A Pluralistic Evaluation of Services for Women with Long-Term Mental Health Problems

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Woman's Own

I am a woman I try so hard
as a family feeder with supportive arms.

I am the sun, I am the light,
I try not to be late when I rise and rise,
gently heading a graceful life with
strength and pride - always !

I am intelligent and could intimidate,
the goodness and faith to celebrate ...

I am all woman.

(Written by a group of women with long-term mental health problems and myself in a poetry workshop which was part of a 'Women's Day' celebration organized by one of the day centres in the Rehabilitation and Community Care Services in Nottingham, 6/3/96).

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Abstract

This thesis presents a pluralistic evaluation of the services provided for women with long-term mental health problems receiving care and support within the Rehabilitation and Community Care Service (RCCS) in Nottingham. The thesis is grounded in data collected within an evaluative research framework and developed within a mental health policy framework. The evaluation consists of a series of six studies which are informed by a set of evaluation criteria which reflect a range of stakeholder perspectives.

The first study examines the socio-demographic and psychiatric characteristics, social functioning and service use of all 480 clients registered with the RCCS. The clients' characteristics are similar to those described in previous studies. There are some differences between the men and the women, notably that the women are under-represented amongst those receiving a high level of input from the services.

The second and third studies explore the extent and adequacy of services for women with long-term mental health problems in the Nottingham district through interviews with small groups of service providers working throughout the RCCS, and through a postal questionnaire to thirty eight organizations outside the RCCS. Special provision made for women is patchy, and there is no overall strategy to ensure even provision throughout the RCCS and the organizations outside the service, or co-ordination between them.

The fourth study assesses the initial socio-demographic and psychiatric characteristics, social functioning, satisfaction with services, and quality of life of 31 men and 10 women at their time of entry into the RCCS and one year later, and their use of all services during this time. The women experienced a greater number of life events than the men, changed their accommodation more frequently, and the services appear to be less responsive to their particular needs. The outcome after twelve months shows that overall the social functioning and quality of life of the clients had not improved. There were some changes in service use, notably the greater number of clients living independently.

The fifth study uses semi-structured interviews to explore the problems service providers experience in planning and delivering a service to women with long-term mental health problems. Two overriding themes emerge from the data; service providers as empathic women, and service providers as professionals, which lead them to experience a conflict between respecting the rights of women with long-term mental health problems and protecting them.

The final study uses focus groups to explore the impact of mental health problems on the lives of women with long-term mental health problems, and their views of the services they currently receive. Three themes emerge from the data; loss, hope and views about services. Despite overwhelming losses many of the women retain hopes and aspirations for the future. The women identify negative and positive aspects of the services they are receiving together with some recommendations for change.

The thesis contributes to current knowledge about the experiences of women with long-term mental health problems in a number of ways. First, the findings of the six studies which make up the evaluation highlight the ways in which the RCCS was successful in meeting these women's needs, and the many gaps in existing provision. Second, women with long-term mental health problems can give coherent and comprehensive accounts of their experiences. Third, the findings illuminate the current predicament of women with long-term mental health problems which is that they remain excluded and marginalised from the communities where they are now living.

Introduction

The process of thinking about, working on and ultimately writing a thesis is a personal and an essentially isolated endeavour. Although contact is made with other researchers through supervision, conferences and informal discussion, the completed thesis represents a piece of work which ultimately stems from the researcher's view of the world. This view of the world is not only constructed through academic background and research training, but also from past work experiences and personal values and beliefs. Of particular interest is the gradual realization that a personal view of the world is not fixed and can undergo radical shifts in response to any number of internal and external events.

Whilst other researchers have emphasized the importance of making explicit their worldview and the impact this has on the way they investigate and conceptualize social phenomenon (c.f. Simmons 1995), little reference is made as to how their world view has shifted during the course of their investigations. Thus the relatively inexperienced researcher who embarks on a long-term study is unprepared for the experience of such shifts and how these are to be accommodated into the research process. There appears to be two ways of addressing this phenomenon. The first is to present the thesis as it was originally conceived whilst acknowledging that its focus and design would now be different as a result of hindsight. A case of 'if I knew then what I know now, things would be different'. The second is to acknowledge the shifts which have occurred in the researcher's worldview and to accommodate these within the thesis. This thesis has adopted the second approach as it now seems inappropriate not to include the changes which have taken place in the researcher's worldview over the last six years.

This thesis was originally designed as an evaluation of services for women with long-term mental health problems who were receiving care and support within the Rehabilitation and Community

Care Service in Nottingham (RCCS). The interest in this area stemmed from an awareness that little research had focused specifically on women with long-term mental health problems, and the limited but growing evidence that these women were disadvantaged in community-based mental health services (Bachrach 1984, 1985; Perkins and Rowland 1991). The pragmatic approach originally taken to the research possibly or perhaps inevitably reflected the researcher's worldview at the start of the work. Coming from a clinical background in mental health nursing, the researcher was keen to find some specific answers to specific questions as a means of providing other clinicians with the information required to improve services for women with long-term mental health problems. Moreover the belief that the evaluation would unearth factual evidence of the disadvantaged position of these women was influenced to some extent by the researcher's natural inclination towards the methodological approaches adopted by much research within mental health services. For example, the unspoken assumption that there is a truth out there waiting to be discovered. The early stages of the investigation were therefore influenced by an almost exclusive adherence to the extensive but methodologically narrow research literature within the field of social psychiatry.

This pragmatic and somewhat altruistic worldview remained fairly constant throughout much of the data collection period. This is possibly a reflection of the all consuming nature of gaining access into the research field and the amount of time and effort that was required to collect the data. It was only towards the end of the data collection period, when much of the data had been analyzed, that the somewhat limited scope of an evaluative framework in which to explore the experiences of women with long-term mental health problems within community-based mental health services began to emerge. Two key factors contributed to a radical shift in worldview which in turn resulted in a reframing of the thesis.

First, the very real methodological problems of evaluative research began to emerge. These centered primarily around the difficulty of selecting criteria against which to judge the success or otherwise of the service and from whose perspective. Second, it became increasingly evident that the experiences of women with long-term mental health problems could not be divorced from the wider social and political context in which they are situated. This issue is eloquently discussed by Prior (1993) in his book which analyses changing definitions of mental illness and the way in which they have been reflected in the organization of health care,

> "....... just as abstract theory requires reference to essential detail, so the study of personal biography and social worlds requires cognizance of larger conceptual and ideational contexts. Such personal detail cannot be fully understood by restricting oneself to the immediate empirical contexts of action in which patients commonly find themselves......Personal biography is forever related to aspects of big structural arrangements and cultural systems, such that we cannot begin to comprehend the one without the other. Consequently, and in order to look at the larger contexts in which mental illness in organized, we have to look beyond the limits of time bound interactions" (Prior 1993, p3)

This thesis therefore stems from a growing interest in how gender is reflected in mental health policy and how the implementation of those policies affects mental health services for women. The overall aims of the thesis are:

- To explore the experiences of women with long-term mental health problems who are receiving care and support within the RCCS in Nottingham. This includes an exploration of their difficulties both within and outside the service, and the identification of good and poor examples of service delivery.

- To contribute to existing knowledge by seeking to understand the way in which the organization and delivery of mental health services impact on the lives of women with long-term mental health problems.

- To produce findings which can be used to inform both mental health policy and practice.

The thesis is grounded in data collected within an evaluative research framework and developed within a mental health policy theoretical framework. The thesis is structured as follows.

Chapter one provides the theoretical context within which this thesis is located. The chapter is divided into four sections. The first section presents an historical account of the way in which services for people with mental health problems have moved from long-stay psychiatric hospitals to care in the community. This account provides the necessary background for understanding the structure and organization of services currently received by people with long-term mental health problems. The account draws on both historical texts and the developments within mental health policy. This evolutionary account of developments in mental health service provision with its emphasis on progress is critically appraised in section two. This critique provides a background from which to argue that, despite the illusion of progress and the increasing emphasis on user involvement and empowerment, mental health policy and services remain a powerful means of regulating and maintaining social order. There are difficulties however with slavishly adhering to one theoretical framework in this context as much recent mental health policy is contradictory which creates difficulties and tensions not only for people with mental health problems but also for the staff caring for them. The third section therefore provides a brief review of the tensions with reference to recent literature which is beginning to explore this issue. The final section explores how gender is reflected in mental health policy. Specifically, by drawing on mainly feminist literature, an attempt is made towards an understanding of women's gendered experiences within mental health services.

Chapter two reviews the specific literature on women with long-term mental health problems. The chapter begins with an overview of the current position regarding the definition and categorization of people with long-term mental health problems. Subsequent sections focus on the differences between men and women with long-term mental health problems, the particular problems faced by these women, and the needs of different group of women. Much of the existing research in this area rests within the broad field of social psychiatry with a bias towards quantitative methodologies. Important contributions have been made however from social scientists and anthropologists using a range of qualitative methodologies and this research has enhanced current understanding about the experiences of living with mental health problems from the clients' perspective.

The third chapter presents the issues which influenced and informed the decision to develop this investigation within an evaluation research framework. It begins with a review of the current debates in the broad evaluative research literature together with an overview of the main theoretical approaches to evaluation. This is followed by a more focused review of evaluative research within the field of mental health care which focuses primarily on the methodological developments to date. The issues raised are then used as a base from which to argue that a pluralistic model of evaluation is the most suitable for this investigation. This argument consists of a defense of a pluralistic model set against an appreciation of other evaluation models.

Chapter four provides a detailed description of the RCCS in Nottingham as the setting for the fieldwork. The chapter also discusses the way in which a pluralistic model of evaluation was used to inform the design of the investigation. Particular emphasis is placed on the complexity of identifying suitable evaluation criteria to inform the series of studies which make up this evaluation. The chapter concludes with a discussion of how access was gained to the research setting and the ethical considerations that were made.

The six studies which make up the evaluation are presented in chapters five to nine. Although each of the studies were designed to explore the impact of mental health policy and the organization and delivery of services on the lives of women with long-term mental health problems within the RCCS, from a range of perspectives, using a variety of data collection methods, each study has a similar structure. They begin with the aims of the particular study, followed by the design, method and findings. They conclude with a discussion of the key findings, and a consideration of the strengths and limitations of the design and methods used.

Chapter ten addresses the overall aims of this thesis and discusses why and in what way current knowledge about the experiences of women with long-term mental health problems is now different as a result of this research. This is achieved in a number of ways. First, the findings of the six studies presented in chapters five to nine are drawn upon as evidence for judging the success or otherwise of the RCCS in meeting the needs of women with long-term mental health problems. This judgement is set against the evaluation criteria identified in chapter four. Second, the current predicament of women with long-term mental health problems is conceptualized by drawing on a range of theoretical perspectives discussed in chapters one and two. Third, the implications of the findings upon policy and practice are considered and a number of recommendations are made. The chapter concludes with some final comments on methodology and suggestions are made for further research.

Chapter One

Background and Theoretical Context

1.1 Introduction

This chapter provides the theoretical context within which this thesis is located. As such it aims to provide the necessary background for understanding the structure and organization of services currently received by people with long-term mental health problems. Theoretically mental health policy and its impact on the structure and organization of services can be approached in a number of ways. For the purpose of this chapter it is argued that these approaches can usefully be explored in the following way. First, it can be argued that mental health policy can be characterized by evolution and progress. Sumathipala and Hanwella (1996) for example, propose a spiral model of evolution of psychiatric care. Drawing on historical developments in mental health policy, they argue that psychiatric care has taken a spiral course of evolution from institutional to community care. This move has been accompanied by progress towards an improvement in the quality of care provided for people with mental health problems. Second, it can also be argued that conversely, mental health policy can be characterized by lack of progress and as a means of perpetuating significant continuities (McCourt Perring 1993, p29).

The first section of this chapter reviews the evidence which supports the argument that mental health policy is characterized by evolution and progress. This will be achieved by presenting an historical account of the way in which services for people with mental health problems have moved from psychiatric hospitals to care in the community, and by highlighting the increasing pressure towards viewing the recipients of mental health services as people rather than patients. The second section critically appraises the notion of evolution and progress by conversely arguing that mental health policy and services contribute to the regulation and maintenance of social order. The conflicting arguments which have been presented are considered in section three where it is argued that much mental health policy is contradictory which creates difficulties and tensions not only for people with mental health problems but also for the staff caring for them. The final section explores how mental health policy is gendered. Specifically, by drawing on feminist literature an attempt is made towards an understanding of women's gendered experiences within mental health services.

1.2 Mental health policy as evolutionary and progressive

There are a number of authoritative and frequently cited texts which have comprehensively traced the move from hospital to community-based care for people with mental health problems (c.f. Busfield 1986, Murphy 1991, Jones 1993, Rogers and Pilgrim 1996, Barham 1997). Consequently there is little mileage in simply summarizing what has been previously described. Instead this section will provide an overview of the key developments in mental health policy over the last fifty years and the impact that these have had on the structure and organization of mental health care. This overview ends in 1996 as the fieldwork for this thesis was completed towards the end of that year. The policy developments from 1996 to the present are briefly reviewed in chapter 10, section 10.4.

Throughout the first half of the twentieth century in Great Britain the number of beds in large psychiatric hospitals continued to rise and peaked at around 150,000 in 1955, after which the numbers started on a downward spiral so that by 1992 this figure was reduced to 50,000 (Rogers and Pilgrim 1996, p66). Cotterill (1994, p5) argues that this shift from hospital to community care was not the product of a clear coherent strategy, but rather the outcome of a number of influences resulting in a complex array of legislation, White Papers and official reports. The origins of the move towards community care are difficult to pinpoint precisely, however much of the impetus for change arose in the 1950's in Great Britain. A number of different explanations have been offered which will be considered in turn. These include the commonly termed pharmacological revolution, the fiscal crisis theory, changes in ideology, and policy developments.

The pharmacological revolution is the most frequently cited explanation given for the beginnings of the move towards community care (c.f. Jones 1993, Turner 1997a). This explanation suggests that the move towards community care was made possible because of the development of neuroleptic drugs and their introduction in 1954. These drugs were widely prescribed to relieve the more distressing symptoms of mental illness and their use enabled some patients to be discharged earlier or not to be admitted at all. The introduction of neuroleptic drugs created much optimism amongst psychiatrists and only gradually was it realized that whilst these drugs alleviated symptoms, they did not cure or deal with the cause of mental illness. There is now a well established critique of the pharmacological revolution explanation. For example, it is argued that there is no evidence of a causal link between the introduction of neuroleptics and the fall in the numbers of patients in psychiatric hospitals. An increased pattern of discharges had occurred prior to the widespread use of these drugs and the pattern of the fall remained consistent with that preceding their use (Murphy 1991, p49; Rogers and Pilgrim 1996, p67; Barham 1997, p4; Pilgrim and Rogers 1997, p127).

A second explanation for the gradual run down of hospital-based psychiatric care from the 1950's is that provided by Scull (1977). Working within a Marxist framework, Scull developed what is commonly termed as his 'fiscal crisis of the state' explanation. He argued that the cost of institutional care became too great for the welfare system to accommodate within a capitalist economy. He identified that the cost of institutional care had spiralled prior to and after the second world war by the elimination of unpaid patient labour and the increasing cost of employees as a result of the unionization of labour. Hence he argues that the development of community based systems of care provided a relatively cheap alternative. This explanation has been criticized mainly on the grounds of timing. Busfield (1986) for example, points out that the State's fiscal crisis actually characterized the post 1970's era rather than the 1950's. Moreover she argues that spending on hospital services actually increased during this period. Busfield's argument is reinforced by Pilgrim and Rogers (1996, p67) who point out that by 1956, two years after the introduction of neuroleptics and at a point when Scull claimed fiscal constraints applied, there were 2,000 more psychiatric beds in use than 1952.

Rogers and Pilgrim (1996, p68) suggest that gradual changes in the ideology underpinning the nature of care provided for people with mental health problems also provided an impetus towards community care. For example, they argue that there were growing societal and professional concerns during this period about a mental health policy being centered on the old asylum system, and that there were pressures and sincere aspirations to improve the care of people with mental health problems. Such a shift in ideology is also highlighted by Jones (1993, p152). She argues that barriers between psychiatric hospitals and the outside world were beginning to crumble prior to the 1950's. She attributes this to the gradual move towards an open-door policy in psychiatric wards over the twentieth century, the increasing number of day hospitals and industrial therapy units where patients could work for a small wage instead of working to maintain the hospital. In addition she suggests that the influence of the therapeutic community movement pioneered by Maxwell Jones led to a general move for services to review their rules and regulations and to introduce more flexible and relaxed programmes of care.

