interview in social research. In D.L. Morgan (ed) *Successful Focus Groups: Advancing the State of the Art*. London: Sage.

Fulop, N.J. (1995) Involuntary outpatient civil commitment: What can Britain learn from the US experience? A civil liberties perspective. *International Journal of Law and Psychiatry*, 18, 3, 291-303.

Guardian, February 6<sup>th</sup> 2004, How the death of one black patient treated as a 'lesser being' showed up race bias.

- Gibbs, G.R. (2002) *Qualitative Data Analysis: Explorations with NVIVO*. Buckingham: Open University Press.
- Giddens, A. (1998) *The Third Way: The Renewal of Social Democracy*. Cambridge: Polity Press.
- Giddens, A. (2000) *The Third Way and Its Critics*. Cambridge: Polity Press.
- Giliker, P. and Beckwith, S. (2001) *Tort*. London: Sweet and Maxwell.
- Glaser, B.G. and Strauss, A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Weidenfeld and Nicolson.
- Glenmullen, J. (2001) *Prozac Backlash: Overcoming the dangers of Prozac, Zoloft, Paxil, and Other Anti-Depressants with Safe, Effective Alternatives*. New York: Simon & Schuster.
- Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. London: Penguin.
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.
- Golding, J. (1997) *Without Prejudice: Mind Lesbian, Gay and Bisexual Mental Health Awareness Research*. London: Mind Publications.
- Golding, P. (1995) *Public attitudes to social exclusion: Some problems of measurement and analysis (p.212-232)* In G. Room (ed) *Beyond the Threshold: The Measurement and Analysis of Social Exclusion*. Bristol: Polity Press.
- Gordon, D. (2000) *Measuring absolute and overall poverty (p. 49-77)* In D. Gordon and P. Townsend (eds) *Breadline Europe: The Measurement of Poverty*. Bristol: The Polity Press.
- Gostin, L. (1985) *Human rights in mental health*. In M. Roth and R. Bluglass (eds.) *Psychiatry, Human Rights and the Law*. Cambridge: Cambridge University Press.
- Gove, W.R. (1970) *Societal reaction as an explanation of mental illness: an evaluation*. *American Sociological Review*, 35, 873-884.
- Gove, W. (1975) *The Labelling of Deviance: Evaluating a Perspective*. New York: Sage.
- Gove, W.R. and Fain, T. (1973) *The stigma of mental hospitalisation: an attempt to evaluate its consequences*. *Archives of General Psychiatry*, 28, Apr., 494-500.
- Gramsci, A. (1971) *Selections from the Prison Notebooks*. London: Lawrence and Wishart.

Green, G., Hayes, C., Dickinson, D., Whittaker, A. and Gilheany, B. (2002) The role and impact of social relationships upon well-being reported by mental health service users: A qualitative study. *Journal of Mental Health*, 11, 5, 565-579.

Gregory, I. (2003) *Ethics in Research*. London: Continuum.

Gubrium, J.F. and Holstein, J.A. (1997) *The New Language of Qualitative Method*. Oxford: Oxford University Press.

Gunn, M.J. (1986) Mental health guardianship: Where now? *Journal of Social Welfare Law*, May, 144-152.

Hafner, H. and Boker, W. (1982) *Crimes of Violence by Mentally Disordered Offenders*. Cambridge: Cambridge University Press.

Hall, A. (1996) Parental psychiatric disorder and the developing child (p. 17-41) In M. Gopfert, J. Webster and M.V. Seeman (eds) *Parental Psychiatric Disorder: Distressed Parents and their Families*. Cambridge: Cambridge University Press.

Hall, S. and Held, D. (1989) Left and rights. *Marxism Today*, June, 16-23.

Hall, G.B. and Nelson, G. (1996) Social networks, social support, personal empowerment, and the adaptation of psychiatric consumers/survivors: path analytic models. *Social Science Medicine*, 43, 12, 1743-1754.

Hamid, W.A., Wykes, T. and Stansfield, S. (1993) The social disablement of men in hostels for homeless people: A comparison with patients from long-stay wards. *British Journal of Psychiatry*, 166, 809-812.

Hammersley, M. and Gomm, E. (1997) Bias in social research. *Sociological Research Online*, 2, 1: [www.socresonline.org.uk/socresonline/2/1/2.html](http://www.socresonline.org.uk/socresonline/2/1/2.html)

Hannigan, B. (1999) Mental health care in the community: An analysis of contemporary public attitudes towards, and public representations of mental illness. *Journal of Mental Health*, 8, 5, 431-440.

Harrison, G. and Bartlett, P. (1994) Supervision registers for mentally ill people: medico-legal issues seem likely to dominate decisions by clinicians. *British Medical Journal*, 309, 551-552.

Hatfield, B., Mohamad, H. and Huxley, P. (1992) The 1983 Mental Health Act in five local authorities: A study of the practice of Approved Social Workers. *International Journal of Social Psychiatry*, 38, 3, 189-207.

Healy, D. (1997) *Psychiatric Drugs Explained*. (2<sup>nd</sup> edition). London: Mosby.

Healy, D. (2001) The SSRI suicides. In C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness Too*. Ross-on-Wye: PCCS Books.

Healy, D. (2004) *Let Them Eat Prozac: The Unhealthy Relationship Between the Pharmaceutical Industry and Depression*. London: New York University Press.

Heater, D. (1999) *What is Citizenship?* Cambridge: Polity Press.

Held, D. (1991) *Between state and civil society: Citizenship*. In G. Andrews (ed) *Citizenship*. London: Lawrence and Wishart.

Henderson, L. (1996) *Selling suffering: mental distress and media values (p.18-36)* In G. Philo (ed) *Media and Mental Distress*. London: Longman.

Henwood, K. and Pidgeon, N. (1994) *Beyond the qualitative paradigm: a framework for introducing diversity within qualitative psychology*. *Journal of Community and Applied Social Psychology*, 4, 225-238.

Henwood, K. and Pidgeon, N. (1995) *Grounded theory and psychological research*. *The Psychologist*, March, 115-118.

Heron, J. (1981) *Philosophical basis for a new paradigm*. In P. Reason and J. Rowan (eds) *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: John Wiley and Sons.

Holmes-Eber, P. and Riger, S. (1990) *Hospitalisation and the composition of mental patients' social networks*. *Schizophrenia Bulletin*, 16, 157-164.

Hogan, T.P. and Awad, A.G. (1983) *Pharmacotherapy and suicide risk in schizophrenia*. *Canadian Journal of Psychiatry*, 28, 277-281.

Hogarty, G. E. (1993) *Prevention of relapse in chronic schizophrenia patients*. *Journal of Clinical Psychiatry*, 54, 18-23.

Hoggett, B. (1996) *Mental Health Law (4<sup>th</sup> edition)* London: Sweet and Maxwell.

Homan, R. (1991) *The Ethics of Social Research*. Essex: Longman.

Hotopt, M., Wall, S., Buchanan, A., Wesseley, S. and Churchill, R. (2000) *Changing patterns in the use of the Mental Health Act 1983 in England 1984-1996*. London: HMSO

Hughes, G. (1996) *Communitarianism and law and order*. *Critical Social Policy*, 49, 16, 17-41.

Hughes, I., Hill, B. and Budd, R. (1997) *Compliance with anti-psychotic medication: From theory to practice*. *Journal of Mental Health*, 6, 5, 473-489.

Humphries, B. (1997) *From critical thought to emancipatory action: Contradictory research goals?*  
*Sociological Research Online*, 2,1: [www.socresonline.org.uk/socresonline/2/1/3.html](http://www.socresonline.org.uk/socresonline/2/1/3.html)

- Hutchins, J. and Gower, K. (1993) Unemployment and mental health. *Journal of Mental Health*, 2, 355-358
- Hutton, W. (1996) *The State We're In*. London: Vintage.
- Ignatieff, M. (1989) Citizenship and moral narcissism. *Political Quarterly*, 60, (1), 63-74.
- Ignatieff, M. (1991) Citizenship and moral narcissism. (p.26-36) In G. Andrews (ed). *Citizenship*. London: Lawrence and Wishart.
- Illich, I. (1977) Disabling professions (p.11-39) In I. Illich et al. *Disabling Professions*. London: Marion Boyars.
- Illich, I. (1978) *The Right to Useful Unemployment and Its Professional Enemies*. London: Marion Boyars.
- Illich, I. (1995) *Limits to Medicine: Medical Nemesis: The Expropriation of Health*. London: Marion Boyars.
- Jenkins, R. (1996) *Social Identity*. London: Routledge.
- Johnstone, L. (2000) *Users and Abusers of Psychiatry* (2<sup>nd</sup> edition). London: Routledge.
- Joint Committee on the Draft Mental Health Bill: First Report (2005) [www.publications.parliament.uk](http://www.publications.parliament.uk)
- Jones, R. (1994) *Mental Health Act Manual* (4<sup>th</sup> edition). London: Sweet and Maxwell.
- Judd, C.M., Smith, E.R. and Kidder, L.H. (1991) (6<sup>th</sup> edition) *Research Methods in Social Relations*. Orlando: Harcourt Brace Jovanovich.
- Keating, F. (1997) *Developing an Integrated Approach to Oppression*. London: CCETSW.
- Keating, F., Robertson, D., McCulloch, A. and Francis, E. (2002) *Breaking the Circles of Fear*. London: SCM.
- Keating, F. and Robertson, D. (2004) Fear, black people and mental illness: a vicious circle? *Health and Social Care in the Community*, 12, 5, 439-447.
- Kennett, T. (1995) Citizenship and social exclusion in Britain and Germany. *Research in Community Sociology*, 5, 225-248.
- Kirk, S. A. (1975) The psychiatric sick role and rejection. *Journal of Nervous and Mental Disease*, 161, 5, 318-325.

Kutchins, H. and Kirk, S. A. (1997) *Making Us Crazy: DSM-The Psychiatric Bible and the Creation of Mental Disorders*. London: Constable.

Kymlicka, W. (2002) *Contemporary Political Philosophy: An Introduction*. (2<sup>nd</sup> edition). Oxford: Oxford University Press.

Lamb, R.H. (1990) Will we save the homeless mentally ill? *American Journal of Psychiatry*, 147, 5, 649-651.

Laurance, J. (2003) *Pure Madness: How Fear Drives the Mental Health System*. London: Routledge.

Law Commission (1991) Consultation Paper No. 119: *Mentally Incapacitated Adults and Decision-Making: An Overview*. London: HMSO.

Law Commission (1995) *Mental Incapacity Law*. Commission No.231. London: HMSO.

Lee, R.M. and Fielding, N. (1996) Qualitative data analysis: Representations of a technology: A comment on Coffey, Holbrook and Atkinson. *Sociological Research Online*, 1, 4: [www.socresonline.org.uk/socresonline/1/4/1.html](http://www.socresonline.org.uk/socresonline/1/4/1.html)

Leff, J. (2001) Why is care in the community perceived as a failure? *British Journal of Psychiatry*, 179, 381-383.

Leff, J. and Trieman, N. (2000) Long-stay patients discharged from psychiatric hospitals. *British Journal of Psychiatry*, 176, 217-223.

Lehman, P. (2001) Coming off neuroleptics (p.81-91) In C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness Too*. Ross-on-Wye: PCCS Books.

Lenoir, R. (1974) (2<sup>nd</sup> ed.) *Les Exclus: Un Francais Sur Dix*. Paris: Sevil. Cited in H. Silver (1994) Social exclusion and social solidarity: three paradigms. *International Labour Review*, 133, (5-6), 530-578.

Levinson, R.M. and Ramsay, G. (1979) Dangerousness, stress and mental health evaluations. *Journal of Health and Social Behaviour*, 20, 178-187.

Levitas, R. (1996) The concept of social exclusion and the new Durkheimian hegemony. *Critical Social Policy*, 46, 16, 5-20.

Levitas, R. (1998) *The Inclusive Society? Social Exclusion and New Labour*. Basingstoke: Macmillan Press.

Lewis, A. and Trieman, N. (1995) The TAPS Project 29: Residential care provision in North London: A representative sample of ten facilities for mentally ill people. *International Journal of Social Psychiatry*, 41, 4, 257-267.



- Lewis, D. A., Shadish, W.R. and Lurigio, A.J. (1989) Policies of inclusion and the mentally ill: Long-term care in a new environment. *Journal of Social Issues*, 15, 3, 173-186.
- Link, B.G. (1987) Understanding labelling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 52, 96-112.
- Link, B.G., Andrews, H. and Cullen, F.T. (1992) The violent and illegal behaviour of mental patients reconsidered. *American Sociological review*, 57, 275-292.
- Link, B.G., Cullen, F., Fran, J. and Wozniak, J. (1987) The social rejection of former mental patients: Understanding why label matters. *American Journal of Sociology*, 92, 1461-1500.
- Link, B.G., Cullen, F.T., Struening, E., Shrout, P.E. and Dohrenwend, B.P. (1989) A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, 54, 400-423.
- Link, B.G., Elmer, L., Struening, M.R., Phelan, J.C. and Nuttbrock, L. (1997) On stigma and its consequences: evidence from a longitudinal study of men with dual diagnosis of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38, 177-190.
- Lister, R. (1990a) *The Exclusive Society*. London: CPAG.
- Lister, R. (1990b) Women, economic dependency and citizenship. *Journal of Social Policy*, 19, 4, 445-467.
- Lister, R. (1997) *Citizenship: Feminist Perspectives*. New York: New York University Press.
- Lister, R. (1998a) Vocabularies of citizenship and gender: the UK. *Critical Social Policy*, 18, 3, 309-331.
- Lister, R. (1998b) Citizenship on the margins: Citizenship, social work and social action. *European Journal of Social Work*, 1, 1, 5-18.
- Lister, R. (2001) New Labour: a study in ambiguity from a position of ambivalence. *Critical Social Policy*, 21, 4, 425-447.
- Lister, R. (2004) *Poverty*. Cambridge: Polity Press.
- Littlewood, R. and Cross, S. (1980) Ethnic minorities and psychiatric services. *Sociology of Health and Illness*, 2, 2, 194-201.
- Littlewood, R. and Lipsedge, M. (1981) Acute psychotic reactions in Caribbean-born patients. *Psychological Medicine*, 11, 303-318.

Lonkila, M. (1995) Grounded theory as an emerging paradigm for computer-assisted qualitative data analysis. In U. Kelle (ed) *Computer-Aided Qualitative Data Analysis: Theory, Methods and Practice*. London: Sage.

Lukes, S. (1974) *Power: A Radical View*. Basingstoke: Palgrave.

Lund, B. (1999) 'Ask not what your community can do for you': obligations, New Labour and welfare reform. *Critical Social Policy*, 19, (4), 447-462.

Maclure, R. (1990) The challenge of participatory research and its implications for funding agencies. *International Journal of Sociology and Social Policy*, 10, 3, 1-21.

MacPherson, S. (1997) Social exclusion. *Journal of Social Policy*, 26, 4, 533-541.

Macmillan, K. and McLachlan, S. (1999) Theory-building with Nudist: Using computer-assisted qualitative analysis in a media case study. *Sociological Research Online*, 4, 2: [www.socresonline.org.uk/socresonline/4/2/html](http://www.socresonline.org.uk/socresonline/4/2/html)

Marshall, E.J. and Reed, J.L. (1992) Psychiatric morbidity in homeless women. *British Journal of Psychiatry*, 160, 761-768.

Marshall, T.H. (1981) *The Right to Welfare and Other Essays*. London: Heinemann.

Marshall, T.H. and Bottomore, T. (1992) *Citizenship and Social Class*. London: Pluto Press.

Martensson, L. (1998) *Deprived of Our Humanity: The Case Against Neuroleptic Drugs*. The Voiceless Movement.