Finally, the 1950's marked the beginning of a plethora of published mental health reports, inquiries, legislation and policy guidance which continue to this day. The key theme running through much of this work was the closure of the old long-stay psychiatric hospitals and their replacement by care in community settings. The impetus for this legal revolution, as described by Jones (1993), must have been influenced by the developments previously discussed. It was also arguably timely as there had been no major review of mental health legislation since the Lunacy Act of 1890 which was still in force. Jones (1993) argues that the legal revolution began with the appointment of the Royal Commission on Mental Illness and Mental Deficiency who met from 1954 to 1957. Their conclusions, published in the Percy Report (1957), involved a total repudiation of the principles of the Lunacy Act of 1890, and recommended a shift in emphasis away from institutional care to a range of facilities in the community. Many of the recommendations were implemented in the Mental Health Act (1959) which repealed all existing mental health legislation. This Act set up the Mental Health Review Tribunals, redefined mental disorder as mental illness, and removed the barriers which isolated mental health services from other health and social services. People could now be admitted to psychiatric hospitals on the same informal basis that accompanied admissions to general hospitals to facilitate a reduction in stigma and to encourage early treatment. In addition the Act emphasized the need to provide alternatives to hospital treatment, clarifying the duties of local authorities to provide a wide range of care and after-care to people with mental health problems.

During the early 1960's the move from hospital to community based care for people with mental health problems was championed by Enoch Powell, the Minister of Health from 1960-1963. Murphy (1991, p58) suggests that his particular interest was not only influenced by the government statistics of the time which showed a downward trend in the number of occupied psychiatric beds. It was also fuelled by the fact that he had witnessed for himself the overcrowded and poor conditions in some hospitals, and had noted the determination of some psychiatrists to create a caring environment outside the confines of the hospital. His vision for the future direction of mental health care was outlined in his now famous and much quoted 'water tower' speech to the National Association of Mental Health in 1961. A year later he launched the official hospital closure programme which was set out in the Hospital Plan (Ministry of Health 1962).

Cotterill (1994) suggests that the Hospital Plan (Ministry of Health 1962) was based on an assumption that none of the 110,000 long-stay psychiatric patients who were in hospital in 1960, would be there in 1975. It was thought by then, they would have died out or been discharged. Furthermore, it was thought that there would be no new long-stay patients to take their place because of the new methods of treatment and changing societal attitudes towards mental illness. According to the Hospital Plan (Ministry of Health 1962), the following fifteen years were to see psychiatric hospital beds reduced by half from 3.4 beds to 1.8 beds per 1000 population (Jones 1993, p181). It was proposed that hospital care would be concentrated in new District General Hospitals which would provide acute treatment in all medical specialties including psychiatry. People with long-term mental health problems would only enter hospital for short periods for diagnosis and assessment, as their continuing care would be provided by community-based services. A further government announcement in 1963 (Ministry of Health 1963) exhorted local authorities to make plans for community care services. No clear direction was given about what kind of provision was required although the emphasis was on local authority provision rather than the involvement of relatives or the voluntary sector (Cotterill 1994).

A number of texts which have analyzed this period of change argue that the government's determination to close psychiatric hospitals received unexpected support from social critics and dissident clinicians who attacked the dehumanization of institutional psychiatry (c.f. Busfield 1986, p326; Jones 1993, p164-178; Rogers and Pilgrim 1996, p72; Pilgrim and Rogers 1997, p121-124). These critiques include Barton (1959), Goffman (1961), Laing (1967), Cooper (1968) and Szasz (1971) amongst others. Although the focus of these critiques are very different from one another, together they illuminated the disadvantaged position of psychiatric patients and the powerful positions of those in control of their lives - the state, psychiatrists and other mental health professionals such as nurses.

In addition to these academic critiques, public and professional concern was further fuelled in the late 1960's and early 1970's by a series of official inquiries into the neglect and mistreatment of people with mental health problems and learning disabilities in hospitals around the country. These included an inquiry into allegations of cruelty and neglect of patients in seven hospitals, mainly for people with learning disabilities (Robb 1967); an inquiry at Ely hospital in Cardiff where allegations of ill treatment and poor standards of care were supported (Department of Health and Social Security 1969); and inquiries at Farleigh (Department of Health and Social Security 1971) and Wittingham hospitals (Department of Health and Social Security 1972). The lessons of these inquiries are reviewed by Martin (1985), who argues that they were an indictment of the long-stay hospitals. He illustrated this by highlighting that hospitals and ward staff often operated in isolation with little supervision; patients were dependent, vulnerable and had little opportunity to complain; professional leadership and management were frequently incompetent; resources were insufficient, with wards severely understaffed; and finally the cruelty and weakness of individual staff played a part.

Whilst it has been argued that the rhetoric of community care was strongly present during the 1960's (Rogers and Pilgrim 1996, p71), and that the focus of attention was kept firmly on the negative effects of living in large institutions (Cotterill 1994), no long-stay psychiatric hospital closed for many years. Indeed this period has been associated with a significant reorientation of services away from the long-stay patients towards those with less serious, shorter term problems (Busfield 1986, p329; Murphy 1991, p60). Rogers and Pilgrim (1996, p70) for example, question Powell's commitment to community care because of his emphasis on the short term role of the district general hospital units and the lack of direction provided for the setting up of community-based facilities for those people with long-term needs in order to provide a real alternative to the back wards of psychiatric hospitals.

By the early 1970's it became increasingly apparent that the run-down and closure of the psychiatric hospitals would not be achieved in the relatively short time scale predicted by the Hospital Plan (Ministry of Health 1962). Cotterill (1994) argues that this was primarily because of the erroneous assumption that the introduction of neuroleptic medication in 1954 would transform the course of illnesses such as schizophrenia. It had been anticipated for example, that these drugs, in addition to other psychiatric treatments such as electro-convulsive therapy, would facilitate the discharge of the old long-stay patients and enable newly diagnosed patients to be treated with short-term admissions in the new District General Hospitals. It became evident however that the needs and problems of people with long-term mental health problems whether or not they had been hospitalized for many years were quite distinct from those with short-term, more transient problems. Furthermore if the hospital closure programme was to continue, the needs of the long-term client group would have to be met by a more systematic approach to developing community care.

In 1975 the White Paper, Better Services for the Mentally Ill (Department of Health and Social Security 1975), was issued when Barbara Castle was Secretary for State for Social Services in the Labour government. The White Paper outlined the necessary conditions for comprehensive community care services for the mentally ill. The main strategy was expansion of local authority personal social services, including residential, domiciliary, day care and social work support; these to be locally based, with good links between different aspects of the service and with a multi professional approach to planning of care. The White Paper however was not overly optimistic about the progress that could be made in the near future. Busfield (1986, p348) for example, highlights that the White Paper clearly identified the limitations of the achievements to date, and that the scope for making progress would be limited in the next few years because of financial constraints. The White Paper however did make an attempt to appease public and professional anxieties by asserting that mental hospitals would not be closed down before community facilities had been provided.

Both Busfield (1986, p350-351) and Rogers and Pilgrim (1996, p74-75) argue that the prospect of developing a well resourced community service for people with long-term mental health problems in the mid to late 1970's was not good; primarily because of the difficulties affecting Western capitalism in the wake of the oil crisis. Britain, under a Labour government, was obliged to go to the International Monetary Fund and ask for financial help. The International Monetary Fund did offer a rescue package but with certain strings attached. One of these was a commitment to reduce public spending. Reduction in spending would be achieved by closing the psychiatric hospitals but not by adequately resourcing community care. Indeed Busfield (1986, p351) argues that there was a belief that costs could and should be cut in the move to community care, moreover that the very purpose of introducing community care was to cut costs.

The mental health policy developments which occurred in the 1980's can best be understood by reflecting back on the developments of the previous decade, and acknowledging the changing political climate. Busfield (1986, p351) for example, argues that the economic constraints of the 1970's had resulted in uneven funding for mental health services, with services for people with acute, less severe mental health problems being less threatened by financial pressures that those for people with long-term mental health problems. As a result a two-tier stratified mental health service was developing; a first rate service for those with acute and more easily treatable problems, and a second rate service for the remainder. The drawing of resources away from clients with long-term mental health problems during this period has also been well documented in a study by Patmore and Weaver (1991).

The new Conservative government elected in 1979 brought about far reaching public sector changes in the 1980's and early 1990's which were to impact heavily on the delivery of mental health services. Rogers and Pilgrim (1996, p77) argue that before 1979 there was a welfare state, whereas after a decade of Conservative governments there was a mixed economy of welfare which contained a blend of public, private and voluntary services. Although none of the large psychiatric hospitals had closed by the early 1980's there remained a consensus about the humanitarian benefits of deinstitutionalisation. This, together with financial considerations pushed the momentum for the closure of the mental hospitals.

The first major piece of mental health legislation produced by the Conservative government was the revised Mental Health Act (1983). Much of the Act was concerned with the legal safeguards surrounding compulsory admission and detention in hospitals in response to evidence of misuses and abuses of various sections of the 1959 Mental Health Act. As a result the rights of appeal of people who were compulsorily admitted or detained were improved with more frequent recourse to Mental Health Review Tribunals, and the Act required that Approved Social Workers should be provided for duties involving compulsory admission. Prior to the Mental Health Act 1983 there was no statutory provision for aftercare of patients discharged from psychiatric hospitals (Wilkinson and Richards 1995). Section 117 of the Act introduced and defined formal aftercare. Although the revised Mental Health Act (1983) did address some of the weaknesses of the previous Mental Health Act (1959), it has been criticized for its lack of direction concerning service improvements (c.f. Busfield 1986, p352; Cotterill 1994, p12; p352; Rogers and Pilgrim 1996, p89). Busfield (1986, p352) summarizes the general criticisms by highlighting that the Mental Health Act (1983) did not require either local authorities or the NHS to make any improvements in services, nor did it make any alterations in the financial provisions which might facilitate such improvements. Furthermore she argues that there was a clear sense that anything with cost implications had been avoided.

From the mid 1980's onwards the Conservative government issued a plethora of government policy and legislation that affected the care of people with mental health problems. These were issued against a backdrop of an accelerating shift in the patterns of health care with the closure of the majority of psychiatric hospitals and the transfer of large numbers of people with mental health problems into the community. Davies and Peck (1994) suggest that the policy and legislative changes which occurred during this period fall into two distinct categories. First, there was that which related to the delivery of general health and social services, of which mental health care formed only a part. These reforms led to dramatic changes in the delivery of mental health care as a consequence of the implementation of legislation not specifically designed to deal with mental health services. Second and simultaneously, the government developed policy and circulated guidance aimed explicitly at mental health services. These two categories of policy and legislation will be considered in turn.

The most important legislation that affected general health and social services delivery was the NHS and Community Care Act (Department of Health 1990a). This Act was the government's response to a series of reports and White Papers produced in the late 1980's. The first of these key and influential Reports was that produced by the Audit Commission in 1986 called 'Making a Reality of Community Care' (Audit Commission 1986). The report severely criticized the existing community care services and highlighted that care in the community was far from a reality in most areas. The following problems were identified: a mismatch of resources to meet the requirements of community policies; the need for short-term bridging finance to further transition to community care; social security policies provided a perverse incentive for residential as opposed to domiciliary care; there were inadequate arrangements for training and providing opportunities in community services for existing staff in long-stay hospitals, and for training sufficient numbers of community-based staff; finally there was fragmented organization, and lack of effective joint working and planning between the different agencies involved in the provision of services.

As a direct result of the Audit Commission's criticisms, the government invited Sir Roy Griffiths to undertake a review of community care policy. The subsequent Report (Griffiths 1988) was perceived as more radical than the Audit Commission Report (Audit Commission 1986) although many of the recommendations were derived from the Audit Commission's findings translated into practical proposals (Murphy 1991, p126). The Griffiths Report (Griffiths 1988) outlined the principles needed for the success of future community policy. These included the need for appropriate services to be provided in good time to people who require them most; the principle that people receiving help will have greater choice and say in what is being done to assist them; that help should be directed at allowing people to stay in their own homes for as long as possible, with nursing home and hospital care being reserved for those whose needs cannot be met in any other way.

The majority of the recommendations made in the Griffiths Report (Griffiths 1988) were embodied in the 1989 White Paper 'Caring for People' (Department of Health 1989a). The recommendations of 'Caring for People' (Department of Health 1989a), together with proposed changes to the health service outlined in the White Paper 'Working for Patients' (Department of Health 1989b), were subsequently translated into the 1990 NHS and Community Care Act (Department of Health 1990a). The NHS and Community Care Act (Department of Health 1990a) implemented measures to establish NHS trusts and fund-holding general practices. The Act also involved local authorities taking the lead in community care; a duty of individual needs assessment and care management to deliver packages of care which would enable people to live at home; Community Care Plans to be drawn up in consultation with local people, either separately or in conjunction with health authorities; the separation of purchaser and provider roles in both health care and social services so that mental health services could be purchased by health authorities and social services departments on a population basis, and by GP fund-holders and care managers on an individual basis; and the retention of responsibility of community health services by the National Health Service. The changes to the structure and organization of the National Health Service were introduced immediately in 1990. Most of the community care sections of the Act however, were delayed in their implementation until April 1993.

Rogers and Pilgrim (1996, p91) argue that the NHS and Community Care Act (Department of Health 1990a) was financially driven and very much reflected the ideology of the Conservative government. For example local authorities were not given the bulk of the budgets for mental health services, which remained within the National Health Service, but they were given the responsibility for co-ordinating community care. Thus local authorities became responsible when services were inadequate, but they were not the main budget holders. In other words blame but not power or resources had been allotted to them by central government. Furthermore the Act encouraged further privatization with the directive that a large proportion of the allocated budget for community care should be spent within the private and voluntary sectors.

Despite the radical implications of the NHS and Community Care Act (Department of Health 1990a), a number of potential problems with the legislation began to emerge. These problems have been widely debated (c.f. Davies and Peck 1994, Thornicroft 1994, Rogers and Pilgrim 1996), but the key issues of relevance to people with mental health problems can be summarized as follows. First, the community care budgets were cash limited. This meant that local authorities often found it difficult to meet the needs of clients once they had been assessed. Second, the shift from expensive hospital care to cheaper alternatives in the community were disguised as de-medicalisation and client empowerment. Third, there were concerns that it may prove difficult to move beyond the rhetoric of user involvement and empowerment. Fourth, that the goal of seamless service delivery may prove difficult with the split between health, local authority and social security agencies. Finally, it has been argued that this Act failed to acknowledge that the quality of life of people with long-term mental health problems in the community is not solely dependent on adequate mental health services but is also dependent on an increasing emphasis on employment opportunities, access to suitable housing and addressing the problems of stigma and discrimination.

Alongside the reforms outlined in the NHS and Community Care Act (Department of Health 1990a) which related to the delivery of general health and social services, the government developed policy and circulated guidance which were aimed explicitly at mental health services. As has been highlighted so far, many of the policy developments which have occurred since the 1950's have reflected a general belief in the potential benefits of community care for people with mental health problems. Muijen (1996) argues however, that from the mid 1980's onwards there were increasing concerns raised in public, professional and political arenas about the mounting evidence that community care was failing to provide adequately for clients with serious and long-term mental health problems. Subsequent policy developments therefore reflect these concerns and emphasize not only the need to protect vulnerable clients, but also to protect the public. From this period onwards the emphasis of mental health policy was very much focused on clients with serious long-term mental health problems.

These concerns were fuelled by a number of dramatic failures of community care to provide adequately for clients with mental health problems. For example the case of Sharon Campbell, a former in-patient, who killed her former social worker Isabel Schwarz at Bexley Hospital in July 1984; and the killing of Jonathon Zito in December 1992 by Christopher Clunis. The subsequent inquiries and reports (c.f. Spokes et al 1988, Ritchie et al 1994) identified a catalogue of deficiencies in the way that these patients had been cared for in the community. These included a lack of communication between the responsible service providers; poorly resourced facilities (from secure psychiatric beds to supported housing); a tendency to attach too little significance to the risk of dangerous behaviour; an over-reliance on medication, and the absence of personal and social support for the patients and their families.