Martin, J. and White, A. (1988) *The Financial Circumstances of Disabled Adults Living in Private Households*. London: OPCS.

Marzuk, P.M. (1996) Violence, crime and mental illness: How strong a link? *Archives of General Psychiatry*, 53, 481-486.

Mays, N. and Pope, C. (2000) Assessing quality in qualitative research. *British Medical Journal*, 320, 50-52.

McGovern, D. and Cope, R.V. (1987) First psychiatric admission rates for first and second generation Afro-Caribbeans. *Social Psychiatry*, 22, 139-149.

McFarlane, L. (1998) *Diagnosis: Homophobic: The Experiences of Lesbians, Gay Men and Bisexuals in Mental Health Services*. London: PACE.

McKnight, J. (1977) Professionalised service and disabling help(p.69-91) In I. Illich et al. *Disabling Professions*. London: Marion Boyars.

Mead, L.M. (1986) *Beyond Entitlement: The Social Obligations of Citizenship*. New York: Basic Books.

- Mehta, N. (2002) Marlboro ward-the land that time forgot. *Openmind*, 118, Nov/Dec. p. 22-23.
- Mendel, W. and Rapport, S. (1969) Determinants of the decision for psychiatric hospitalisation. *Archives of General Psychiatry*, 20, 321-328.
- Mental Health Act Commission (2005) *In Place of Fear: Eleventh Biennial Report 2003-2004*. London: TSO.
- Mental Health Foundation (1997) *Knowing Our Own Minds: A Survey of How People in Emotional Distress Are in Control of Their Lives*. London: MHF.
- Mental Health Foundation (2000) *Strategies For Living*. London: MHF.
- Mental Health Foundation (2005) *Up and Running*. London: MHF.
- Merlucci, A. (1995) The new social movements revisited: reflections on a sociological understanding. In L. Maheu (ed) *Social Movements and Social Classes: The Future of Collective Action*. London: Sage Publications.
- Midgley, G. (1990) The social context of vocational rehabilitation of ex-psychiatric patients. *British Journal of Psychiatry*, 156, 272-277.
- Milham, S., Bullock, R., Hosie, K. and Haak, M. (1985) *Children Lost in Care: The Family Contact of Children in Care*. London: Gower.
- Mind (2000) Mind's response to the Government's consultation paper on reform of the Mental Health Act 1983. [www.mind.org.uk/campaigns/govresponse/html](http://www.mind.org.uk/campaigns/govresponse/html)
- Mishler, E. and Wexler, N. (1963) Decision processes in psychiatric hospitalisation. *American Sociological Review*, 28, 576-587.
- Monahan, J. (1988) Risk assessment of violence among the mentally disordered: generating useful knowledge. *International Law and Psychiatry*, 11, 249-257.
- Monahan, J. (1992) Mental disorder and violent behaviour: Perceptions and evidence. *American Psychologist*, 47, 511-521.
- Moncrieff, J. (2003) The politics of a new Mental Health Act. *British Journal of Psychiatry*, 183, 8-9.
- Moore, M.S. (1984) *Law and Psychiatry: Rethinking the Relationship*. Cambridge: Cambridge University Press.
- Morrall, P. (2000) *Madness and Murder*. London: Whurr Publishers.
- Mosher, L. and Burti, R. (1989) *Community Mental Health: Principles and Practice*. New York: Norton.

- Mossman, D. (1997) Deinstitutionalisation, homelessness and the myth of psychiatric abandonment: a structural anthropology perspective. *Social Science Medical*, 44, 1, 71-83.
- Mortensen, P.B. and Juel, K. (1993) Mortality and causes of death in first admitted schizophrenic patients. *British Journal of Psychiatry*, 163, 183-189.
- Muijen, M. (1995) Care of mentally ill people. *Community Care*, 7-13 Sept., ii-viii.
- Mulgan, G. (1991) Citizens and responsibilities. In G. Andrews (ed) *Citizenship*. London: Lawrence and Wishart.
- Mulvany, J. (2000) Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. *Sociology of Health and Illness*, 22, 5, 582-601.
- Mulvey, E.P. (1994) Assessing the evidence of a link between mental illness and violence. *Hospital and Community Psychiatry*, 45, 663-668.
- Mulvey, E.P. and Lidz, C.W. (1995) Conditional prediction: a model for research on dangerousness to others in a new era. *International Journal of Law and Psychiatry*, 18, 2, 129-143.
- Munetz, M.R. and Geller, J.L. (1993) The least restrictive alternative in the post-institutional era. *Hospital and Community Psychiatry*, 44, 10, 967-973.
- Munro, E. and Rungay, J. (2000) Role of risk assessment in reducing homicides by people with mental illness. *British Journal of Psychiatry*, 176, 116-120.
- Murray, C. (1989) 'The Underclass', *Sunday Times Magazine*, 26<sup>th</sup> November, pp. 26-45.
- Neville, P. and O'Dwyer, J. (1991) Appeals against section 2 of the Mental Health Act 1983. *Psychiatric Bulletin*, 15, 642.
- Nieradzik, K. and Cochrane, R. (1985) Public attitudes towards mental illness-the effects of behaviour, role and psychiatric labels. *International Journal of Social Psychiatry*, 31, 23-33.
- Nunnally, J.L. (1961) *Popular Conceptions of Mental Health*. New York: Henry Holt.
- O'Brien, K. (1993) Improving survey questionnaires through focus groups. In D.L. Morgan (ed) *Successful Focus Groups: Advancing the State of the Art*. London: Sage.
- Observer, 27<sup>th</sup> February, British liberty is under threat. [www.observer.co.uk](http://www.observer.co.uk)
- Office of the Deputy Prime Minister (1998) 1998 Index of Local Deprivation. [www.odpm.gov.uk](http://www.odpm.gov.uk)
- O'Kelly, R. (2004) Springing the poverty trap. *Mental Health Today*, October, 32-34.

- Oliver, D. and Heater, D. (1994) *The Foundations of Citizenship*. London: Harvester Wheatsheaf.
- Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan Press.
- Oliver, M. (1992) Changing the social relations of research production? *Disability, Handicap and Society*, 7, 2, 101-114.
- Oliver, M. (1994) Moving on: from welfare paternalism to welfare citizenship (The ungrateful bastards) *Social Action*, 2, 1, 12-16.
- Oliver, M. (1996) *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan Press.
- Olshansky, S., Grob, S. and Malamud, I.T. (1958) Employers' attitudes and practices in the hiring of ex-mental patients. *Mental Hygiene*, 42, 391-401.
- Page, S. (1977) Effects of the mental illness label on attempts to obtain accommodation. *Canadian Journal of Behavioural Science*, 9, 84-90.
- Parker, I., Georgala, E., Harper, D., McLaughlin, T. and Stowell-Smith, M. (1995) *Deconstructing Psychopathology*. London: Sage.
- Parshad Griffin, A. (2003) Making rights real. *Openmind*, 124, 18-19.
- Pattie, C., Seyd, P. and Whiteley, P. (2004) *Citizenship in Britain: Values, Participation and Democracy*. Cambridge: Cambridge University Press.
- Peay, J. (1989) *Tribunals on Trial*. Oxford: Clarendon.
- Peck, E., Gulliver, P. and Towel, D. (2002) Information, consultation or control: User involvement in mental health services in England at the turn of the century. *Journal of Mental Health*, 11, 4, 441-451.
- Pedler, M. (1999) *Mind the Law: Mind's Evidence to the Government's Mental Health Act Review Team*. London: Mind.
- Penn, D.L. and Martin, J. (1998) The stigma of severe mental illness: some potential solutions for a recalcitrant problem. *Psychiatric Quarterly*, 69, 3, 235-247.
- Penhale, B. (1999) Introduction (p.1-15) In N. Stanley, J. Manthorpe and B. Penhale (eds) *Institutional Abuse: Perspectives Across the Life Course*.
- Perakyla, A. (1997) Reliability and validity in research based on transcripts (p.201-220) In D. Silverman (ed) *Qualitative Research: Theory, Method and Practice*, London: Sage.
- Perkins, E. (2003a) *Decision-Making in Mental Health Review Tribunals*. London: Policy Studies Institute.

- Perkins, R. (2003b) Economic and social inclusion. *Openmind*, 121 (May/June). 6.
- Perkins, R.E. and Repper, J.M. (1999) Compliance or informed choice. *Journal of Mental Health*, 8, 2, 117-129.
- Perkins, R. and Silver, E. (1994) Report of the Wandsworth Mental Health Needs Assessment Project. London: Pathfinder NHS Trust.
- Phillips, D.L. (1963) Rejection: A consequence of seeking help for mental disorders. *American Sociological Review*, 28, 963-972.
- Phillips, D.L. (1964) Rejection of the mentally ill: the influence of behavior and sex. *American Sociological Review*, 29, 679-687.
- Phillips, D. L. (1966) Public identification and acceptance of the mentally ill. *American Journal of Public Health*, 56, 755-763.
- Phillips, N. and Hugman, R. (1999) The users' perspective: The experience of being a parent with a mental health problem. In A. Weir and A. Douglas (eds) *Child Protection and Adult Mental Health: Conflict of Interest?* Oxford: Butterworth Heinemann.
- Philo, G. (1996a) A sense of perspective: The media and Boyd Inquiry (p.37-44) In G. Philo (ed) *Media and mental Distress*. London: Longman.
- Philo, G. (1996b) The media and public belief (p.82-104) In G. Philo (ed) *Media and Mental Distress*. London: Longman.
- Philo, G., McLaughlin, G. and Henderson, L. (1996) Media content (p.45-81) In G. Philo (ed) *Media and mental Distress*. London: Longman.
- Pickering, M. (2001) *Stereotyping: The Politics of Representation*. Basingstoke: Palgrave.
- Pilgrim, D. (2001) Disordered personalities and disordered concepts. *Journal of Mental Health*, 10, 3, 253-265.
- Pilgrim, D. and Hitchman, L. (1999) User involvement in mental health service development (p.179-193) In C. Newnes, G. Holmes and C. Dunn (eds) *This is Madness*. Ross-on-Wye: PCCS Books.
- Pilgrim, D. and Rogers, A. (1994) *Sociology of Mental Health and Illness*. Buckingham: Open University Press.
- Pilgrim, D. and Rogers, A. (1997) A confined agenda? *Journal of Mental Health*, 6, 6, 539-542.
- Pilgrim, D. and Waldron, L. (1998) User involvement in mental health service development. *Journal of Mental Health*, 7, 1, 95-104.

Piliavin, I., Westerfelt, H. and Elliot, E. (1989) Estimating mental illness among the homeless: The effects of choice-based sampling. *Social Problems*, 36, 5, 525-531.

Pipe, R., Bhat, A., Matthews, B. and Hampstead, J. (1991) Section 136 and African/Afro-Caribbean minorities. *International Journal of Social Psychiatry*, 37, 15-23.

Pols, J. (1989) Mental illness and rationality: a critique. *International Journal of Law and Psychiatry*, 12, 71-79.

Pound, A. (1996) Parental affective disorder and childhood disturbance (p.201-218) In Gopfert, J. Webster and M.V. Seeman (eds) *Parental Psychiatric Disorder: Distressed parents and their Families*. Cambridge: Cambridge University Press.

Priestley, M. (1999) *Disability Politics and Community Care*. London: Jessica Kingsley.

Prior, D., Stewart, J. and Walsh, K. (1995) *Citizenship, Rights, Community and Participation*. London: Pitman Publishing.

Punch, M. (1998) Politics and ethics in qualitative research. In N.K. Denzin and Y.S. Lincoln (eds) *Handbook of Qualitative Research*. London: Sage.

Rabkin, J. (1974) Public attitudes towards mental illness: A review of the literature. *Schizophrenia Bulletin*, 10, 9-33.

Ramcharan, P. and Grant, G. (1994) Setting one agenda for empowering persons with a disadvantage within the research process. In M.H. Rioux and M. Bach (eds) *Disability is Not Measles: New Research Paradigms in Disability*. Ontario: L'Institut Rocher.

Rapp, C.A., Shera, W. and Kisthardt, L. (1993) Research strategies for consumer empowerment of people with severe mental illness. *Social Work*, 38, 6, 727-735.

Ratcliffe, P. (1999) Housing inequality and 'race': Some critical reflections on the concept of 'social exclusion'. *Ethnic and Racial Studies*, 22, 1, 1-22.

Read, J. and Baker, S. (1996) *Not Just Sticks and Stones: A Survey of the Stigma, Taboos and Discrimination Experienced by People with Mental Health Problems*. London: Mind.

Read, J. (2000) Thinking about a drug-free future for mental health services. *Mind Annual Conference*, 16<sup>th</sup> Nov. 2000. Bournemouth, England.

Reason, P. (1994) Inquiry and alienation. In P. Reason (ed) *Participation in Human Inquiry*. London: Sage.

- Reason, P. and Rowan, J. (1981) Issues of validity in new paradigm research. In P. Reason and J. Rowan (eds.) *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: John Wiley and Sons.
- Rees, A.M. (1995a) The promise of social citizenship. *Policy and Politics*, 23, 4, 313-325.
- Rees, A.M. (1995b) The other T.H. Marshall. *Journal of Social policy*, 24, 3, 341-362.
- Rees, A.M. (1996) T.H. Marshall and the progress of citizenship (p.1-23). In M. Bulmer and A.M. Rees (eds.) *Citizenship Today: The Contemporary Relevance of T.H. Marshall*. London: UCL Press.
- Rees, T. (1991) Ethical issues. In G. Allen and C. Skinner (eds.) *Handbook for Research students in Social Sciences*. London: Falmer Press.
- Repper, J., Sayce, L., Strong, S., Willmot, J. and Haines, M. (1997) *Tall Stories from the Backyard*. London: Mind Publications.
- Richards, T.J. and Richards, L. (1994) Using computers in qualitative research. In N.K. Denzin and Y.S. Lincoln (eds.) *Handbook of Qualitative Research*. London: Sage.
- Richards, T.J. and Richards, L. (1998) Using computers in qualitative research. In N.K. Denzin and Y.S. Lincoln (eds) *Collecting and Interpreting Qualitative materials*. London: Sage.
- Richardson, C. (2003) One in four. *Mental Health Today*, Nov., 12-13.
- Richardson, G. and Machin, D. (2000) Doctors on tribunals: a confusion of roles. *British Journal of Psychiatry*, 176, 110-115.
- Rioux, M.H. (1994) Introduction: Research directions and paradigms: Disability is not measles. In M.H. Rioux and M. Bach (eds) *Disability is not Measles: New Research Paradigms in Disability*. Ontario: L'Institut Roehar.
- Ritchie, J.H., Dick, D. and Lingham, R. (1994) *The Report of the Inquiry into the Care and Treatment of Christopher Clunis*. London: TSO
- Robinson, F. and Gregson, N. (1992) The 'underclass': a class apart? *Critical Social Policy*, 12, 1, 38-51.
- Roche, M. (1992) *Rethinking Citizenship: Welfare Ideology and Change in Modern Society*. Cambridge: Polity Press.
- Rogers, A. and Faulkner, A. (1987) *A Place of Safety: Mind's Research into Police Referrals to the Psychiatric Services*. London: Mind Publications.
- Rogers, A., Pilgrim, D. and Lacey, R. (1993) *Experiencing Psychiatry: Users' Views of services*. Basingstoke: Macmillan Press.



Rogers, A. and Pilgrim, D. (2003) *Mental Health and Inequality*. Basingstoke: Palgrave Macmillan.

Rogers, E.S. and Palmer-Erbs, V. (1994) Participatory action research: implications for research and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation*, 18, 2, 3-12.