The recommendations of the Spokes Report (Spokes et al 1988) were subsequently enshrined in the Care Programme Approach. The Care Programme Approach (Department of Health 1990b) was introduced in 1991 to provide a framework for effective and comprehensive care for vulnerable psychiatric patients outside hospital. It required that district health authorities, in collaboration with local authority social services departments, put in place specified arrangements for the care and treatment of mentally ill people in the community. The Care Programme Approach consists of four main elements: systematic arrangements for assessing the health and social needs of people accepted by specialist psychiatric services; a care plan which addresses the identified health and social care needs of the patient; an appointed key worker who must keep in close touch with the patient and monitor care; and finally the care provided must be regularly reviewed and changed if required. The first Circular introducing the Care Programme Approach (c.f. Department of Health 1990b) stated that it should apply to all in-patients considered for discharge, and all new patients accepted by the specialist psychiatric services from April 1991. However, the second edition of the Health of the Nation Key Area Handbook on Mental Illness (Department of Health 1994a) made it clear that the Care Programme Approach should apply to all mentally ill patients aged 16 or over who are accepted by the specialist psychiatric services, including those who have received care continuously since before 1991 but who have not required hospital admission during the intervening period. This was to ensure that all patients are assessed and that no-one who might be vulnerable is missed. The Care Programme Approach also applies to mentally disordered offenders, and all patients who have been detained under the 1983 Mental Health Act.

The introduction of the Care Programme Approach was followed in 1993 by further government proposals to reinforce and strengthen community care for people with serious long-term mental health problems. These proposals outlined in the Ten Point Plan (Department of Health 1993a) included issuing new guidance on the discharge of patients from hospital and their continuing care in the community; the establishment of supervision registers; and the introduction, subject to Parliamentary approval, of a new power of supervised discharge. Supervision registers were introduced in May 1994 (Department of Health 1994b); the guidance on discharge was published in May 1994 (Department of Health 1994c); and finally in April 1996, the new legislation on supervised discharge, the Mental Health (Patients in the Community) Act (Department of Health 1995a), came into affect. Finally, the report Building Bridges (Department of Health 1995b) was published as a guide for mental health professionals, provider managers and purchasers to promote close and effective inter-agency working to ensure the delivery of well co-ordinated care for people with serious long-term mental health problems. As well as reviewing the working of the Care Programme Approach and supervision registers, the report clearly identified the principles of inter-agency working, the roles of agencies involved in caring for people with mental health problems, and made recommendations for the continuing education and training of key workers.

It is important to note however, that the introduction of the Care Programme Approach (Department of Health 1990b) and the recommendations in the Ten Point Plan (Department of Health 1993a) and Building Bridges (Department of Health 1995b) should not be seen as isolated initiatives to combat growing concerns about the implementation of community care policy but should be viewed alongside other policy developments occurring at the time, notably the publication of the White Paper, The Health of the Nation (Department of Health 1992).

The Health of the Nation (Department of Health 1992) set out a national framework for achieving health gains in five selected priority areas, one being mental health. The Mental Health Key Area Handbook published a year later identified three targets (Department of Health 1993b). These were to improve significantly the health and social functioning of mentally ill people; to reduce the overall suicide rate by at least 15% by the year 2000 from 1990 levels of 11 per 100,000; and to reduce the lifetime suicide rate of severely mentally ill people by at least 33% by the year 2000. Its key strategic approach included the development of comprehensive local services. This was to be achieved via the Mental Health Task Force who were set up to help ensure the completion of the transfer of services away from the large old psychiatric hospitals to a balanced range of comprehensive locally based services. In addition the handbook acknowledged that the key to achieving its targets was the successful implementation of the Care Programme Approach. In a review of the Mental Health Key Area Handbook (Department of Health 1993b), Jenkins (1994) argues that this is the first comprehensive document on mental illness for health and social service managers since 1975, and that its strength lies in its detailed guidance on the range of services they should be providing for mentally ill people.

This account of progress and change in the delivery of mental health care fits in well with Sumathipala and Hanwella's (1996) spiral model of evolution. Despite a growing list of the inadequacies of community care in meeting the needs of people with long-term mental health problems (c.f. Audit Commission 1986, Spokes et al 1988, Ritchie et al 1994, Mental Health Foundation 1994, Audit Commission 1994), the last fifty years has seen an accelerated shift from medically dominated hospital care towards care provided by a range of agencies in community-based settings. Such progress has been accompanied by the slow but growing movement towards reconceptualizing recipients of mental health services as people with rights and a voice.

The philosophy of normalisation for example, has been very influential in underlining the rights of people with mental health problems to make choices on their own behalf and also to receive services sensitively tailored to their needs (Wistow and Barnes 1993). The philosophy was initially applied in the British setting to provide a framework of values and principles which would underpin services for people with learning disabilities. However, it has since been generalized to other client groups such as people with mental health problems and its influence was strongly reflected in the White Paper 'Caring for People' (Department of Health 1989a). At the core of this philosophy is an emphasis on the rights of people with health and social care needs to live a life as close to normal as possible; that is to participate in socially valued lifestyles which maximize opportunities for choice, self realization and independence. In stressing the importance of gaining access to ordinary life styles, normalisation implies an increasing role for mainstream services such as housing, leisure, education and employment. The rights of people with long-term mental health problems were again strongly emphasized in the report 'Creating Community Care' (Mental Health Foundation 1994). The rights highlighted included an appropriate place to live, an adequate income, a varied social life, employment and other day activities, help and support, respect and trust, and choice and consultation.

The importance of acknowledging the views of people with mental health problems has also gained momentum over the last ten to fifteen years with the growth of the user/survivor movement which has enabled many to speak out about the short-comings of mental health services. The user/survivor movement is characterized by a large number of diverse groups. Most of the groups are involved in grass root initiatives although there is growing evidence that as the movement becomes more organized it is becoming increasingly influential at policy making levels (Cohen 1998). Alongside this movement an increasing number of government initiatives have identified the role that service users should have in shaping the services they receive (c.f. Griffiths 1988, Department of Health 1990a; 1991). There is now frequently user representation at Health Board and NHS Trust levels as well as involvement in local services and advocacy of individual patient views. The growing presence of the user perspective is evident from the proliferating literature. For example, studies which allow user accounts to 'speak for themselves' (c.f. Shields 1990, Rogers et al 1993); a large body of literature emerging from users themselves (c.f. Pembroke 1991, Cresswell 1993); and finally studies which have involved users in reviewing mental health services (c.f. Hamilton and Farebrother 1995, Williams 1995).

1.3 Mental health policy as a means of perpetuating continuities

The previous section put forward evidence to support the argument that the provision of mental health care for people with long-term mental health problems has changed considerably over the last fifty years. It was also argued that the nature of the care delivered has also improved with the move towards acknowledging that people with mental health problems have certain rights and that they have a useful part to play in the planning and organization of services which meet their needs. This evolutionary account is critiqued in this section. This critique provides a background against which to argue that, despite the illusion of progress and the increasing emphasis on user involvement and acknowledging rights, mental health policy and the subsequent organization of services remain a powerful means of regulating and maintaining social order.

The term social control as a mechanism for regulating and maintaining social order is a difficult concept to define. Morrall (1998) attempts to do this with a broad definition in which he argues that,

> "Political, legal, religious, educational and medical institutions all play a part in maintaining the stability of a given society. Threats to society, or to those groups that have an interest in sustaining the social system (the wealthy and/or powerful), are curbed by these institutions. For example, criminals are jailed, and the mad are incarcerated or supervised in the community. Social systems are liable to, and capable of, much adaptation to internal and external pressures. However, the fabric of a given society is intrinsically durable, and is only at risk of disintegration at times of momentous upheaval, such as civil war, famine or economic collapse" (Morrall 1998, p3)

Although this definition is a good starting point, it leaves a number of questions unanswered. For example, why are people with mental health problems perceived to be a threat to society, and what roles do society, policy makers and professionals take in controlling such people ? These questions are best understood with reference to key theoretical approaches which have been developed to explore this complex issue, for example the work of Durkheim (1964), Navarro (1976), Scull (1977), and Foucault (1965). Although each of these approaches view the issues from different perspectives, they share the view that mental health services contribute to the regulation and maintenance of social order.

Recurring themes in Durkheim's work include the foundations of social order, the maintenance of social equilibrium, and deviance. He viewed modern society as a fragile affair, a potentially unstable mix of elements that was always on the verge of dissolving into chaos (Gane 1988). The situation of people with long-term mental health problems can be best understood from this perspective by drawing on the theory of deviance outlined by Durkheim in the 'Rules of the Sociological Method' (Durkheim 1964). Although Durkeim focuses on crime, useful parallels can be drawn between this and mental illness. Durkheim challenged the conventional idea that crime is a symptom of social malfunctioning and incipient disorder. On the contrary he argues that crime is an integral part of all healthy societies. Its effect is to strengthen collective sentiments in the law-abiding majority. The acts of the wrongdoer serve to solidify and strengthen the collective consciousness. Lee and Newby (1984) argue that from this perspective, deviance promotes social integration by defining the boundaries of acceptable conduct; by highlighting weak spots in the social order which can then become the concern of law enforcement agencies; and finally it cements a sense of identification with the culture among members of conventional society. By substituting mental illness for crime and mental health policy and services for law enforcement agencies it can be seen how Durkheim's theory could be used towards an understanding of the control and regulation of people with mental health problems. Finally Pilgrim and Rogers (1997) and Morrall (1998) draw on Durkheim's theory of social forces to explain the position of mental health professionals in the control and regulation of people with mental health problems. They suggest that Durkheim viewed health professionals as an impartial and cohesive social force which counterbalanced the tendency of egotistical individuals (i.e. people with mental health problems) to fragment society. Professionals contribute to the stability of society by regulating their own practice through codes of conduct and punishing failing colleagues, and by regulating the lives of patients for the benefit of society.

An alternative perspective on the issue of social control is that offered by theorists working within a Marxist framework. Navarro (1976) in his book 'Medicine under Capitalism' for example, argues that health and health care services can only be understood by analyzing contemporary society as a whole, that is a capitalist society characterized by class stratification in which power is concentrated in the hands of the ruling class. Navarro (1976) argues that the nature of health services can be explained in terms of the role they play in sustaining the three major tasks of a capitalist society. These include the production of commodities, the reproduction of the labour force, and the legitimation of the capitalist order. Therefore, according to Navarro (1976), the medical profession does not have independent power, but is itself subject to powerful external forces which guide its activities. The profession is therefore just one part of the apparatus that has been developed by the ruling class to control and constrain individuals who threaten the capitalist order. As a result he argues that medicine has become a source of harm and oppression rather than a vehicle of relief and liberation.

Still within a Marxist framework but notably influenced by Marx's concept of political economy, Scull (1977) and Warner (1985) offer further explanations for the way in which the state controls people with mental health problems. The segregation of the mad and the delegation of powers by the state to doctors to keep madness under control are central to Scull's argument. He explains the rise and maintenance of psychiatry in terms of its functional value for economic order and efficiency under capitalism. Thus he saw psychiatrists as agents of social control employed by the state to contain the threat of one section of the underclass, the mad. Warner (1985) argues that the underlying theme of mental health policy over the past 150 years has been the management and control of what he terms disposable people. He argues that people with schizophrenia form part of what Marx termed the relative surplus population of the unemployed. Furthermore Warner (1985, p137) argues that efforts to rehabilitate and reintegrate the chronically mentally ill will only be seen at times of extreme labour shortages. At other times, the primary emphasis will be one of social control.

The third perspective which has influenced understanding of mental health policy over the last ten to fifteen years particularly, has been the work of Foucault. His first influential book, 'Madness and Civilization', published in English in 1965 (Foucault 1965) investigated the historical relationships between the development of psychiatry, psychology and psychoanalysis on the one hand, and the exclusion of the mad from society on the other. He suggests that the appearance of madness as an object of policy and a field of research and treatment resulted from a combination of circumstances. These included removing the mad from eighteenth century houses of internment. Prior to the nineteenth century, madness was not distinguished from idleness, infirmity, destitution or delinquency as they all represented people who were unwilling or unable to live within the bounds of social order. From the end of the eighteenth century however, the segregation of the mad from the bad and destitute was undertaken for a number of reasons. For example, the mad were seen as disruptive as they undermined the rehabilitation or recovery of others; madness became an important category of medical discourse and an object of psychiatric knowledge; madness became increasingly medicalized; and finally new rules of moral culpability in law divided madness from criminality. The introduction of asylums as a place of retreat and treatment of the mad followed on from these changes. Foucault (1965) argues however that the mad were not segregated on humanitarian or therapeutic grounds and then placed in asylums for treatment. Rather, it was the visibility of madness, the uncontrollability of the mad in the workplace, the difficulty of subjecting the mad to trial by reason, and their subsequent concentration in the asylums that ultimately gave rise to the classifications of mental illness and the range of treatments and therapies.

Throughout 'Madness and Civilization', Foucault (1965) describes the complex interrelationships between legal, economic, political and medical interests in the segregation and classification of madness. All of these interests combined in the organization and control of the mad whilst pursuing different goals such as an efficient workforce, the rationalization of criminal justice and the legitimation of new medical therapies and hierarchies. The system of classification of the mad and the social institutions which maintained them comprise what Foucault (1965) terms a discourse on madness and unreason. Foucault (1965) importantly stresses the continuity of the discourse on unreason or madness. For example, he contests the idea that contemporary approaches to controlling and managing madness are more humane than in the past. Rather, he argues that how madness and unreason are perceived today purely reflect a shift in knowledge about human nature. In other words we are no nearer to understanding the 'truth' about madness than in the past as the 'truth' purely reflects the particular discourses of a given period.

As 'Madness and Civilization' appeared at the time of the anti-psychiatry movement, Foucault's work is often interpreted purely as a contribution to social control theory (Armstrong 1997). In a broad review of Foucault's work however, Turner (1997b) argues that whilst he was obviously interested in the issue of social control, this interest has to be situated in the overriding theme of power which dominated much of his later work. Between his analysis of reason (c.f. Foucault 1965), discipline (c.f. Foucault 1977), and sexuality (c.f. Foucault 1981) he developed three interrelated strands of his theory on power. First, Foucault critiqued the historical accounts of psychiatry, medicine, law and the social sciences which tend to portray their development as a history of growing humanity. Thus contemporary practice is frequently depicted as good and humane in contrast to the barbaric practice of the past. Instead Foucault argues that the more 'enlightened' contemporary approach to deviance, sexual or mental difference purely represents a reorganization in the power-relations that sustain definitions of what is normal, abnormal and how it should be treated. As O'Brien and Penna (1998) suggest, this shift represents a displacement of one type of power which is exclusive (just persons in authority), for one which is general (a large number of officially sanctioned social authorities). The second strand of Foucault's theory on power is the emphasis on peripheral and marginal psychological differences, sexualities and illegalities. Here Foucault argues that an extensive and increasingly penetrating system of monitoring and surveillance, socialization and normalisation has developed on the basis of widespread information both held on people and available to them. The third strand builds on this argument by suggesting that the assessments, judgements and sanctions that surround sexuality, deviance and madness are therefore not the sole province of the state or the capitalist ruling class. Although the state plays a role in enacting legislation and for setting goals for resolving social problems, the system of power described by Foucault are not instituted by coercive state agencies but by a wide range of institutions in society. As O'Brien and Penna (1998) describe, these systems of power are embedded in the behaviour and practices of everyone so that the procedures of regulation and control are experienced as normal features of institutional and everyday life.

In summary, Foucault saw power as something which was localized, dispersed, diffused and frequently disguised. For example, Turner (1997b) seeks to explain Foucault's concept of power by equating it to a colour dye diffused through the entire social structure and embedded in daily practices. Using this analogy, power is therefore embedded in the day to day practices of mental health professionals, and in the practices adopted by society as a whole to exclude those perceived as transgressing the boundaries of normal behaviour. Foucault however, rejects the view that power is an essentially repressive force. Instead power is viewed as productive in that it can produce knowledge and consequently shape and change the prevailing discourses of a given period. He argues for example, that there are always a number of discourses about a given phenomenon or event (e.g. madness) and that the dominant discourse is continually subject to contestation and resistance. Thus power and resistance are two sides of the same coin in that power implicit in one discourse in only apparent from the resistance implicit in another (Burr 1995).