Room, G. (1995) Poverty and social exclusion: the new European agenda for policy and research (p.1-9) In G. Room (ed) *Beyond the Threshold: The Measurement and Analysis of Social Exclusion*. Bristol: Polity Press.

Room, G. (2000) Trajectories of social exclusion: The wider context for the third and first worlds (p.407-439) In D. Gordon and P. Townsend (eds) *Breadline Europe: The Measurement of Poverty*. Bristol: The Policy Press.

Rose, D. (2001) *Users' Voices: The Perspectives of Mental Health Service Users on Community and Hospital Care*. London: SCMh.

Rose, D., Ford, R., Lindley, P., Gawith, L. and the KCW Mental Health Monitoring Users' Group (1998) *In Our Experience: User-Focused Monitoring of Mental Health Services in Kensington and Chelsea and Westminster Health Authority*. London: SCMh.

Rowan, J. (1981) A dialectical paradigm for research. In P. Reason and J. Rowan (eds) *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: John Wiley and Sons.

Rowe, M., Kloos, B., Chinman, M., Davidson, L. and Boyle Cross, A. (2001) Homelessness, mental illness and citizenship. *Social Policy and Administration*, 35, 1, 14-31.

Rowland, L.A. and Perkins, R.E. (1988) You can't eat, drink or make love eight hours a day: The value of work in psychiatry-a personal view. *Health Trends*, 20, 75-79.

Rubin, H.J. and Rubin, I.S. (1995) *Qualitative Interviewing: The Art of Hearing Data*. London: Sage.

Runciman, W.G. (1996) Why social inequalities are generated by social rights (p.49-62) In M. Bulmer and A.M. Rees (eds) *Citizenship Today: The Contemporary Relevance of T.H. Marshall*. London: UCL Press.

Rutter, M. and Quinton, D (1984) Parental psychiatric disorder: Effects on children. *Psychosocial Medicine*, 14, 853-880.

Sainsbury Centre for Mental Health (1998) *Acute Problems: A Survey of the Quality of Care in Acute Psychiatric Wards*. London: SCMh.

Sayce, L. (1998) Stigma, discrimination and social exclusion: What's in a word? *Journal of Mental Health*, 7, 4, 331-343.

Sayce, L. (1999) Parenting as a civil right: supporting service users who choose to have children. In A. Weir and A. Douglas (eds) *Child Protection and Adult mental Health: Conflict of Interest?* Oxford: Butterworth Heinemann.

Sayce, L. (2000) *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion*. Basingstoke: Macmillan Press.

Sayce, L. (2003) Making rights real. *Openmind*, 124, Nov/Dec, 18-19.

Schizophrenia Media Agency (no date) *Freed To Kill*.  
[www.poptel.org.uk/mind/sma/freed/html](http://www.poptel.org.uk/mind/sma/freed/html)

Scheff, T. (1966) *Being Mentally Ill: A Sociological Theory*. Chicago: Aldine.

Schroder, D. and Ehrlich, D. (1968) Rejection by mental health professionals: a possible consequence of not seeking appropriate help for emotional problems. *Journal of Health and Social Behaviour*, 9, 222-232.

Schwartz, C.C., Myers, J.K. and Astrachan, B.M. (1974) Psychiatric labelling and the rehabilitation of the mental patient: Implications for research findings for mental health policy. *Archives of General Psychiatry*, 31, 329-334.

Scott, J. (1993) Homelessness and mental illness. *British Journal of Psychiatry*, 162, 314-324.

Seale, C. (1999) *The Quality of Qualitative Research*. London: Sage.

Secker, J. and Platt, S. (1996) Why media images matter. In G. Philo (ed) *Media and Mental Distress*. London: Longman.

Shaughnessy, P. (2000) An Eye to the Future. *Mind Annual Conference*, 16<sup>th</sup> Nov. Bournemouth, England.

Shakespeare, T. (1993) Disabled people's self-organisation: a new social movement. *Disability, Handicap and Society*, 8, 3, 249-264.

Shakespeare, T. (1996) Rules of engagement: doing disability research. *Disability and Society*, 11, 11, 115-119.

Shepherd, G., Muijen, M., Dean, R. and Cooney, M. (1996) Residential care in hospital and in the community. *British Journal of Psychiatry*, 168, 448-456.

Silver, H. (1994) Social exclusion and social solidarity: three paradigms. *International Labour Review*, 133, 5-6, 531-578.

Silverman, D. (2000) *Doing Qualitative Research: A Practical Handbook*. London: Sage.

- Smith, J.A., Hughes, IC.T. and Budd, R.J. (1999) Non-compliance with anti-psychotic depot medication: users' views on advantages and disadvantages. *Journal of Mental Health*, 8, 3, 287-296.
- Snow, D.A., Baker, S.G., Anderson, L. and Martin, M. (1986) The myth of pervasive mental illness among the homeless. *Social Problems*, 33, 5, 407-423.
- Socall, D.N. and Holtgraves, T. (1992) Attitudes toward the mentally ill: the effects of label and beliefs. *The Sociological Quarterly*, 33, 3, 435-445.
- Social Exclusion Unit (1998) *Bringing Britain Together: A National Strategy for Neighbourhood Renewal*. London: SEU.
- Social Exclusion Unit (2003) *Mental Health and Social Exclusion*. London: SEU.
- Social Exclusion Unit (2004) *Mental Health and Social Exclusion*. London: SEU.
- Somerville, M.A. (1985) Changes in mental health legislation as indicators of changing values and policies. In R. Roth and R. Bluglass (eds) *Psychiatry, Human Rights and the Law*. Cambridge: Cambridge University Press
- Stainton, T. (1998) Rights and rhetoric in practice: contradictions for practitioners (p.135-144) In A. Symonds and A. Kelly (eds) *The Social Construction of Community Care*. Basingstoke: Macmillan Press.
- Stansfield, D.S. (2002) Work, personality and mental health. *British Journal of Psychiatry*, 181, 96-98.
- Star, S. (1955) *The Public's Ideas About Mental Illness*. Chicago: National Opinion Research Centre.
- Steadman, H.J. (1983) Predicting dangerousness among the mentally ill: art, magic and science. *International Journal of Law and Psychiatry*, 6, 381-390.
- Stepney, P., Lynch, R. and Jordan, B. (1999) Poverty, exclusion and New labour. *Critical Social Policy*, 19, 1, 109-127.
- Stewart, D.W. and Shamdasani, P.N. (1990) *Focus Groups*. London: Sage.
- Strauss, A. and Corbin, J. (1994) Grounded theory methodology: an overview. In N. Denzin and Y. Lincoln (eds) *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. London: Sage.
- Strauss, J. et al. (1989) Subjective experiences of schizophrenia: towards a new dynamic psychiatry. *Schizophrenia Bulletin*, 15, 2, 179-188.

- Swanson, J. W. (1994) Mental disorder, substance abuse and community violence: an epidemiological approach (p. 101-136) In J. Monahan and H.J. Steadman (eds) *Violence and mental Disorder: Developments in Risk Assessment*. London: University of Chicago Press.
- Swanson, J.W., Holzer, C.E., Ganju, V.K. and Jono, R.T. (1990) Violence and psychiatric disorders in the community: evidence from the Epidemiological Catchment Area Survey. *Hospital Community Psychiatry*, 41, 761-770.
- Szmukler, G. (2000) Homicide inquiries-what sense do they make? *Psychiatric Bulletin*, 24, 6-10.
- Szmukler, G. and Holloway, F. (2000) Reform of the Mental Health Act: health or safety? *British Journal of Psychiatry*, 177, 196-200.
- Tam, H. (1998) *Communitarianism: A New Agenda for Politics and Citizenship*. Basingstoke: Macmillan Press.
- Taylor, P.J. and Gunn, J. (1999) Homicides by people with mental illness: myth or reality? *British Journal of Psychiatry*, 174, 9-14.
- Taylor, S.M. and Dear, M.J. (1981) Scaling community attitudes toward the mentally ill. *Schizophrenia Bulletin*, 7, 225-240.
- Teicher, M.H., Glod, C. and Cole, J.O. (1990) Emergence of intense suicidal preoccupation during fluoxetine treatment. *American Journal of Psychiatry*, 147, 207-210.
- Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of mental Health*, 13, 6, 549-559.
- Tesch, R. (1990) *Qualitative Research Analysis Types and Software Tools*. New York: Falmer Press.
- Thornicroft, G. and Goldberg, D. (1998) *Has Community Care Failed?* London: Institute of Psychiatry.
- Thompson, K. (1998) *Moral Panics*. London: Routledge.
- Thompson, N. (1998) *Promoting Equality: Challenging Discrimination and Oppression in the Human Services*. Basingstoke: Macmillan Press.
- Tonge, J. (1999) New packaging, old deal? New Labour and employment policy innovation. *Critical Social Policy*, 19, 2, 217-232.
- Townsend, P. (1979) *Poverty in the United Kingdom*. London/Berkeley, CA: Allen Lane and Penguin/University of California Press.
- Turner, B.A. (1993) First person account: the children of madness. *Schizophrenia Bulletin*, 19, 3, 649-650.

- Turner, B.S. (1990) Outline of a theory of citizenship. *Sociology*, 24, 2, 189-217.
- United Nations (1995) The Copenhagen Declaration and Programme of Action: World Summit for Social Development. 6-12 March 1995. New York: United Nations Department of Publications.
- Valenstein, E.S. (1998) *Blaming the Brain: The Truth About Drugs and Mental Health*. New York: The Free Press.
- Waddington, J.L., Youssef, H.A. and Kinsella, A. (1998) Mortality in schizophrenia: anti-psychotic polypharmacy and absence of adjunctive anticholinergics over the course of a 10-year prospective study. *British Journal of Psychiatry*, 173, 325-329.
- Waddington, L. (1997) European Community and disability discrimination: time to address deficit of powers? *Disability and Society*, 12, 3, 465-479.
- Wahl, O.F. (1987) Public vs. professional conceptions of schizophrenia. *Journal of Community Psychology*, 15, 285-291.
- Wahl, O.F. (1995) *Media Madness: Public Images of Mental Illness*. New Brunswick, NJ: Rutgers University Press.
- Wahl, O.F. (1999) *Telling is a Risky Business: Mental Health Consumers Confront Stigma*. New Brunswick, NJ: Rutgers University Press.
- Waldron, J. (ed) *Theories of Rights*. Oxford: Oxford University Press.
- Walker, A. (1997) Poverty and social exclusion in Europe (p.48-74) In A. Walker and C. Walker (eds). *Britain Divided: The Growth of Social Exclusion in the 1980s and 1990s*. London: CPAG.
- Wall, S., Churchill, R., Hotopf, M., Buchanan, A. and Wessely, S. (1999) A systematic review of research relating to the Mental Health Act 1983. London: HMSO
- Walsh, E., Moran, P., Scott, C., McKenzie, K., Burns, T., Creed, F., Tyrer, P., Murray, R.M. and Fahy, T. (2003) Prevalence of violent victimisation in severe mental illness. *British Journal of psychiatry*, 183, 233-238.
- Walton, P. (2000) Psychiatric hospital care: a case of the more things change, the more they remain the same. *Journal of Mental Health*, 9, 1, 77-88.
- Ward, L. and Flynn, M. (1994) What matters most: disability research and empowerment. In M.H. Rioux and M. Bach (eds) *Disability is Not Measles: New Research Paradigms in Disability*. Ontario: L'Institut Roehrer.
- Warner, R. (1987) *Recovery from Schizophrenia: Psychiatry and Political Economy*. London: Routledge and Kegan Paul.

- Warr, P.B. and Jackson, P.R. (1984) Men without jobs: Some correlates of age and length of employment. *Journal of Occupational Psychology*, 57, 77-85.
- Warr, P., Jackson, P. and Banks, M. (1988) Unemployment and mental health: some British studies. *Journal of Social Issues*, 44, 4, 47-68.
- Webster, J. (1990) Parenting for children. *Adoption and Fostering*, 14, 37-43.
- Webster, J. (1992) Split in two: experiences of the children of schizophrenic mothers. *British Journal of Social Work*, 22, 309-329.
- Webster, L., Dean, C. and Kessel, D. (1987) Effect of the 1983 Mental Health Act on the management of psychiatric patients. *British Medical Journal*, 295, 1529-1532.
- Weinstein, R.M. (1983) Labelling theory and the attitudes of mental patients: a review. *Journal of Health and Social behaviour*, 24 (March), 70-84.
- Weir, A. (1999) An introduction to the issues: A new holistic approach outlined. In A. Weir and A. Douglas (eds) *Child Protection and Adult Mental Health: Conflict of Interest?* Oxford: Butterworth Heinemann.
- Whatley, C. (1959) Social attitudes toward discharged mental patients. *Social Problems*, 6, 313-320.
- White, S. (2001) The ambiguities of the third way. In S. White (ed) *New Labour: The Progressive Future*. Basingstoke: Palgrave.
- Whitmore, E. (1994) To tell the truth: Working with oppressed groups in participatory approaches to inquiry. In P. Reason (ed) *Participation in Human Inquiry*. London: Sage.
- Wight Felske, A. (1994) Knowing about knowing: Margin notes on disability research. In M.H. Rioux and M. Bach (eds) *Disability Is Not Measles: New Research Paradigms in Disability*. Ontario: L'Institut Rocher.
- Williams, J.B., Gibbon, M., First, R.L., Spitzer, M., Davies, J. Burns, M., Howes, J., Kane, H.G., Pope, B. and Wittchen. H.V. (1992) The structured clinical interview for DSM-III-R (SCID): 11. Multi-site test-retest reliability. *Archives of General Psychiatry*, 49, 630-636.
- Williams, J. and Keating, F. (1999) The abuse of adults in mental health settings (p.130-151) In N. Stanley, J. Manthorpe and B. Penhale (eds) *Institutional Abuse: Perspectives Across the Life Course*. London: Routledge.
- Williamson, T. (2004) User involvement: a contemporary overview. *The Mental Health Review*, 9, 1, 6-12.
- Wilson, M. (1998a) Citizenship and welfare (p. 11-30). In M. Lavalette and A. Pratt (eds) *Social Policy: A Conceptual and Theoretical Introduction*. London: Sage.

Wilson, M. (1998b) Public perceptions: The psychology of image. In S. Fernando, D. Ndegwa and M. Wilson. *Forensic Psychiatry, Race and Culture*. London: Routledge.

Wilson, C., Nairn, R., Coverdale, J. and Panapa, A. (2000) How mental illness is portrayed in children's television: A prospective study. *British Journal of Psychiatry*, 176, 440-443.

Wolff, G., Pathare, S., Craig, T. and Leff, J. (1996) Community attitudes to mental illness. *British Journal of Psychiatry*, 168, 183-190.

Wolff, J. (2003) *Why Read Marx Today?* Oxford: Oxford University Press.

Wood, J. (1993) Reform of the Mental Health Act 1983: an effective tribunal system. *British Journal of Psychiatry*, 162, 14-22.

Woodhams, C. and Corby, S. (2003) Defining disability in theory and practice: a critique of the British Disability Discrimination Act 1995. *Journal of Social Policy*, 32,, 2, 159-178.

Wright, C., Burns, T., James, P., Billings, J. Johnson, S., Muijen, M., Priebe, S., Ryrie, I., Watts, J. and White, I. (2003) Assertive outreach teams in London: models of operation. *British Journal of Psychiatry*, 1, 83, 132-138.

Young, I.M. (1989) Polity and group difference: a critique of the ideal of universal citizenship. *Ethics*, 99, 250-274.

Young, I.M. (1995) Polity and group difference: a critique of the ideal of universal citizenship (p.175-207). In R. Beiner (ed) *Theorizing Citizenship*. New York: State University of New York Press.

Zarb, G. (1992) On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, handicap and Society*, 7, 2, 125-138.