Despite their diversity, the theoretical perspectives discussed in this section have been drawn upon to support the argument that mental health policy and the organization of services, rather than being evolutionary and progressive, can be viewed as a means of perpetuating continuities. That is, they are a means of regulating and maintaining social order through a mechanism commonly referred to as social control. The limitations of the social control thesis as the sole means of understanding contemporary mental health policy is explored in the next section. The work of Foucault however, will be drawn upon again in the discussion presented in chapter ten. Although Foucault excluded gender from his analyses and theories (Mowforth 1999, p43), valuable insights have been gained from researchers drawing on his work in the health field (c.f. Bloor and McIntosh 1990, Busfield 1996, Opie 1997, Peterson and Bunton 1997, Miers 1999).

1.4 Conflicts and contradictions

The previous two sections have presented a set of diverse arguments about the nature of mental health policy. On the one hand there is the view that mental health policy over the last fifty years has become increasingly progressive and enlightened with the move away from incarcerating people with mental health problems towards enabling them to live more 'normal' lives in a range of community-based settings. On the other hand arguments were presented to support the view that mental health policy has in the past, and continues to be, a powerful mechanism for regulating and maintaining social order. In this section however, it argued that contemporary mental health policy is more accurately characterized by a number of conflicts and contradictions. This argument is graphically illustrated by Morrall (1998) when he notes that not only is there little cohesion amongst politicians and leaders of the mental health disciplines about the aims of contemporary mental health policy, but that he frequently observes incongruity and contradictions in his own views. In his words,

> "Sometimes within the same conversation I deliver a diatribe on the need to empower such socially marginalised groups as the mentally disordered, then, lo and behold, I am fervently voicing concern about social order and the need to take seriously the threat of violence from (some of) those people who are perceived as mad" (Morrall 1998, p3)

This section begins therefore by highlighting some of the key conflicts and contradictions which exist in contemporary mental health policy. It is then argued that it is not only mental health services which feel the pressure of such contradictions, but individual mental health clinicians of all disciplines in the course of their daily work.

Ideologically, a consensus has gradually emerged over the past fifty years that community care is desirable for people with mental health problems. It is viewed as a means of removing the problems associated with segregation, improving quality of life, and ensuring the rights of citizenship. Rogers and Pilgrim (1996, p200) argue however that successive governments, whilst expounding the benefits of community care, have failed to provide the necessary support required for the successful implementation of community care policies. This is evident from the failure to offer wider supportive social policies to enable people with mental health problems to achieve the rights of citizenship. A key example is the short sighted housing policy which has promoted the run-down of affordable public and private rented accommodation. People with mental health problems therefore have problems securing reasonable, affordable accommodation and are often housed in inadequate and sub-standard housing in run-down areas (Means and Smith 1998). Much attention has also been placed on the increasing problems of homelessness amongst people with mental health problems. MIND (1991) suggest that people do not become homeless as a direct result of hospital discharge or community care policies, but that it is due to chronic housing shortages that affect disadvantaged groups such as those with mental health problems disproportionately. The importance of adequate housing for people with mental health problems has been emphasized. Conning and Rowland (1991) for example, found that the nature of accommodation provided for people with long-term mental health problems was one of the most important contributors to quality of life. Furthermore people with long-term mental health problems related living conditions as a more important contributor to quality of life that did people without such problems.

A second major contradiction in mental health policy in recent years is about the rights of people with mental health problems. There appears to be a tension between the emphasis on citizenship embodied in the Patient's Charter (Department of Health 1991) and Working for Patients (Department of Health 1989b) and the move towards strengthening community surveillance and control with the introduction of supervision registers (Department of Health 1994b) and the new legislation on supervised discharge, the Mental Health (Patients in the Community) Act (Department of Health 1995a). This contradiction is exacerbated by the apparent lack of clarity about the overall aims of recent mental health policies. On the one hand there is the official rhetoric of empowerment, citizenship and meeting the needs of vulnerable people. On the other hand there appears to be an underlying agenda of controlling and monitoring clients perceived to be dangerous as a means of protecting the public.

The third major contradiction is about the value placed on the views of people with mental health problems at the level of service delivery up to policy making. Again an increasing number of policy initiatives have emphasized the role that service users should have in shaping the services they receive (c.f. Griffiths 1988, Department of Health 1990a; 1991). There is evidence however, that many people with mental health problems continue to be denied a valid viewpoint. Rogers et al (1993) illustrate this by identifying four ways in which people with mental health problems' views are often disregarded. These include the disregarding of users' views that do not coincide with the views of mental health professionals; the notion that people with mental health problems are continually irrational and so incapable of giving a valid view; patients and relatives are assumed to share the same views, and where they do not, the views of the former are disregarded; and finally that patients' views are frequently framed in terms which suit professionals. A Foucauldian analysis might suggest that this situation reflects the dominant psychiatric discourse that 'professionals know best', and professional resistance to user-centered discourse (Opie 1997).

This account has highlighted some of the key conflicts and contradictions which exist in contemporary mental health policy. It is becoming increasingly recognized however, that such contradictions and conflicts not only affect mental health services generally, but impact on the way in which mental health professionals of all disciplines work with their clients (Stainton 1998). In an exploration of this issue, Perkins and Repper (1998) argue that most mental health professionals probably adopt some form of compromise in their practice. For example, while care may be important, few professionals are prepared to adopt a totally paternalistic stance and completely deny the agency and citizenship of those with mental health problems. Likewise while civil rights are important, few would be prepared to hold someone who is extremely distressed and disturbed fully responsible for their behaviour at all times. The responsibilities placed upon mental health professionals by the current framework of mental health legislation however, necessarily lead to day-to-day conflicts between ensuring the rights of the individual client, acceding to their wishes and protecting both the public, and the individual from their actions.

1.5 Women and mental health

The purpose of this section is to highlight the key approaches which have been taken towards understanding women and mental health and their subsequent experiences within the mental health services. The increasing research interest in this area stems from the evidence that overall more women than men are diagnosed as having a mental health problem, and that they are more likely to receive psychiatric treatment. Women are overrepresented amongst those diagnosed as suffering from depression, anxiety, anorexia and deliberate self-harm; whereas men tend to be diagnosed as having schizophrenia, personality disorder and/or an addiction (Verbrugge 1984, Ashton 1991, Miles 1991). As a consequence women represent the majority of patients in most treatment settings (Crimlisk and Welch 1996). Women are more likely than men to be admitted to hospital for psychiatric treatment at some point in their lives, and both first-time and total admissions to psychiatric hospitals are dominated by women (Miles 1988, Payne 1995, 1998). In addition, more women than men are treated by general practitioners and community psychiatric teams for mental health problems (Wooff et al 1986, Miles 1988, Payne 1998).

The theoretical approaches which are commonly drawn upon to explain the greater overall incidence of mental health problems amongst women and their overrepresentation in the psychiatric services fall into three broad categories. These include social causation theories, the so-called 'artefact' theories, and finally the loosely termed social constructionist theories which include the work of feminists and labelling theorists. These will be considered in turn.

The social causation theories are underpinned by the argument that women experience stresses and hardships to a greater extent that do men and are literally 'driven mad' by oppressive social structures (Miles 1993). Although this approach accepts that not all women are worse off in every way than men, it is generally accepted that in most societies men are more highly valued than women and are advantaged materially. The material disadvantages that many women experience have been extensively documented and include their greater poverty; the discrimination they experience in accessing education and employment; and their lack of representation at powerful policy and decision making levels (Carmen et al 1981, Doyal 1995).

The research in this area attempts to draw a link between women's disadvantaged status and their mental health in order to understand how the social context contributes to the origin and persistence of their mental health problems. Many of the studies have focused on the link between the stress of women's lives and the incidence of mental health problems. The two key and much cited studies which have explored this link are the work of Gove (1984) and Brown and Harris (1978). Gove (1984) for example, suggests that the amount and particular type of stress experienced by women results in the higher incidence of mental health problems. He focuses on two aspects of women's societal role in particular. First, he argues that the lack of structure in many women's roles (especially domestic) makes them more vulnerable to mental health problems because they have time to brood on their problems. Second, he argues that the social demands and lack of privacy associated with nurturing roles, such as mothering, may contribute to poor mental health. In a study of depression in London, Brown and Harris (1978) identified three groups of factors which interact with one another to produce depression; namely vulnerability factors, provoking agents, and symptom formation factors. The vulnerability factors included the loss of mother before 11 years of age, the absence of a confiding relationship with a partner, lack of employment outside the home, and having three or more children under 14 years old living at home. Brown and Harris (1978) argued that such factors might make women more susceptible to depression if they additionally experienced a loss or another major negative life event. Provoking agents included loss through bereavement or marriage breakdown, or episodes of serious illness. The occurrence of these events determines when the depression will arise. Finally, symptom formation factors determine the severity and form of depression. For example, Brown and Harris (1978) found that depression was more severe if there was a history of previous mental health problems or if the woman was over 50 year old. A later study by Bebbington et al (1984) which investigated the vulnerability model proposed by Brown and Harris (1978) and developed it further, found that working class women with children seemed particularly prone to develop mental health problems in response to adversity.

More recent research in this field however, has questioned the notion that women experience stresses and hardships more frequently than do men. Kessler and McLeod (1984) for example, argue that men and women do not differ greatly in the number of undesirable life events they experience. Instead some research supports the view that whether or not women face more stressful circumstances they are more vulnerable to them. A number of suggestions have been put forward to account for this possible difference. One is that women have fewer supportive relationships to help them cope with stress (c.f. Berkman and Breslow 1983); another is that women are more vulnerable to events involving someone in their close social network such as their children (c.f. Kessler and McLeod 1984). The increased incidence of depression in women may then be linked to emotional losses coupled with their general lack of supportive relationships.

Despite the developments in this field of research there is a strong critique of its usefulness in explaining the greater incidence of mental health problems amongst women. It has been argued for example, that the epidemiological approach usually adopted often generates a rather static picture with little attention being given to the structural and cultural features of society. Moreover, the methodology of the studies raises a range of problems concerning the adequacy of the measures of different variables (Busfield 1996, Pilgrim and Rogers 1997). Busfield (1996) comprehensively highlights the methodological problems as follows. First, she highlights that the concept of stress is imprecise as the term is used in diverse and contradictory ways . Second, whilst the number of factors which could be stressful for any one individual are infinite, in practice researchers limit the range quite considerably thus incorporating varying assumptions as to what is stressful into their research. Third, much of the research has tended to assume that it is undesirable events or circumstances that are stressful, despite evidence that any change, however desirable is stressful (c.f. Holmes and Rahe 1967). Finally, research in this field tends to assess the presence of mental health problems using established symptom inventories or scales which rely on self-reported psychological distress rather than clinical assessment. This critique forms the basis of the artefact explanation which suggests that epidemiological measurement and its interpretation are faulty.

From the artefact perspective, some or all of the greater incidence of mental health problems amongst women is not 'real' but is created by the design, assumptions and interpretations inherent in the many measures used to assess mental disorder. As many such measures rely on self-reported psychological distress, they may not be identifying a greater incidence of mental health problems amongst women, but rather women's greater propensity to disclose their symptoms. As Pilgrim and Rogers (1997) argue, self reported mental health problems are determined not only by the presence of symptoms but also by the interpretation of the symptoms by the person and their willingness to report them. This process involves a willingness on the part of an individual to view their problems in psychiatric terms and to seek help once a problem has been identified. The greater incidence of mental health problems amongst women could therefore simply reflect the fact that women may be more likely to recognize and label their problems as psychiatric ones than men (Dohrenwend and Dohrenwend 1977). The artefact explanation is strengthened by evidence that women tend to seek help for their perceived mental health problems more than men. For example, Rogers et al (1993) found that more women than men requested counselling for psychological problems, and Williams et al (1986) found women tend to consult general practitioners at all level of stress more than men.

The third explanation for the greater incidence of mental health problems amongst women is that proposed by feminist researchers. Drawing on the foundations provided by labelling theorists and the anti-psychiatry movement, and more recently by insights provided by social constructionist theorists; the feminist critique of psychiatry has focused primarily on the social construction of disease, the uses of psychiatry as social control and the deconstruction of scientific claims to objectivity (Tomes 1994). It is however, as Ussher (1991) points out, very difficult to provide a complete overview of the feminist position on women's madness, as the field is very diverse and rapidly expanding. Instead this account will focus on the key feminist contributions to this field of study.

Early feminist analyses were typically constructed using both the foundations provided by the anti-psychiatrist movement and feminist theory. The anti-psychiatric movement and what came to be known as the social labelling or social control school drew on the work of psychiatrists such as Laing (1967) and Szasz (1971) as well as sociologists such as Goffman (1961) and Scheff (1966). They questioned whether mental illness was in fact a disease at all. In their view, madness was more properly thought of as a form of social deviance. People with mental health problems were simply individuals who transgressed certain basic societal norms. Labelling such people as mentally ill allowed society more easily to remove their disturbing presence from the community. Furthermore, the anti-psychiatrists argued that to justify this process of exclusion, psychiatry provided a medical model of madness which gave psychiatrists considerable power and social rewards. The psychiatric science of diagnosing and treating mental illness they argued, was a thinly disguised form of social control in that a patient's psychiatric history did not reflect the physiological courses of disease but depended on societal needs and values. The anti-psychiatrists' attack on expert authority and scientific objectivity powerfully reinforced and was in turn strengthened by the feminist critique of psychiatry (Tomes 1994). In other words, the anti-psychiatrists' claim that psychiatry served as an institution of social control was added to by the feminist theory of patriarchy. That is, the repressive control of psychiatry was typically exercised by men over women (Busfield 1996). Influential examples of work in this field includes that of

Ehrenreich and English (1974, 1978), Chesler (1972) and, more recently, Showalter (1987).

Ehrenreich and English (1974, 1978) argued that male healers in general, not just psychiatrists, tended to define women's emotional problems and suffering as sickness. Thus male doctors usurped the traditional powers and responsibilities of the female caring/healing role by drawing on "scientific evidence that women's essential nature was not to be a strong, competent help-giver but to be a patient" (Ehrenreich and English 1978, p91). As a patient, women could have no autonomy or power; and if frailty was essentially intertwined with femininity, they could not act independently (Ehrenreich and English 1978, p129). Ussher (1991, p63-97) draws on the work of Ehrenreich and English in her exploration of the rise of the Victorian madwoman. She uses the work to support her argument that the Victorian era marked an important change in the discursive regimes which confined and controlled women, because it was in that period that the close association between femininity and pathology became firmly established within the scientific, literary and popular discourse. Furthermore she argues that it was during the Victorian era that madness became synonymous with womanhood (Ussher 1991, p64). Other writers have argued however, that the links between women and madness began much earlier (c.f. Tonks 1994, Newton 1996). Newton (1996, p105) for example, suggests that it can be traced to at least the mediaeval period when women were accused of witchcraft and sentenced to violent deaths following trials which offered little opportunity for defense. The mismanagement of witches she argues, can be linked to the oppressive treatment of women that developed in the name of madness and psychiatry.

Chesler's (1972) analysis of gender and constructs of mental illness begins by arguing that the way behaviour is defined and interpreted is vital to an understanding of the differences between men and women in patterns and levels of illness. Men, she suggests, are generally less likely to be labelled mentally ill than women, even if they are disturbed. She explains this through her exploration of the links between gender, madness and the departure from normal role expectations. On the one hand, men are liable to be labelled as mentally ill if they reject their masculine role and act in more female ways. On the other hand she argues, that since madness embraces not only "the total or partial rejection of one's sex role stereotype but also the acting out of the devalued female role" (Chesler 1972, p56), woman are doubly disadvantaged. She argues therefore, that women are liable to be identified as mentally ill if they either deviate from the female role by being more masculine, or if they fully act out the female role. Busfield (1996) argues that this is the 'catch 22' of women's mental health in that both close conformity to, and departure from, female roles are liable to generate a diagnosis of mental illness. Chesler (1972) suggests therefore, that there is a marked asymmetry in the situation of men and women, which she sees as a fundamental feature of patriarchal societies.

This asymmetry, resulting from the ready pathologising of women as mentally ill, has also been demonstrated in a number of other studies. Possibly the best known and most frequently cited study is that by Broverman et al (1970) on judgements of mental health. The study examined clinicians' conceptions of mental health using gender stereotyped items about behaviour. It showed not only that the conceptions of women's adult mental health differed from that of men's, but also that the conception of men's mental health was far closer than women's to that of adult mental health, gender unspecified. Broverman et al (1970) therefore argue that as long as men conform to the conception of male mental health they can escape from being diagnosed as mentally ill. Women, however, by conforming to the female conception are simultaneously in danger of departing from the general conception of adult mental health. What is appropriate for women is close to mental disorder. Consequently, they are in danger of not meeting the required standards whether they act in masculine or feminine ways. A more recent study by Jones and Cochrane (1981) found that gendered notions of mental health and illness are prevalent amongst lay people as well as clinicians. They found that respondents clearly differentiated in the adjectives they chose to describe the differences between mentally ill men and women. In contrast, the terms used to describe normal women and mentally ill women were similar.

The feminization of madness was further explored by Showalter (1987) in her book 'the Female Malady'. In this book she combined a critique of art, novels, poetry, and scientific texts to explore the link between women and madness at two different levels. These were the representation of madness as essentially female, and the actual treatment of women in psychiatric hospitals. Women, she argues, are more likely to be labelled as mentally ill because of the historical and prevailing dual images of female insanity. That is, madness is perceived as one of the wrongs of women, and that madness is an essential part of feminine nature which is inevitably picked up by 'rational' male psychiatrists (Showalter 1987, p5). Thus she argues that societal ideas about femininity and its links with madness have in turn influenced psychiatric judgement and established psychiatric knowledge. Similar ideas about the link between women and madness are put forward by Ussher (1991) when she demonstrates how women tend to be positioned as mad and argues that this is a product of misogyny which silences women and renders them powerless (Ussher 1991, p7).

From the feminist theoretical viewpoints discussed, the overrepresentation of women in mental health statistics have been explained by the feminization of madness with the result that women are vulnerable to be labelled as mentally ill when they fail to conform to, or when they deviate from, the stereotyped female role. In addition psychiatric discourse is deemed to be patriarchal and misogynistic. There is increasing evidence however that this phenomenon is not confined to male psychiatrists but is operating throughout the health services. For example, Barrett and Roberts (1978) found that male general practitioners construed their middle-aged female patients to be more likely to be suffering from neurotic illness and requiring minor tranquillizers than male patients; Goldberg and Huxley (1980) found that general practitioners are more likely to diagnose psychological difficulties in women than men; and Sheppard (1991) found that general practitioners discriminate against seriously mentally ill women as they were more likely to refer women for compulsory hospital admission than men. Additional questions have also been raised about the assumption that patriarchal practice, particularly in psychiatry, is solely attributable to the fact that men have dominated the medical profession. Pilgrim and Rogers (1997) argue for example, that sexism in psychiatry has its roots in, and can be transmitted in, the types of knowledge, diagnostic categories and practices which can still be called patriarchal even when used by female workers. This point is supported by the work of Davis et al (1985) who found that female social workers were as likely as their male counterparts to judge women with long-term mental health problems according to a sexist stereotype of the female role.

This evidence and the subsequent concerns about the discrimination and oppression of female patients have culminated in the recent MIND campaign in the United Kingdom concerning women and mental health (MIND 1992). As part of this campaign, an extensive review of mental health services for women highlighted a number of discriminatory processes (c.f. MIND 1993a). The report identified for example, that services are prone to misdiagnose women's distress; they fail to help women deal with the cause of their problems; they mistreat women's distress by using inappropriate medication and ECT, and by inappropriately admitting them to hospital; and they are frequently unsafe for women. Although the MIND campaign, along with the large body of literature which has highlighted women's negative experiences and oppression within the mental health services in particular, is laudable; it can be argued that this is a simplistic and one dimensional perspective of a very complex phenomenon. How appropriate is it to talk purely of oppression and social regulation when confronted with the very real difficulties faced by women with long-term mental health problems ?

In general, feminists have tended to deny the existence of the serious social disabilities experienced by women with long-term mental health problems and have assumed that all women's problems are essentially remediable with the correct theoretical approach, the elimination of patriarchal oppression, or both. Perkins (1992) argues however, that whilst it is undoubtedly the case that many difficulties are remediable and that oppressive patriarchal structures generate much distress, the assumption that all difficulties are a product of oppression seems dangerous. It has to be acknowledged that within existing patriarchal structures profound social disablement does exist. Women with long-term mental health problems who suffer from illnesses such as schizophrenia, have major disturbances of thought, feeling and behaviour and consequently experience life in a way that is profoundly different from most people. Their often terrifying reality is typically shared by no-one else, can render them totally isolated, and lead to behaviour that seems unpredictable and unusual (Perkins and Dilks 1992). The denial of the associated social disabilities experienced by these women has two major consequences. First, these women are marginalised from the mainstream interest in women and mental health (both theory and practice), which renders them even more powerless than they actually are. Second, the denial or avoidance of social disability means that little interest is shown in providing for their particular needs in specialist mental health services (Perkins 1991).

Women who experience social disabilities as a consequence of their long-term mental health problems are unable to negotiate the social world, and fulfill all the required social and domestic roles without special help and support. Such support in the present climate is typically only provided within the specialist mental health services together with the increasing involvement of the social services and the voluntary sector. If it is accepted that in the foreseeable future many women with long-term mental health problems will require help and support, then it is important to move beyond the premise that such support purely contributes to their particular difficulties. Instead it is argued that the analysis of these women's experiences must be seen from a two dimensional rather than a one dimensional perspective. Feminist theorists who have proposed a more complex analysis of women's experiences within mental health services are Penfold and Walker (1984) in 'Women and the Psychiatric Paradox', and Busfield (1996) in 'Men, Women and Madness'.

Penfold and Walker's analysis begins with an examination of the character of psychiatry and psychiatric practice before moving on to a detailed consideration of the place of women. Drawing on a Marxist theoretical framework, they position psychiatry in relation to the state and other institutions, such as business and the legal system. Drawing on a range of evidence they argue that where women are concerned,

> "...most psychiatric theories and practices validate the male as prototype, legitimize women's second class status as male property, validate dominant-subordinate relationships between men and women, re-enforce the institution of motherhood as a sacred calling, urge women to view their identity in terms of their success as wife, mother and sexual companion, and reflect descriptions and prescriptions based on archetypal images. Thus, psychiatry is a very powerful force towards preserving a situation which works for the material gain of men" (Penfold and Walker 1984, p244).

Penfold and Walker (1984) also strongly point out the contradictory nature of the psychiatric system with its explicit objective of helping women as patients alongside its simultaneously coercive and regulatory role, through the ways it views distress as personal pathology and its stereotypical images of women. They therefore question whether the debate about women's mental health should remain focused on the issue of therapy versus control as this results in a stalemate from which there are only two courses of action. Namely, improving psychiatric services along existing lines or abolishing it entirely. Instead, they propose that charting a course between the two allows for the possibility that both therapy and control could exist side by side.

Busfield (1996) agrees with Penfold and Walker's (1984) argument that any examination of the experiences of women (and men) within the mental health services needs to offer an analysis of these institutions themselves, including the ideas with which they operate, which in turn are embedded in their practice. Drawing on the work of Foucault, she argues that madness and mental disorder are concepts which set the boundaries of 'unreason'. Moreover what counts as 'unreason' is socially variable as it changes over time and differs between societies. In setting the boundaries of unreason, the concepts of madness and mental disorder play a part in, and contribute to social order. This contribution to social order occurs in two ways. First, these concepts provide a background through which everyday social behaviour is classified and given meaning. Second, these concepts are embedded in the practices of mental health services and are then used as one of the mechanisms for dealing with madness in a practical way. These practical ways, she argues, can be both humane and regulatory. Furthermore she argues that care and control are not mutually exclusive. The key issue is not the absence or presence of regulation and control, but on what grounds, for what purpose, in whose interests any regulation occurs, and the degree of voluntarism involved. Busfield (1996) concludes by arguing that regulation and control tend to be construed as negative phenomenon. Instead she argues that conversely whilst mental health services are regulatory and do contribute to the social order, when the individual's interests are kept to the fore then any regulation is often considered acceptable and the notion of care is more likely to be emphasized.

The arguments forwarded by both Penfold and Walker (1984) and Busfield (1996) have been drawn upon to illustrate that the experiences of women in mental health services cannot simply be construed as oppressive. For women with long-term mental health problems, who often require the intensive support provided by specialist mental health services, it is vital that their experiences are understood within the inevitable conflicts which exist in such services. Although the regulatory function of mental health services cannot be denied, this has to be considered alongside the caring and therapeutic functions, and the willingness or otherwise of women to engage with the services.

1.6 Conclusion

This chapter, which is divided into four sections, provides the theoretical context within which this thesis is located. The chapter begins by comprehensively tracing the move from hospital to community-based care for people with mental health problems. The increasing emphasis placed in mental health policy on the particular problems posed by, and the particular difficulties experienced by people with long-term mental health problems are extensively explored. As such, this section provides a background for understanding the complexities of organizing and delivering services for this client group.

Whilst the accelerated move towards community-based mental health services can be construed as progressive and enlightened, the second section highlighted a range of theoretical perspectives which conversely support the argument that mental health policy and services contribute to the regulation and maintenance of social order through the mechanism of social control. This was achieved by drawing on the work of Durkheim (1964), Navarro (1976), Scull (1977), Foucault (1965) and Warner (1985). Foucault's theories of madness, and his concept of the dispersed, diffused nature of power were particularly emphasized as they are increasingly being drawn upon by feminists exploring the issues around women and mental health (c.f. Busfield 1996), and other researchers working in the health field (c.f. Bloor and McIntosh 1990, Opie 1997, Miers 1999).

The diverse arguments presented in sections one and two were reconsidered in the third section when it was argued that contemporary mental health policy is more accurately characterized by a number of conflicts and contradictions. Key examples which illustrate these were discussed.

The final section focused on the key theoretical approaches which have been taken towards understanding women and mental health and their subsequent experiences within the mental health services. These approaches have stemmed from the increasing concern about the overrepresentation of women in mental health statistics and each offers a different explanation for this phenomenon. The approaches discussed included the social causation theories, the artefact explanation, and the broad range of theories provided by researchers working primarily from feminist perspectives. The work of Penfold and Walker (1984) and Busfield (1996) were specifically emphasized as their perspectives highlight yet again the conflicts and tensions inherent in the delivery of mental health services. That is, that mental health services have both regulatory and caring functions. Their work provides a useful framework from which to begin to explore the experiences of women with long-term mental health problems who, because of their profound disabilities, often rely on the support and care provided by mental health services to help them manage in their day to day lives.

Chapter Two

Women with Long-Term Mental Health Problems

2.1 Introduction

Within the large and diffuse literature on women and mental health there is a small but growing interest in the particular needs of women with long-term mental health problems and their experiences within the mental health services. Much of the recent research in particular has focused on the specific impact of the move towards community care on the lives of such women. There remains, however a paucity of research in this area (Test and Berlin 1981, Bachrach 1984, 1985). This lack of research does not necessarily suggest lack of interest or concern, but may reflect the reluctance of funding bodies to award research grants to projects which focus on women (Russo 1990, Nadelson 1993). In addition Russo (1990) suggests that mental health research has a long-standing reluctance to consider gender-related issues. This has resulted in assumptions of homogeneity which have pervaded many investigations (Steinwachs et al 1992). Women are therefore largely ignored in studies which focus on the long-term client group and consequently "remain a largely invisible group lost in the mass of chronic patients" (Perkins 1991).

Whilst acknowledging the general lack of research about such women, the literature that there is suggests a bias of interest towards certain areas to the detriment of others. For example there has been much interest in identifying sex differences and issues concerning sexuality, whereas little is known about how the women themselves perceive their lives and their experiences within community-based mental health services. The purpose of this chapter therefore, is to review the existing research concerning women with long-term mental health problems in order to draw attention both to the areas which have attracted particular interest, and to those which remain relatively unexplored. The chapter begins with an overview of the current position with regard to the definition and categorization of people with long-term mental health problems. The subsequent sections focus on the differences between men and women with long-term mental health problems, the particular problems faced by these women, the needs of different groups of women, and finally their experiences within long-term mental health services. The final section reviews the scanty yet illuminative research which has explored how the clients' themselves perceive their lives. The chapter concludes by highlighting a number of key themes that emerge from the review which, together with the issues raised in chapter one, provide the base from which this study was developed.

2.2 Defining people with long-term mental health problems

A variety of terms have been used in research and practice to refer to these clients. These terms include the chronically mentally ill, the long-term mentally ill, people with enduring mental health problems and people with severe and persistent mental illness. The term 'chronic' in particular is controversial, although it is likely that any word suggesting a long-term continuing illness will eventually be viewed as inappropriate (Bachrach 1988, 1993). For the purpose of this study the term - people with long-term mental health problems - will be used, primarily to avoid using the stigmatized word chronic, and also because the term is commonly used in current mental health research.

The problems of defining a client group which is large and diverse is evident in the literature. Early definitions were based primarily on prior or current hospitalization and little consideration was given to the distinction between different diagnoses or illnesses and disability (Bachrach 1988, Schinnar et al 1990). However the pressure to define this group of clients and to acknowledge distinctions between people with mental health problems for the purposes of service planning, delivery and evaluation has increased with the move towards community care (Deitchman et al 1981, Schinnar et al 1990). The late 1970's began a period of proliferation of definitions of long-term mental health problems whose focus shifted away from in-patient care as the critical element, to criteria such as diagnosis, functional disability and illness duration (Goldman et al 1981, Krauss and Slavinsky 1982). These three criteria provide a useful framework for describing this population. However it should be recognized that the operationalization of these criteria has yet to be universally agreed, and that there is currently little consensus on the specific nature and relative importance of each (Bachrach 1988, Schinnar et al 1990).

People with long-term mental health problems fall into a number of diagnostic categories although the majority suffer from schizophrenia (Test and Berlin 1981, Clifford et al 1991). In a review of the literature Schinnar et al (1990) also included the diagnoses of major affective disorder, and other psychoses. There is however, less certainty about the inclusion of diagnoses such as personality disorder, alcohol and drug abuse and learning disability (Goldman et al 1981).

Disability in people with mental health problems refers to physical, social and psychological difficulties. A person is considered to be disabled if they are unable to perform socially to the standards expected by themselves, people important to them, or society in general (Wing and Morris 1981). The fact that residual disability may last long after the primary symptoms of illness have disappeared (Shepherd 1984), has led to the suggestion that the disability criterion should be given equal weight with diagnosis in the definition of long-term mental health problems (Pepper and Ryglewicz 1984). Wing and Morris (1981) suggest that disablement in people with long-term mental health problems results from three interrelated factors. First, primary impairments arising from their illness such as disturbances of cognition, affect and behaviour. Second, adverse personal reactions to illness such as denial, loss of confidence or an avoidance of stress for fear of exacerbating problems. Third, social disadvantages which include those preceding illness, such as poor education, poverty, sexual abuse and those which result as a consequence of illness such as poverty, homelessness, unemployment, stigmatization and disrupted family and social networks. Shepherd (1984) suggests therefore, that the difficulties experienced by people with long-term mental health problems can be best understood as an inability to cope in various everyday roles.

Historically people became recognized as having long-term mental health problems, either through repeated admissions or through remaining in hospital over a long period of time. This view however has been criticized now that increasing numbers of clients live in the community and may never have been admitted to hospital (Bachrach 1988). The duration criterion therefore has stimulated much debate around such issues as how long a period before an illness becomes long-term, and if the illness is episodic, how many episodes constitute a long-term illness ? Although these issues have yet to be resolved, duration of contact with services, and the nature of this contact, have been used to identify subgroups of people with long-term mental health problems. These are the 'old long-stay', the 'new long-stay', the 'new long-term', and the 'young adult chronic patient'. These subgroups are useful as a guide for service planning and research, although the categorization is artificial and clients may straddle two categories.

Old long-stay patients are those who were admitted to psychiatric hospital long ago and have remained institutionalized in spite of deinstitutionalization efforts (Bachrach 1988). They are an ageing group, many are physically frail, and they are generally socially isolated (Christie-Brown et al 1977, Ford et al 1987). They require full time care in view of their physical frailty and the duration of their hospitalization (Shepherd 1984). New long-stay clients are generally younger than the old long-stay group and have not experienced such prolonged periods of hospitalization. Despite their youth however, they have long psychiatric histories, considerable social difficulties and require intensive long-term rehabilitation in supported settings as they have tried to live in a variety of community settings unsuccessfully (Bachrach 1988). The new long-term group do not stay in hospital for long periods of time, instead they move between hospital admission wards, day services, hostels and family homes (Shepherd 1984). As a group they have repeated and prolonged contact with the services but have not experienced long-term hospitalization (Bachrach

1988).

Since deinstitutionalization a group of young adult chronic patients has emerged. They are usually under 35 years old and are characterized by poor social functioning, a need for a wide variety of services and their inability to use those services consistently (Pepper et al 1981, Harris and Bergman 1984). These clients tend to have more multiple diagnoses than other groups, including personality disorder or substance misuse (Caton 1981, Pepper et al 1981, Safer 1987, Caton et al 1989, Drake and Wallach 1989), their compliance with medication is poor (Lamb 1982), and a large proportion tend to deny a need for mental health treatment (Pepper et al 1981). As a group they are particularly vulnerable to stress and have difficulties in forming stable and supportive relationships. Consequently they are handicapped by impoverished social networks that are typically unavailable in times of crisis (Harris and Bergman 1984).

Since these categories were first described in the literature in the 1980's, an increasing number of clients with long-term mental health problems are cared for in a variety of community settings as few long-stay psychiatric hospitals remain open. This form of categorization will therefore become increasingly irrelevant as the older clients die and the possibility of long-term hospitalization diminishes. Bachrach (1996) describes the resultant emergence of a group of clients termed the new chronic patients who represent a truly deinstitutionalized population. This group represent the first generation of clients, who since the onset of their illness, have lived exclusively in an era of deinstitutionalization. She suggests that what distinguishes them from the long-term clients of the past, is not their illnesses, but their unique impact on the mental health services. Many of these clients for example, are pervasive users of the system, whereas others are not in contact with any services. Those who do use the services tend to use them in a 'revolving door' manner and frequently move among facilities. There is a high prevalence of alcohol and other substance misuse, and a high risk of suicide, vulnerability to stress and personal rejection.

The current position with regard to a universally agreed definition of long-term mental health problems therefore remains unresolved. Consequently long-term mental health services resort to developing their own criteria, generally focused around diagnosis, level of disability and duration of illness. In addition there are no agreed operational definitions of different categories of long-term clients (Ford et al 1987, Kastrup 1987 a, b, Bigelow et al 1988, Shepherd 1989). In research it is particularly important to acknowledge this lack of precision as it is difficult to generalize from the findings of many studies of this client group as local interpretations of the definition vary and frequently the definition is not made explicit (Bachrach 1988).

2.3 Differences between women and men

Much of the research which has looked at the differences between women and men has focused on clients with a diagnosis of schizophrenia rather than on clients with long-term mental health problems as a whole. This may reflect the difficulties of clearly defining this group of clients as identified in the last section. As the majority of clients with a long-term mental health problem do have a diagnosis of schizophrenia (Test and Berlin 1981, Clifford et al 1991) many of the research findings are pertinent.

It is generally agreed that the prevalence of schizophrenia is equal in women and men (Seeman 1982, Attkisson et al 1992, Hafner et al 1993), although some studies indicate that it might be slightly higher in men (Iacono and Beiser 1992, Lewis 1992). A more important sex difference is that of age of onset. Women develop schizophrenia three to four years later than men irrespective of whether onset is defined as first hospital admission, first appearance of a psychotic symptom, or first sign of mental disorder (Hafner et al 1993). Reviews of schizophrenia research suggest that 50% - 60% of men but only about one third of women have their first episode of illness by the age of 25 years (Lewis 1992), and that the mean age at onset for men is 24.3 years and 27.9 years for women (Goldstein et al 1989). There is however a predominance of women in late-onset schizophrenia (Castle and Murray 1993, Hafner et al 1993). Onset at 40 years or older for example, occurring in approximately 8% of the women compared to 1% of the men (Goldstein et al 1989). Life events prior to onset appear to be more commonly reported by women (Bardenstein and McGlashan 1990).

Lewis (1992) suggests that schizophrenic men are more prone to express negative, defect symptoms such as social withdrawal and blunted affect whereas women are more likely to present with dysphoria and depressive symptoms. Substance misuse and anti-social behaviour are more common in schizophrenic men (Bardenstein and McGlashan 1990), although this may reflect sex differences in social behaviour in the general population (Lewis 1992). It has also been suggested that times of low or falling oestrogen levels in women such as pre menstrually, post menopausally or post partum often coincide with a worsening of psychotic symptoms (Gerada and Reveley 1988, Seeman and Lang 1990).

The similarity in the prevalence of schizophrenia among women and men is not reflected however in the long-term care mental health services. Evaluations of such services suggest a client group which is dominated by men (Affleck et al 1976, Mann and Cree 1976, Christie-Brown et al 1977, Stein and Test 1980, Schwartz and Goldfinger 1981, Bachrach 1982, Lamb 1982, Marks et al 1994, Ford et al 1995). These repeated reports of fewer women than men in the long-term care services may possibly reflect other identified sex differences in schizophrenia such as course of illness, treatment response and societal expectations.

Angermeyer et al (1990) in a review of the effects of gender on the course of schizophrenia concluded that the outcome of schizophrenia was better in women, at various lengths of follow-up. Women, for example, are less likely to relapse than men (Hogarty et al 1974) and are less likely to be hospitalized (Affleck et al 1976). Women have a better employment record than men following a schizophrenic illness and their social adjustment following hospitalization is also superior (Affleck et al 1976, Seeman 1982). This may be explained by a better response both to drug treatment (Hogarty et al 1974, Zito et al 1985, Seeman and Lang 1990, Szymanski 1995) and family interventions (Zito et al 1985, Haas et al 1990). Women's superior response to drug treatment has been explained by their ability to tolerate higher doses without side effects, different subjective experience of side effects, and better drug compliance (Seeman 1982).

Further explanations for the minority of women in the long-term care services suggest the greater tolerance of society towards women with mental health problems and their perceived superior coping skills. Ussher (1991) suggests that women and their families may tolerate symptoms of psychosis for longer than men without demanding specialist treatment. In a study by Seeman (1983) it was found that families of male schizophrenics were primarily concerned with violence, drugs, alcohol and the burden of caring, whilst families of schizophrenic daughters appeared more protective and worried about them being sexually abused or getting pregnant or expressed general concerns about physical health and interpersonal relationships. In addition attitudes within the general population towards women with mental health problems have been found to be less stigmatizing than towards men (Farina 1981), possibly because men are perceived as potentially more capable of dangerous and violent behaviour whereas women are merely seen as odd or bizarre (Rabkin 1980). Women with long-term mental health problems appear to be better than men at forming relationships which lead to cohabitation and marriage, sustaining those relationships, staying in close contact with their families, and forming networks of friends (Bamrah et al 1991, Conning and Rowland 1991, Cotterill 1994). They are also more likely to have children (Test and Berlin 1981, Seeman 1983, Test et al 1990). Although this is possibly due to the later onset of illness in women, these factors may provide women with the necessary support to stay out of the long-term care services. However there is evidence that the onset of a major mental illness takes its toll on personal relationships and that the separation and divorce rates for these women is high (Cheadle et al 1978). Finally Seeman (1982) suggests that women with schizophrenia are more capable than men with regards cooking, housework and budgeting so tend to manage better in the community without intensive support.

The key findings from this body of research into the differences between women and men with schizophrenia suggest a number of explanations for the low numbers of women found in the long-term care services. Women for example, respond better to treatment, they appear more able to cope with daily living in the community, and are more likely to be tolerated and / or protected by their families and communities. An alternative explanation may be that women do require the support provided by the long-term care services but are unwilling to use the facilities available because they do not meet their needs.

2.4 Issues of concern

Over a decade ago Bachrach (1984) voiced her concerns about the effects of deinstitutionalization on the lives of women with long-term mental health problems. Of particular concern were the issues surrounding their vulnerability to abuse and violence, and the problems associated with an increased sexual freedom. These issues remain pertinent as staff and researchers have struggled to reconcile the women's rights to fit in and belong to the communities in which they now find themselves (Perkins 1992), and with the need to protect them. This tension is best illustrated in the literature on abuse, physical health and sexuality which will be discussed in this section. The literature on sexuality is particularly well developed, possibly because of the controversial issues around the control of fertility.

2.4.1 Sexuality

Deinstitutionalization has resulted in an increased likelihood that women with long-term mental health problems will have a greater opportunity to develop sexual relationships (Nicholson et al

1996). Compared to men, this issue is particularly pertinent, as they have shorter hospital stays than men with the same diagnosis, are more sociable, and are more likely to be sexually active and to cohabit (Seeman 1982, Goldstein 1988, Goldstein and Link 1988, Test et al 1990, Miller and Finnerty 1996). In the past it was assumed that sexual activity among such women declined below that of the general population as a result of thought disturbance, prolonged hospitalization, motivational deficits and drug-induced dysfunctions (Akhtar and Thompson 1980). However a number of reports discredit the notion of a uniform loss of sexual interest among women with long-term mental health problems and suggest that their sexual activity is more often limited by lack of social skills and a deterioration in social functioning rather than by lack of interest (Shearer et al 1968, Verhulst and Schneidman 1981, McEvoy et al 1983).

In a more recent study Miller and Finnerty (1996) compared the sexual lives of women with long-term mental health problems with a group of women without mental illness. Whilst they found that women with long-term mental health problems were sexually active, their sexual lives were more chaotic, less consensual and less fulfilling than those of the control group. This can possibly be explained by the other findings of the study which suggested that women with long-term mental health problems had more lifetime partners, were less likely to have a current partner, were more likely to have been raped or engaged in prostitution and had fewer planned pregnancies, more unwanted pregnancies, more abortions and were more often victims of violence during pregnancy.

Although the sexual lives of women with long-term mental health problems may not always be fulfilling, mental health services are having to acknowledge that such women are increasingly likely to have a parenting as well as a patient role (Apfel and Handel 1993, Nicholson et al 1996). Since the onset of deinstitutionalization there has been a dramatic increase in pregnancies among these women (Shearer et al 1968, Erlenmeyer-Kimling et al 1969, Verhulst and Schneidmen 1981, Miller 1992), and many of these pregnancies are unwanted or unplanned (Abernethy 1974, Coverdale and Aruffo 1989, Miller and Finnerty 1996).

This situation has caused great concern amongst staff and researchers working within the field of mental health and the resultant literature suggests a polarization of views. On the one hand there are the arguments which suggest that pregnancy and parenting place an undue stress on women with long-term mental health problems who find it difficult to meet the needs of their children. On the other hand there are strong arguments to suggest that the women's rights to be mothers should be respected and that services should provide the necessary facilities and support to enable them to perform that role adequately (Test and Berlin 1981, Perkins 1990, Nicholson et al 1993). There are inevitable grey areas within such a complex debate and the tensions between respecting the women's rights and protecting them and their children are evident.

The arguments which mitigate against these women being able to tolerate the stress of pregnancy and cope with parenting centre around their mental health problems, their social situation and the needs of the child. It has been suggested, for example, that many of these women risk a relapse in their psychotic symptoms as a result of the stresses incurred from pregnancy and child care (Yarden et al 1966, Coverdale et al 1992). Those women who deny their pregnancy may receive inadequate prenatal care and consequently endanger their health and the health of their unborn child (Miller 1990, Rudolph et al 1990). It has also been argued that their mental health problems may have impaired their ability to form a nurturing bond with their children or to respond to their needs (Goodman 1989, Coverdale et al 1992).

The problems associated with their mental illness which may make ordinary everyday living an enormous struggle are further exacerbated by the social situation which many women with long-term mental health problems find themselves in. They face the prospect of bringing up a child in probable poverty, possibly without a partner and often without the support of family and friends

(Test and Berlin 1981, Miller and Finnerty 1996). These factors have contributed to the view that the well-being of these women's children is paramount. Concerns have been expressed for example, about the potential effects of psychotropic medication on the foetus which may include morphological and behavioural teratogenicity, toxicity and withdrawal (Miller 1991). Merkatz et al (1993) and Yonkers and Harrison (1993) argue that because women of reproductive age and childbearing potential have been routinely excluded from psychopharmacological studies, adequate data are not available to assist psychiatrists in fine-tuning medication regimes. This problem is potentially exacerbated if the woman is not seen regularly during the ante-natal period. It has also been recommended that psychotropic drugs should be withheld from breastfeeding women (Poole et al 1980), however this may not always be possible for women with long-term mental health problems whose continuing mental health may be dependent on regular medication. The limited interest shown in the literature concerning this issue may reflect the belief that as a group, women with long-term mental health problems are unlikely to maintain breastfeeding particularly if the child is to be taken into care or adopted. Once born there is evidence to suggest that the children of schizophrenic mothers in particular have an increased risk for developing schizophrenia or other psychological difficulties (Garmezy 1974, Coverdale et al 1992, 1993).

Finally women with long-term mental health problems are particularly vulnerable to parenting dysfunction with the inevitable sequelae that they frequently lose custody of their children to either foster care or adoption (McEvoy et al 1983, Coverdale and Aruffo 1989, Coverdale et al 1992, Nicholson et al 1993, Miller and Finnerty 1996). This loss of custody may be in the best interests of the child, but the associated profound feelings of loss experienced by the mother has only recently been recognized. Apfel and Handel (1993) argue that many opportunities to help these clients cope with their loss are missed and consequently the 'lost' children are 'replaced' by efforts to become pregnant again.

Whilst it cannot be denied that women with long-term mental health problems face huge obstacles as mothers, there are strong arguments which suggest that their special service needs are seldom addressed (Test and Berlin 1981, Nicholson et al 1993). This may be because the parenting capacity of these women may be routinely viewed in a negative light (Nicholson et al 1993). In addition Perkins (1990) suggests that mental health professionals may have unspoken assumptions about the wisdom of allowing or encouraging these women to parent, in her words "there appears to be a prevailing assumption that the mad shouldn't breed". Consequently support and skills training for the parenting role has lagged behind vocational rehabilitation, and there is a lack of family orientated and supported housing services with help continuously available where severely disabled women can live with their children (Miller 1992, Perkins 1990, Nicholson et al 1993, Blanch et al 1994).

A similar set of dilemmas are faced by staff working with women who are at risk of unwanted pregnancies. On the one hand they may wish to respect the woman's autonomy but on the other want to help her to avoid the potential adverse consequences of an unwanted pregnancy (Coverdale et al 1993). It has been widely reported that many women with long-term mental health problems fail to use contraceptives or use them ineffectively (Grunebaum et al 1971, Abernethy 1974, McEvoy et al 1983). The need for routine family planning is therefore advocated as a crucial part of these women's care (Abernethy et al 1976, Miller 1992). However a number of studies have shown that mental health staff rarely talk with clients about their need for contraceptive or gynaecological services and that taking sexual histories may make staff feel uncomfortable (Merrill et al 1990, Coverdale et al 1990, Coverdale and Aruffo 1992, Singh and Beck 1997). This reluctance to discuss issues around sexuality and contraception may also stem from an assumption that women with long-term mental health problems are unable to make decisions about their behaviour, health care and treatment (Grunebaum and Abernethy 1975, McEvoy et al 1983, Rudolph et al 1990).

2.4.2 Abuse

Women with long-term mental health problems are particularly vulnerable to sexual exploitation and violence (Test and Berlin 1981, Browne and Finkelhor 1986, Mullen et al 1988, Darvez-Bornoz et al 1995). The literature suggests that sexual and physical victimization amongst people with mental health problems is higher than in the general population (Jacobson 1989, Muenzenmaier et al 1993), and that the problem is more prevalent among women with mental health problems than men (Carmen et al 1984, Jacobson and Richardson 1987, Swett et al 1990).

It has been suggested that the social drift that is linked to their long-term mental health problems plays an important role in exposing women to the risk of sexual and physical victimization. Poverty, unsafe housing and lack of transport all contribute to their general vulnerability (Test and Berlin 1981, Darvez-Bornoz et al 1995). Loneliness, poor judgement and lack of coping skills increase their psychological vulnerability. For example, their flattened or inappropriate emotional expression, their lack of awareness of their rights to their own bodies, their need for support, comfort and intimacy creates risk situations in which they find difficulties in protecting themselves (Test and Berlin 1981,Darvez-Bornoz et al 1995).

Compared to the large body of literature which is concerned with the control of these women's fertility, there has been little research concerning their sexual and physical victimization (Beck and Van der Kolk 1987). The research that has been conducted however, does suggest that the problems are widespread. Studies of female psychiatric in-patients suggest that the prevalence of physical or sexual assault and sexual abuse is high. Carmen et al (1984) reported a prevalence rate of 43%, and Bryer et al (1987) who defined abuse as people who have been pressurized into doing more than they wanted to do, reported a prevalence rate of 54%. Women may also be more vulnerable to experiences of sexual assault, harassment and intimidation by fellow patients within psychiatric settings (Bartlett and Mezey 1995).

Interestingly, studies of female psychiatric out-patients report higher rates of abuse. In a study of 31 psychiatric out-patients, Jacobson (1989) found that histories of major physical and/or sexual assault were reported by 68% of the patients. In a larger study by Muenzenmaier et al (1993) which looked at the prevalence of childhood sexual abuse, physical abuse and neglect among 78 women out-patients with a long-term mental health problem the rates were similar. 65% reported histories of some type of abuse or neglect during childhood, 45% had been sexually abused, 51% had been physically abused, and 22% had experienced neglect. In addition 74% of the sexually abused women, 70% of the physically abused women and 94% of the women who experienced neglect reported at least one additional form of abuse or neglect. A final but very interesting finding was that the women who had been abused in childhood had higher rates of sexual victimization in adulthood than those who had not been abused (Muenzenmaier et al 1993).

Although these studies indicate that the prevalence of sexual exploitation, and physical and sexual abuse is high amongst women with long-term mental health problems, the actual rate may be far higher. Shame, guilt and fear of being blamed make reporting such histories difficult for these women (Lister 1982, Jacobson 1989). In addition mental health professionals are often reluctant to enquire about abuse histories (Jacobson et al 1987, Jacobson and Richardson 1987, Rose et al 1991, Jennings 1994, Singh and Beck 1997). When a woman does reveal abuse it has been suggested that frequently the complaints are not taken seriously, seen merely as a symptom of her illness, or the account is disbelieved (Briere and Zaidi 1989, Darves-Bornoz et al 1995).

2.4.3 Physical health

The poverty of so many people with mental health problems creates a vulnerability to a range of physical illnesses (Sayce 1993). People with long-term mental health problems, especially if they also misuse alcohol and/or drugs, experience a higher level of physical illness than the general population, and this is often undiagnosed and untreated (Wells et al 1989, Attkisson et al 1992).

There is also a high prevalence of serious chronic diseases such as hypertension, cardiovascular disease, arthritis and chronic lung disease (Koran et al 1989). Physical health issues are of particular importance because physical illness can further limit the level of functioning of people with long-term mental health problems (Attkisson et al 1992). Particular health issues for women include alcohol and drug misuse, the side effects of neuroleptic medication, particularly in pregnancy, and the risk of acquiring HIV infection.

The prevalence of alcohol and drug misuse amongst these clients is higher than in the general population (Smith and Hucker 1993). It is particularly common in young men living in urban areas (Drake and Wallach 1989), although there is some evidence to suggest that the prevalence is increasing among women (Goddard and Ikin 1988). The particular problems associated with alcohol and drug misuse in these clients include an exacerbation of psychotic symptoms, non-compliance with treatment and medication, increased rate of readmission to hospital, violence, criminal behaviour and family discord (Smith and Hucker 1993). As women metabolize alcohol differently from men, they are more likely to develop physical complications such as liver disease and alcohol related brain damage. These problems occur after a shorter drinking history and at lower levels of alcohol intake (Dunne 1988, Seeman and Cohen 1998). Many of the complications of drug misuse are common to men and women. However, some are specific to women or affect them in different ways. Women misusing drugs are at high risk of obstetric complications for reasons such as poor nutrition, poor ante natal care, poor physical health, adverse life events and violence. Opiate dependent mothers are also at increased risk of premature deliveries, intrauterine growth retardation and neonatal deaths. Babies may also be born with opiate withdrawal symptoms (Davison and Marshall 1996).

The benefits of treatment with neuroleptic medication are attained at the expense of a number of side effects that vary in severity but are experienced by the majority of men and women with long-term mental health problems (Lader 1994). These side effects include extrapyramidal effects such as akinesia with motor retardation, rigidity and tremor, akathisia (motor restlessness), and sedation and cognitive impairment. Although women generally respond more favourably to neuroleptic medication than men, Seeman (1992, 1993) found that they frequently complained of side effects such as weight gain, skin problems, menstrual difficulties, constipation and pseudopregnancy. It has also been reported that some women experience diminished vaginal lubrication and orgasmic dysfunction (Verhulst and Schneidman 1981), and there is some evidence to suggest that they tend to have a higher prevalence of more severe forms of tardive dyskinesia than men (Smith and Dunn 1979). Pregnant women taking neuroleptic medication are particularly vulnerable to side effects and toxicity as a result of unpredictable changes in plasma volume, glomerular filtration rate and gastrointestinal absorption (Miller 1994).

People with long-term mental health problems have been identified as a high risk group for HIV infection and AIDS (Carmen and Brady 1990, Aruffo et al 1990, Attkisson et al 1992, Gottesman and Groome 1997). It has been reported that unsafe heterosexual activity was by far the most common risk behaviour, rather than the classical risk factors of male homosexuality and drug abuse in this client group (Cournos et al 1993). This places women at particular risk because of their reported reluctance to use any form of contraception, and their greater likelihood to be sexually active and have multiple partners. There is also evidence to suggest that these women have very little knowledge about HIV and AIDS and about safe sex practices (Aruffo et al 1990).

2.5 The acknowledgement of heterogeneity

Alongside the general problems experienced by women with long-term mental health problems, there exist the more specific needs of subgroups within this population. The heterogeneity of these women has already been described in terms of the length and nature of their contact with the mental health services. The literature however, has also identified additional groups who have specific needs, namely women from black and ethnic minority groups, lesbian women, older women, homeless women, and women in prisons. The research in this area is relatively underdeveloped but serves to highlight particular issues and areas which require further exploration.

Three reports have highlighted the major difficulties which exist in the provision of mental health services to black and ethnic minority groups (Department of Health/Home Office 1992, Department of Health 1993c, MIND 1993b). These reports have identified that alternatives to hospital admission are less likely to be offered to these people, that they have restricted access to the less stigmatized services such as counselling and psychotherapy, and that they have prejudiced access to primary care and community services which results in a higher incidence of admission to in-patient services by the police under the provisions of United Kingdom mental health legislation. Consequently black and ethnic minority people are more likely to be detained under the provisions of the Mental Health Act 1983, to be diagnosed as suffering from schizophrenia or other forms of psychotic illness, to be detained in locked wards, to be regarded as dangerous and treated accordingly, often leading to over-representation in secure settings.

Much of the research interest has focused on the high prevalence of schizophrenia amongst Afro-Caribbean men or on disorders where the psychopathology is a spillage of traditionally western illnesses into specific ethnic groups, such as eating disorders among Asian women (Ismail 1996). Consequently the appropriateness and acceptability of mental health services for these women is largely unknown (Subotsky 1991). Although there is a dearth of research in this area, it has been suggested that racism, poverty and isolation shape the lives and experiences of women from black and ethnic minority groups who use mental health services (Currer 1984, Holland 1992).

There is a growing body of literature which has explored the health care needs and experiences of lesbians and gay men. The literature demonstrates that these people are exposed to many specific and additional stresses as users of health services. For example, they report experiencing negative and hostile reactions from health care workers when their sexual orientation is known and the fear of such reactions may prevent them from seeking health care when it is needed (RCN 1994). Hellman (1996) suggests that lesbian women and gay men with long-term mental health problems are an invisible and ignored group both within the mental health services, and in the gay and lesbian community. It has been argued that anti-lesbianism within mental health services takes a variety of forms. For example Perkins (1995) suggests that many mental health professionals continue to believe that lesbianism is an index of underlying pathology. Professionals frequently assume heterosexuality, they may view lesbianism as a sin or they may reassure themselves that a woman is not really a lesbian because she has had sexual relationships with men in the past, or has had bad experiences with men, or that she will simply grow out of it. There is also little acknowledgement that being a lesbian affects the whole of a woman's life and it is not merely a sexual preference. Perkins (1995) suggests that there are particular stresses attached to lesbian life such as being ridiculed, beaten up, losing a job and/or children, being disowned by family and friends, and having significant relationships denied and marginalized. Assumed heterosexuality can intensify the stress already experienced by these women and mental health services often minimize major life events experienced by lesbian women, such as relationship difficulties or loss or death of a partner (Martin and Lyon 1984, MIND 1993a).

Little is known about the experiences of elderly women with long-term mental health problems even though it has been suggested that they may be one of the most disadvantaged and neglected groups (Test and Berlin 1981). This is surprising considering that women constitute the major proportion of the elderly population living in the United Kingdom and similarly of elderly people with long-term mental health problems (Bachrach 1985, Hazel et al 1991, Mulsant et al 1993). It has been identified that older women, particularly those living in institutional care, are vulnerable to physical, sexual and emotional abuse. They may be stripped of their dignity, given intimate personal care by a variety of people with little attention to issues of consent, called by their first names without permission, and treated as though they were children and lacking in valid opinions (MIND 1992). The effects of poverty, isolation and ill health can make living in the community problematic particularly if they are placed in unsupported or inappropriate settings (Seeman 1983, Slavinsky and Cousins 1992).

Although age may temper many psychotic symptoms, for women over the age of 65 years, there is a high risk of suicide and self inflicted injury (Angst 1988, Subotsky 1991), an increased likelihood that they will experience the side effects of medication (Grohmann et al 1989, Woerner et al 1991), they have a high level of physical problems (Hazel et al 1991), and they are less likely to be offered counselling and other supportive therapies (Wallen et al 1987). A recent study by Cohen et al (1996) which looked at 117 elderly people with schizophrenia has also suggested that depressive symptoms were significantly higher among elderly women than men. This was particularly marked in women of late middle age rather than the very elderly. Depression amongst these women was strongly associated with poverty, poor mobility, limited outside activities and poor social networks, and they were consequently at increased risk of physical illness and diminished social functioning.

It has been estimated that between one and two million people in Great Britain are currently homeless (Scott 1993). This includes people living in hostels, bed and breakfast accommodation, squats, in prison and those staying with friends (Cook and Marshall 1996). There are however, many difficulties in obtaining accurate figures because there has been little effort to standardize definitions of homelessness which constantly change (Santiago et al 1988). What is clear is that the number of homeless people has increased significantly over the last two decades (Conning and Rowland 1991).

The number of homeless women is also growing (Weller et al 1987), and it has been estimated that they currently comprise between 10-25% of the homeless population (Marshall 1996). The number of homeless women is particularly difficult to estimate. Cook and Marshall (1996) argue for example, that women are more likely to conceal homelessness by staying with friends or remaining in abusive relationships. Studies have suggested that homeless women are more likely to report mental health problems and to have been hospitalized in the past than men (Crystal et al 1986, Hagen 1990, Scott 1993, Marshall 1996), and that they are marginally more likely to have physical problems including oro-dental, gynaecological and anaemia (Breakey et al 1989). Although a lower proportion of homeless women misuse alcohol and drugs than men, research findings suggest nevertheless, that the prevalence is relatively high. Breakey et al (1989) in a screening of 298 homeless men and 230 homeless women in Baltimore, found that 69% of the men and 38% of the women were definite or probable alcoholics. Similarly Marshall and Reid (1992) reported that 36% of a sample of 70 homeless women were drinking heavily and that 10% admitted to a current drug problem.

Although it is not possible to provide precise estimates of the proportion of women with long-term mental health problems who are homeless, a recent review of studies of homeless women in London hostels reported rates of schizophrenia ranging from 19% to 64% (Marshall 1994). This wide variation in rates was explained by the different age range of women in the samples, with older women being more likely to suffer from schizophrenia (Marshall 1984). The increasing number of homeless women with long-term mental health problems has been attributed to deinstitutionalization and the lack of suitable accommodation in the community (Bachrach 1984, 1985, Conning and Rowland 1991). It has also been suggested that such women, particularly if they also misuse alcohol and/or drugs, frequently end up in hostels for homeless people because they are unable to cope on their own or secure their own housing (Cook and Marshall 1996). There is some evidence which suggests that homelessness is experienced differently by men and women with long-term mental health problems. First, although the provision of shelter is inadequate for both sexes, responses to homeless women have focused primarily on the provision of emergency services and little provision is made for transitional or longer-term housing (Weller et al 1987, Hagen 1990). Second, there appear to be differences in the social climate of men and women's shelters and hostels. The men's hostels for example, tend to be characterized by widespread physical violence, whereas the women's are characterized by rules and regulations which effectively deny admission to women who are pregnant or misuse drugs and alcohol (Bachrach 1984, 1985, Marriott et al 1997). Despite the commitment of staff working in shelters or hostels for homeless women, a recent study suggests that such places are ill equipped to meet the needs of those with a long-term mental health problem (James 1991).

The final group of women discussed in the literature are those found in prison, although they comprise only 4% of the prison population (Crimlisk and Welch 1996). In a study which looked at the experiences of women generally in prison, Heidensohn (1991) suggests that their experiences are quite different from those of men. First, it appears that criminal convictions are more stigmatizing for women than for men. They are considered to be doubly deviant in that they have transgressed both the criminal law and the social expectations of appropriate feminine behaviour. Second, the educational and training facilities for women are particularly poor, possibly because they are fitted into a system designed to control the larger and more visible problem of male crime. Third, it appears that women react more adversely to prison conditions. Although male suicides are more common, more discipline offences are recorded for women and the incidence of non-suicidal self injury is relatively frequent. In addition a recent report by Guite and Field (1997) suggests that women in prison often feel unsafe particularly if they have to live in close proximity to men, many of whom have histories of domestic and sexual violence.

Although women constitute a minority of the prison population, they are more likely than men to have a mental health problem. In a study which compared a cross sectional sample of 25% of all women serving a prison sentence in England and Wales with a 5% sample of male prisoners, Maden et al (1994) found that the prevalence of psychosis (2%) was similar in the two groups but that women had higher rates of learning disabilities (6% versus 2%), personality disorder (18% versus 10%), neurosis (18% versus 10%), and substance abuse (26% versus 12%). The failure to find elevated rates of psychosis in female prisoners was explained by reference to the filters which exist to divert people with long-term mental health problems away form the criminal justice system. Maden et al (1994) suggests that such women are possible treated differently than men in that they are more likely to be dealt with in the psychiatric rather than the prison system.

Nevertheless there are a small but significant number of women with long-term mental health problems who are in prison. Their particular difficulties have been graphically described in a study by Lamb and Grant (1983) of 101 women prisoners in a large urban county prison in the United States of America. They found that these women's lives prior to prison were chaotic and characterized by anxiety, depression, fear and deprivation. They had been unable to find suitable housing, relied heavily on prostitution, frequently engaged in violent crimes, were unable to look after their children, and despite being offered psychiatric treatment and residential services over the years consistently refused them or used them only for brief periods.

This section has looked at the specific needs of five groups of women with long-term mental health problems, namely women from black and ethnic minority groups, lesbian, elderly and homeless women and those in prison. There are of course numerous other groups of women such as those living in rural areas or those with physical disabilities. The literature in these areas however is extremely scarce although they undoubtedly have specific needs in addition to those which arise from their mental health problems.

2.6 Women's experiences of mental health services

Before the nineteenth century it is unclear whether more women or men were resident in institutions for the mentally ill. However, from about 1830, significantly more women than men were admitted to psychiatric asylums in Britain (Johnson and Buszewicz 1996). It is difficult to compare the diagnoses of that time with those used today, but several writers have pointed out that many women were admitted to institutions for what might be seen as socially unacceptable behaviour such as pregnancy outside marriage, sexual promiscuity or a reluctance to undertake normal womanly tasks within marriage or the home (Chesler 1972, Showalter 1987, Ussher 1991).

Within these institutions, the women experienced a relatively inferior position among the patient population. This is evident not only from the general degradation they experienced (Chesler 1972, Showalter 1987), but also in the work roles they were allocated. Work was considered psychologically more important for male patients who were allocated the more prestigious jobs on the hospital farm or in the bakery and kitchens. They were also frequently given the responsibility for helping to care for the least able patients. In contrast the women were encouraged towards domestic pursuits such as working in the laundry, sewing or cleaning (Perkins 1991). Whilst the work of Chesler (1972) and Showalter (1987) provide a graphic account of the particular problems experienced by women in the old psychiatric institutions, they have been criticized for not acknowledging the prevailing social conditions of the period. Allen (1986) for example, argues that the lives of women in institutions mirrored those of the majority of women living in the Victorian era. Women's roles were very clearly defined and limited during this period and there was an expectation that they remained within the domestic rather than the work environment.

It might be expected that the recently developed community-based mental health services which have replaced the old mental hospitals would reflect the changing roles and expectations of women over the last three decades in particular. The limited research in this area however, suggests that service provision and expectations reflect outdated gender stereotypes and fail to acknowledge the disadvantaged position of many women with long-term mental health problems. Consequently services are designed primarily to meet the needs of clients who are most demanding in both numbers and behaviour, namely young men with a diagnosis of schizophrenia (Okin 1989).

In an evaluative study of a community rehabilitation project in the United States of America, for example, Keskinker et al (1983) found that the staff and the clients themselves placed more emphasis on the male clients obtaining a job. It was also more acceptable for women clients to assume relatively dependent social roles, providing they maintained acceptable levels of self-care, housekeeping and social contacts. Although Keskinker et al (1983) perceived this difference as advantageous for women, Bachrach (1985) argues that they have not considered the fact that unemployment or domestic pursuits might have proved unfullfilling for some women. In the United Kingdom, Perkins and Rowland (1991) examined service use among long-term clients in a district wide service and found a similar difference in expectations. Despite comparable levels of functioning, women were more likely to be placed in less demanding work areas, stayed in the service for longer, and were over-represented in skills training classes. Bachrach (1985) has argued that different expectations of, and service provision for, women with long-term mental health problems in addition to the disadvantages of their illness and subsequent social disability effectively "downgrade women to second-class citizens in a second-class world", and deprives them of access to the care they need.

The one area of service provision that has attracted attention in terms of its acceptability to women is that of single sex provision in hospitals and hostels. A recent study by Barlow and Wolfson (1997) highlighted the vulnerability of women with long-term mental health problems, especially on rehabilitation wards, to being asked to have intercourse for favours and of being at risk of sexual assault. The women clients interviewed were reluctant to disclose these matters to staff because they feared they would not be believed, there might be reprisals, and they would suffer the embarrassment and shame of legal proceedings. Some believed it was due to the perpetrator's mental illness that they had been pestered and therefore did not report the incidents. Other studies have found that many women dislike mixed sex wards and hostels, they feel safer in single sex environments, and concerns have been raised about placing women who have been abused by men in male dominated environments (Patel et al 1994, Crimlisk and Welch 1996, Henderson and Reveley 1996).

There has been mounting public and professional concern about the security and safety of women, particularly those who are admitted to in-patient units (Subotsky 1991). Explanations for women being at greater risk include staff shortages causing reduced supervision, the decline of in-patient beds creating a high turnover of younger and more disturbed patients, and lack of resources to provide single sex facilities (Tonks 1993). The Patients' Charter has now incorporated the right of female patients to be admitted to female-only wards (Department of Health 1995c) but extra resources are not being made available to implement this (Barlow and Wolfson 1997).

Although there is an acknowledged paucity of research concerning the service usage and needs of women with long-term mental health problems (Perkins and Rowland 1991), even less is known about what the women themselves feel about the services they receive. There are however, two studies which have attempted to fill this gap. First, a recent questionnaire survey of 107 women and 59 men with long-term mental health problems by Ritsher et al (1997) explored issues of living with a mental illness, personal relationships, and professional relationships and health care. The results of the questionnaire suggested that overall the women were satisfied with the care they received and had good relationships with the service providers. These results have to be treated cautiously however as they differ from the concerns expressed in the focus groups which were conducted to generate the questions for the survey. The women in the focus groups for example, expressed the view that they are often made to feel like children and that their complaints are seldom taken seriously. The second study by Perkins (1996) used discussion groups to explore the needs of 24 women in a long-term rehabilitation and community care service in London. The needs identified by the women included the provision of some women-only facilities and a choice of the sex of their key worker; minimizing the dangers of harassment, sexual abuse and violence; access to friends, partners and children; having a choice about the services they receive; access to someone to talk to who will listen; and a recognition of their hopes and aspirations.

2.7 The experience of living with mental health problems from the clients' perspective

The previous sections have comprehensively discussed the problems and difficulties faced by women with long-term mental health problems and their experiences within community-based mental health services. With the exceptions of the work of Cotterill (1984), Perkins (1996) and Ritsher et al (1997), much of the work has been conducted from the perspective of the researchers. This one dimensional perspective has many limitations, not least that it fails to recognize that the client's perspective on the issues being investigated may be very different from that of the researcher. This problem with mainstream mental health research has been highlighted by Strauss (1994). Drawing on his experience as both a psychiatrist and a researcher, Strauss provides a number of examples which illustrate that the way mental health professionals view a client's illness and experience of life is often very different from the way that the client sees it. Strauss (1994) therefore suggests that listening to and endeavouring to understand the world from the client's perspective has to be the way forward for both practice and research. Moreover he advocates drawing upon the more subjective methodological approaches used by qualitative researchers and anthropologists.

Examples of such research includes the work of Estroff (1985), McCourt Perring (1993) and Barham and Hayward (1995). These examples have been identified for discussion as they exemplify attempts to see the world through the eyes of the clients, and they differ both in their approach to gathering the data and in their findings. Although these studies focus on men and women with long-term mental health problems, the work nevertheless provides enormous insights and useful frameworks within which to attempt to understand the specific experiences of women.

Estroff's (1985) study was based on two years of anthropological fieldwork among people with long-term mental health problems living in Madison, Wisconsin. The focus of her study was 43 clients (28 men and 15 women) who were receiving support and treatment within a community-based mental health programme called PACT (Programme of Assertive Community Treatment). From her detailed exploration of how the clients viewed their lives, Estroff devised a typology or categorization in which the clients were described as 'crazies', and those people without mental health problems and the staff as 'normals'. She does not use this in a derogatory way but as a means of illustrating the gap between the two groups.

Estroff's particular interest, which developed throughout the fieldwork, was how and why the clients in her study came to accept the crazy identity and live their lives in a way that simply perpetuated and maintained their difference from the so-called normal people. In her view the mental patient role is a learnt identity which clients come to adopt for lack of any alternative. Although the clients in her study appeared to embrace the role of mental patient, she also found that the behaviour, attitudes and working practices of the mental health professionals in particular actively contributed towards it. For example, she argues that the practices of controlling the clients' finances, the reinforcement of their isolation and difference by reminding them of their incompetencies and introducing them to peers with whom they may be more comfortable, and the petty inequalities between the staff and clients; did not enable them to prove themselves independent, competent and adequate when faced with the tasks of daily living (Estroff 1985, p185).

Ultimately Estroff (1985) viewed both the clients and the staff as caught up in a web of contradiction, a catch-22 situation of their own and others making. The clients for example, appeared unable or lacked the desire to move beyond the crazy role towards taking responsibility for or control of their lives. This situation was exacerbated by the way they were treated by the normals. Conversely, she argues that although many of the staff attempted to help the clients, their psychiatric beliefs and systems of delivering care and support merely perpetuated the crazy role and attributed to the gulf of difference between the clients and the rest of society. She concludes by arguing that at the time of the study there did not appear to be alternative social roles for these clients other than that of being crazy or a mental patient. Consequently she argues that the roles, expectations and stereotypes that surround these clients in the community are not so very different from those which had accompanied the patients in the back wards of the old psychiatric hospitals.

The study by Barham and Hayward (1995) was a further attempt to explore the problems of identity encountered by a group of people with long-term mental health problems living in a town in the north of England. The study was built around a series of semi-structured interviews with 24 clients (20 men and 4 women). By drawing on the comprehensive data gathered in the interviews, Barham and Hayward (1995) argued that many of the negative experiences encountered by the clients can be understood in terms of the difficulties they came across when trying to establish their personhood.

Throughout the text which is illustrated with extracts and quotes from the interviews, Barham and Hayward (1995) comprehensively detail the difficulties experienced by the clients. These include problems with housing and unemployment where the clients feel powerless to influence their fates and had no choice but to accept what was given to them; poverty as a result of living on welfare benefits which led to clients having to make choices between recreation and basics such as warmth and food; difficulties in maintaining and sustaining friendships; and finally lack of mobility as few had cars or sufficient money for longer trips or holidays using public transport. The particular difficulty experienced by the clients however was how to surmount their identity as a mental patient. They felt that their personhood was constantly on probation and that they were continually required to demonstrate that they were normal. This was made more difficult as they were frequently viewed as different by others and that the pressure to hide their past history often contributed to their stress.

In the discussion Barham and Hayward (1995) emphasize two key points highlighted by the clients. First, the clients overwhelmingly felt that society viewed them as different. Consequently they did not feel as if they really belonged. Second, the tendency of the clients to be marginalized was exacerbated by their poverty and the subsequent constraints on their participation. The authors argue therefore that this client group are effectively shut out from membership of larger society which is evident from not only how they are seen but also by the limited options (such as housing, employment and recreation) that are available to them.

In contrast to Estroff's (1985) study, the clients studied by Barham and Hayward (1995) were more combative and wanted help in resisting becoming trapped in the patient role. Above all, they wanted access to opportunities that led somewhere and would enable them to establish a direction to their lives. These differences between the two studies were highlighted by Barham and Hayward (1995) who suggest two possible explanations. Namely that the clients in Estroff's (1985) study were more enmeshed in the treatment programme and therefore had less opportunity to distance themselves from the patient role; and also that the Barham and Hayward (1995) study was conducted more recently on clients who had not been socialized into docility and the role of the patient from prolonged hospitalization and/or intensive treatment in the community.

In contrast to the studies by Estroff (1985) and Barham and Hayward (1995), McCourt Perring (1993) does distinguish between the particular problems experienced by the men and the women with long-term mental health problems in her anthropological study of the clients' experience of hospital closure. Using participant observation as the main method of data collection, she explores the lives of a group of 20 clients who have been moved out of a long-stay psychiatric hospital into three group homes in the community. This study is of particular interest in that she not only seeks to understand the move from the clients' perspective, but also compares their views with those put forward by the service providers.

As part of this study, McCourt Perring (1993) spent considerable time with a group of women with long-term mental health problems who lived together in one of the group homes. By encouraging the women to talk about their lives prior to becoming mentally ill, she was able to construct a picture of their lives which showed that they had been involved in different roles over their lifetimes and had considerable insight into their own experiences. The themes which emerged from the exploration of these women's life histories included the attachments and problems of family life; home and work; and the huge number of losses which had resulted from their illnesses such as loss of home, family and their ordinary identity. The accounts also showed ways in which the women tried to make sense of their lives as they looked for reasons to explain what had happened to them. McCourt Perring (1993, p76) concluded this part of the study by highlighting a number of key issues. First, she argues that these women's desires to talk about ordinary life, rather than just their lives as psychiatric patients, reflects an unmet need to escape from the patient role. As patients they had come to be seen as somehow less of a person. Second, although the women preferred to talk about their ordinary lives before they became ill, these past lives were generally characterized by hardship, poverty, hard work and family stress. Finally, the issue of grief featured strongly. One of the women for example, described not only mourning the loss of her loved ones but also the loss of her own life.

It is important to note however, that despite the insights gained from these studies, it is difficult to really know what it is like to experience life as a person with long-term mental health problems. Our current understanding is based only on what these people choose to reveal. This issue is explored in a paper by Estroff (1995) when she describes accompanying a woman who was participating in her current study to choir practice at church,

> "When the choir began to sing, my acquaintance's face and posture were transformed - from troubled and self-conscious to joyful, free and flowing.........she was a different person from the psychotic, confused, fearful woman I had first interviewed in a hospital two years previously. After practice, she chatted easily with friends of many years (none of the people I saw her with that night appeared on the social network I had painstakingly elicited from her on two separate occasions), and introduced me to a sister I had not heard about in four research interviews..........I had had no way of knowing what she was missing when she had mentioned that she had missed going to church and singing in the choir. Now it was evident that she was retrieving lost social roles and contacts, reconstructing herself and her life in all the ways rehabilitation professionals hope for...... (Estroff 1995)

Estroff (1995) uses this example to illustrate that the research instruments and interviews that she had used in the study failed to capture the significance of what she had observed in the church. Moreover she argues that this example challenges the current methods of collecting data used by both qualitative and quantitative researchers, as neither approach can truly capture the scenes she had witnessed.

2.8 Conclusion

The purpose of this literature review was to highlight the particular needs and difficulties of women with long-term mental health problems, and their experiences within the mental health services. Throughout, attention has been drawn to areas which have attracted considerable research attention and to those where little attention has been paid. In considering the literature as a whole, two overriding themes emerge. These themes serve to highlight the gaps in the existing research, and provide a base together with the issues raised in chapter one from which this research study was developed.

First, there is a lack of comprehensive and systematic research studies into the appropriateness, adequacy and accessibility of services provided for women with long-term mental health problems. The research to date suggests that statutory mental health services may not meet these women's needs, however little is known about their experiences of other services outside this sphere. This is particularly important as these women, because of their illnesses and related disabilities, require a wide variety of psychiatric, medical, social, rehabilitative, vocational services and occasional asylum. Historically these services were provided within one physical setting - the mental hospital - but with the advent of community care these are increasingly being provided not only by the statutory mental health services but also by a range of non-statutory, voluntary and charity organizations.

Second, women with long-term mental health problems are a relatively silent group as their views are not routinely included in research studies which have focused on their particular problems, needs, and experiences of services. The work of Estroff (1985), McCourt Perring (1993) and Barham and Hayward (1995) however, provides many insights into the lives of people with long-term mental health problems, and useful frameworks from which to attempt to understand the specific experiences of women.

Chapter Three

Research Approach

3.1 Introduction

The purpose of this chapter is to set out the arguments to support the selection of a pluralistic model of evaluation as a methodological framework for this investigation. Links are made to the literature reviewed in chapters one and two, and to chapter four where the key issues raised here will be further developed with reference to this investigation. The arguments will be developed in this chapter as follows.

First, women with long-term mental health problems have a range of difficulties and needs but little is known about their experiences within community-based mental health services particularly from their perspective. Section 3.2 summarizes the key issues which emerged from chapter two and presents the aims of the investigation.

Second, it is argued that an evaluative research approach is the most suitable for this investigation as it provides a framework for exploring and analyzing the experiences of women within community-based mental health services. Section 3.3 explores the process that was undertaken to select a suitable methodological approach for this investigation, and draws on the literature reviewed in chapter one to reiterate that the problems experienced by these women have to be viewed within a wider political and societal context.

Third, the evaluation literature reflects a move away from an adherence to the traditional models of evaluation situated within the positivistic approach to research towards alternative approaches situated within the interpretivist and critical science paradigms. This argument is begun in section 3.4 with reference to the current debates in the broad evaluation literature exemplified by the contributions made primarily within the fields of education and social science. The argument is further developed in section 3.5 by focusing on the recent developments in evaluative research within the mental health field.

Finally, it is then argued that a pluralistic model of evaluation is the most suitable methodological framework for this investigation. The model which is described by Smith and Cantley (1985) was developed within a powerful critique of the traditional approach to evaluation and exemplifies an attempt to incorporate the dynamic and evolving nature of services, the views of a range of stakeholders, and a means of looking behind and beyond the professional rhetoric of what constitutes a successful service. Section 3.6 justifies the choice of the pluralistic model of evaluation for this investigation. This justification build upon the arguments developed in the chapter and is set against an appreciation of other evaluation models.

3.2 Gaps in existing knowledge

As was demonstrated in chapter two, women with long-term mental health problems have particular difficulties and needs which in many instances have arisen as a consequence of deinstitutionalisation. These include the issues surrounding the expression of their sexuality, their vulnerability to abuse and exploitation, and their physical health needs. In addition, imprisoned women, lesbians, and elderly and homeless women face additional difficulties on top of those associated with their mental health problems. These women, because of the debilitating nature of their social disabilities, require the continuing support of the specialist psychiatric services to enable them to manage their lives on a daily basis. Little is known however, about their experiences within such services. The limited research to date suggests that service provision and expectations reflect outdated gender stereotypes, and that their special needs are often overlooked as they are a minority group within community-based long-term psychiatric services. Few attempts have been made by researchers to explore the experiences