## **Appendix 1: Written introduction to the research**

### **Citizenship of Mental Health Service Users in Political, Professional and Personal Contexts**

#### **Overview:**

My research concerns the citizenship status of mental health resource users. Citizenship, in this research, is loosely defined as community membership and participation. The subject of my research is the social location of people with psychiatric diagnoses whereby mass deinstitutionalisation of psychiatric patients has led to the emergence of questions relating to the social position of previously institutionalised individuals. Some, for instance SANE and the Zito Trust have questioned whether certain groups of people with a mental disorder are safe to be located in the community and others, for instance Barham and Hayward (1995) and Liz Sayce (2000), have questioned whether people with mental health problems are truly integrated into society, citing discrimination as a barrier to 'inclusion'.

My research hopes to elicit mental health service users' views on what constitutes meaningful social participation and the extent to which such participation is experienced by respondents in the research.

My research questions are:

1. Do mental health service users experience broad denial of citizenship rights?
2. What is the relationship between user involvement and citizenship?



3. What are the indicators of social exclusion and can these be analysed as indicators of citizenship status?

The basic propositions of my thesis are as follows:

- People who use mental health services are disproportionately more likely to be excluded from opportunities for social participation than people without a psychiatric diagnosis
- That such exclusion is the direct result of institutionalised discrimination
- That current mental health policy is incongruent with New Labour's populist rhetoric on citizenship and social inclusion
- That professional espousal of 'user involvement' is merely rhetorical with minimal relinquishment of power by professionals and is questionable within the context of broad social exclusion

In relation to the latter point, much mental health research is problematic in examining people with mental health problems *only* in the context of their service use and not as individuals with lives to pursue outside of the mental health system.

The first research question is to be examined by conducting one-to-one semi-structured interviews with individuals who have used mental health services in order to examine how service use impacts on community membership and participation.

The second research question will be examined by conducting focus groups with both user groups and groups comprised of mental health professionals in order to compare their accounts of user involvement.

The third research question will be examined in the individual interviews by discussing participants' experiences of community living, mental health services and encounters with legal institutions. I have suggested in my literature review that social exclusion may relate to housing, employment, income, social relationships, parental rights, and education and training. Interviewees may suggest additional or alternative areas of exclusion and explain how their use of services has impacted on areas identified.

Official mental health policy is contrasted with rhetorical discussions of citizenship and social inclusion by conducting a textual analysis of key government documents. I have already examined the Government's proposals for the reform of the Mental Health Act, Modernising Mental Health Services and the National Service Framework for mental health, alongside documents produced by the Social Exclusion Unit, speeches made by Tony Blair and Peter Mandelson, and by examining texts produced by 'intellectuals' associated with Labour rhetoric, such as Anthony Giddens, Michael Sandel and Alasdair MacIntyre.

In the description of my assumptions underlying the research, I stated that people with a psychiatric diagnosis are one of the most socially excluded groups in British society. I would like to discuss this assertion with other marginalised groups, such as disability groups, gay and lesbian activists and unemployed or homeless persons in order to compare experiences across groups.

I want to examine official accounts (i.e. by professionals and policy makers) of citizenship and social inclusion critically because such terms, like 'user involvement', are buzz words often used opportunistically with little comprehension of application and implications.

Therefore, I want to compare such official accounts with accounts of community membership provided by mental health service users.

I also wish to avoid the victimology of much mental health research by avoiding the depiction of mental health service users as victims to be pitied and in need of professional intervention.

I also want to eschew the tradition of orthodox research which depicts the researcher as the expert and participants as passive in the research process. I want to avoid the exploitative 'hit-and-run' approach of much research by involving participants in research design, interpretation and dissemination.

As a recognition of participants' expertise, I will pay participants at the rate of £5 per hour (or part of an hour) cash-in-hand. Research procedures will be negotiated with participants (eg. length and frequency of interviews and boundaries of self disclosure over which the participant may not wish to step) and participants will be given the opportunity to provide feedback on the experience of being a participant in the research. Moreover, participants will be asked to sign a contract which will emphasise their freedom to withdraw from the research at any time. Of course, all the material will be anonymised and remain confidential, although it will be clearly explained that the intention of the research is to be published in the form of a PhD thesis. However, I must stress that participants will not be identifiable in the completed thesis.

## **Biography**

I am a final year PhD student at the Tizard Centre, University of Kent. I have a degree in psychology, a diploma of social work and an MSc in psychiatric social work. I have worked as a volunteer in a Mind day centre, been a telephone counsellor, a citizen advocate in a mental health advocacy scheme, a support worker in a residential project for women with mental health problems and a care manager in an old age psychiatry service. I have brief personal experience of using mental health services and significant experience of mental health problems but I do not regard myself as a survivor due to not having been subject to the coercive side of mental health services. I am interested in individuals' rights and would like to work in mental health advocacy or a similar field, rather than remaining in academia.

**Contact:**

(Student's contact details)

## **Appendix 2: Poster Presentation**

### **Citizenship of Mental Health Service Users**

My name is Maya Float. I am conducting PhD research at the University of Kent into the citizenship of people who use/have used mental health services. I would be very interested in hearing from people who would like to discuss their experiences of community living. I am interested in people's experiences and views of:

- **mental health legislation**
- **current mental health policy**
- **mental health services**
- **user involvement**
- **employment**
- **financial issues**
- **housing**
- **social contacts**
- **parenting**
- **education and training**

Participants will be paid £5 per hour (or part of an hour) and travel expenses. If you would like more information, please leave a message for me, Maya Float, on the notice board in the Purbeck Foyer. I will also be standing by this poster at all lunch and refreshment breaks throughout the conference, or contact:

(Student's contact details)

## **Appendix 3: Verbal presentation**

### **Research Presentation**

#### **Biography**

I am a final year PhD student at the Tizard Centre, the University of Kent. I have a degree in psychology, a diploma of social work and an MSc in psychiatric social work. I have worked as a volunteer in a Mind day centre, been a citizen advocate in a mental health advocacy scheme, a support worker in a project for women with mental health problems and a care manager in an old age psychiatry service. I have brief experience of mental health services and significant experience of mental health problems but I do not consider myself a survivor because I have never been subject to the coercive side of the mental health system. I am interested in individuals' rights (although users of mental health services do not have many rights) and I would like to work in advocacy or generalist advice work. I do not want to remain in higher education following completion of the PhD.

#### **Research**

My research concerns the citizenship of people who use mental health services. Citizenship is loosely defined by those offering a definition as involving community membership and participation in society. To explain what I mean by citizenship, it might be helpful to describe where the idea from my research came from. A few years ago I was working as a volunteer in a mental health advocacy scheme in North Wales. After a while, I realised that many of the people I was seeing in the advocacy service were experiencing problems with housing and did not have jobs and were experiencing financial problems due to lack of employment. We had an office in the local in-patient unit and I began to wonder whether it was hospitalisation that was causing disruption to work, housing, friendships and family relationships. I now

realise this was probably a simplistic explanation but I believe mental health service use has a major disrupting effect on people's lives, from the disruption caused by repeated hospitalisations to the destructive side effects of medication. I want to find out in this research whether problems with housing, money, jobs, ect. are common amongst users of mental health services and, if so, to ask why this might be the case. Much existing research confirms my initial suspicions about disadvantages mental health service users experience. However, no-one has looked at such problems within the context of citizenship.

Citizenship is a useful tool for research because it examines how people fit into society and the opportunities they experience or are denied in relation to participating in society. Citizenship covers a lot of ground and enables a broad picture to be built up of people's lives within the community.

However, citizenship is an awkward concept because it is not obvious what it means. It is a complex concept but it can be simplified. I have broken citizenship down into a number of areas. If citizenship means membership and participation in society, I think a citizen is someone who has access to:

- decent housing
- opportunities for full-time employment in the mainstream labour market
- a reasonable income
- opportunities to develop social relationships (e.g. friendships)
- political influence
- does not have restrictions placed on their civil liberties
- is treated fairly before the law

Therefore, in my research, I would like to interview at least 20 people who use/ have used mental health services in order to discuss their experiences and views of:

- public attitudes
- mental health legislation
- mental health services
- current mental health policy
- housing
- work
- money
- friendships
- parenting
- education and training

I don't expect every person being interviewed to discuss everything on this list but I hope to build up a picture of community living by interviewing enough people to suggest some common experiences. I also don't claim that this list is complete. There are probably a number of areas I have not yet thought of.

So, there are two main aims of my research:

- To examine whether people who use mental health services are more likely to be excluded from opportunities to participate in society
- To examine whether politicians' and mental health professionals' accounts of citizenship are relevant to the experiences of community living by people using mental health services



The problem with all research on citizenship to date is that it ignores the views of people with mental health problems and instead covers views of ‘citizenship’, ‘social inclusion’ and ‘user involvement’ from the perspectives of policy makers and professionals. Terms such as ‘citizenship’ and ‘social inclusion’ are buzz words in that they are trendy and tend to attract people using these concepts in a way that is beneficial only to themselves. Therefore, I want to take a critical view of dominant notions of citizenship by changing the balance of power in debates towards the perspectives of mental health service users.

The problem with much mental health research is that it fails to consider people with mental health problems as anything but users of mental health services. My research looks at people’s experiences of mental health services but also their wider experiences as citizens: as people living in the community. My research aims to obtain a broader view of what it is like to live with a mental health problem in current society.

## **Appendix 4: Topic Guide**

**Topic Guide:** This is a rough guide to interview topics. I would like participants to contribute whatever they feel they can contribute and not expect to cover everything in the topic guide. This topic guide encompasses experiences and opinions.

### **Civil Citizenship (Law):**

Use of the Mental Health Act:

- Compulsory hospitalisation/treatment
- Mental Health Review Tribunals/ Hospital Managers' Hearings: access? usefulness?
- Community care legislation: aftercare?
- Decision-making: consent, compliance, insight
- Reaction to proposed Community Treatment Orders
- Experience of compulsion in the community: supervised discharge, supervision registers?
- Public and professionals' attitudes towards dangerousness
- Experiences of assertive outreach
- Experiences of and attitudes towards advocacy

### **Political Citizenship (Political influence)**

- Current mental health policy
- Involvement in user groups
- Public attitudes: stigma? discrimination?
- Nimbyism: harassment in the neighbourhood? opposition to psychiatric facilities?
- Media representations of people with mental health problems

## **Social citizenship (Is there discrimination in the following areas?):**

### **Housing:**

- Type
- Physical condition
- Facilities
- Experience of residential accommodation
- Integration in the local community
- Location
- Nimbyism: public hostility to psychiatric facilities
- Independence in accommodation
- Privacy
- Professionals' expectations of independent living
- Choice of housing
- Homelessness

### **Employment:**

- Type
- Participation in open labour market? Minimum wage? Rehabilitative earnings?
- Vocational schemes
- Unemployment
- Stress of work?
- Professionals'/ employers' attitudes

- Employment in mental health services: attitudes? experiences?

### **Money:**

- Credit
- Banks
- Insurance
- Income from work
- Benefits
- Poverty trap
- Attitudes towards money
- Definitions of poverty
- Aspirations for finances

### **Social networks:**

- Size of network
- How has service use affected friendships?
- Choice of friends
- Support from family and friends
- Rejection from family and friends
- Opportunities to meet people
- Acceptance by others
- Stigma
- Disclosure of mental health problems to others

**Parenting (either as a parent or childhood experience of parental mental health problems):**

- Professionals' attitudes towards the person's ability to parent
- Custody and access to children
- Difficulties and positives of parenting
- Experience of local authority intervention
- Effects of hospitalisation on parenting

**Mental Health Services:**

- Expectations from professionals of service users
- Range and choice of services
- Experiences of compulsion
- Professionals' attitudes
- Notions of insight, compliance
- Involvement in decision-making
- Usefulness of the medical model
- Medication: side-effects, information, usefulness
- Coercion in treatments and services
- Hospitalisation: does a stay in hospital help? does hospitalisation have a negative impact?  
how does hospitalisation affect housing, employment, friendships, parenting? how  
voluntary is informal admission? experiences of staff? experiences of seclusion, locked  
wards or physical intervention?

- Alternative services: should services be user-run? would services be improved by employing people with mental health problems?

### **User involvement:**

- Involvement in groups?
- Function of groups?
- Professional attitudes to user groups
- Opportunistic buzz-word? does it have real meaning?
- Are users 'consumers'?
- What does 'consumerism' mean?
- How should users be involved? consultation? decision-making? user-run services?
- Level of actual and desired participation
- Relationships with professionals
- Representation? can users claim to be representative? do we need representativeness?
- Aims of user movement?

### **Education and training:**

- Impediments to access?
- Support?
- Difficulties?
- What's needed?
- Usefulness?

## **Appendix 5: Consent Form**

### **Consent Form**

The purpose of this consent form is to ensure you understand the nature of this research and agree to participation. It is also to establish the strict ethical guidelines you can expect me to adhere to. I am interested in discussing the topics already mentioned in addition to any topics you think may be relevant. You can agree to as many or as few interviews as you like and you can decide how long you want each interview to last. You will be paid £5 per hour (or part of an hour), in cash, plus travel expenses (and childcare expenses if required).

Please read the following guidelines and sign at the end if you agree to the guidelines. If you disagree, we can discuss anything that is not to your liking.

- You can end an interview at any time and withdraw from the research without giving a reason if you so wish
- You should not say anything that makes you feel uncomfortable or discuss anything you are unhappy discussing with me
- Everything you say to me will be treated in the strictest of confidence. Your confidentiality and anonymity is guaranteed
- Each interview will be tape recorded unless you do not agree to this. Tape recordings will be transcribed (written word-for-word) by myself. No-one else will hear the tape recording or read the transcription
- General findings will be published as a PhD thesis and, possibly, in journal and magazine articles and a book. *However*, you will not be mentioned by name and identifying details will not be included in the final thesis

- The PhD thesis will be held at the Templeman Library at the University of Kent and at the British Library in London
- Feedback on the general findings of the research will be given if you would like to be contacted upon completion of the research. You will be asked to provide comments on the findings and, with your permission, such comments will be included in the final thesis
- At the end of the final interview, you will be asked to complete a questionnaire to give me information on how you found the experience of participating in this research. This is so that I know whether or not the experience was positive and how research can be improved in the future. You can decline to complete this questionnaire if you wish.
- If you have any complaints about this research, please contact my supervisor, Frank Keating at the Tizard Centre, Beverley Farm, University of Kent, Canterbury, Kent, CT2 7LZ . Tel: (01227) 764000 ext.3955 or ask someone to do this on your behalf.

I .....(name) understand the nature of the research and the behaviour I can expect from Maya Float during the course of the research. I agree to participate in this research and understand that I can withdraw from the research at any time.

Signed.....



## **Appendix 6: Receipt**

I ..... acknowledge receipt of £..... for participation in a focus group for Maya Float, PhD Student, lasting ..... hours at a rate of £5 per hour.

Signed .....

## Appendix 7: Letter to request feedback

(Student's name and address)

8/2/05

(Participant's address)

Dear (Participant)

### Re: Citizenship research

I am writing to you following your participation in my citizenship research in 2001. Once again, thank you for your participation in the research; your contribution has been very valuable. I have now completed the writing up of the research and wonder whether you would like to receive a copy of the findings chapter. I would be happy to send you a copy and would like to invite you to comment on the findings so that your feedback can be included in the final thesis, which is due for submission at the end of March 2005. I would be grateful if you could use the reply slip at the bottom of this letter and the enclosed stamped addressed envelope to inform me whether or not you wish to receive a copy of the findings. I look forward to hearing from you.

Yours sincerely

Maya Goia (formerly Float)

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I do/do not (please delete as appropriate) wish to receive a copy of the research findings.

Name:

Address:

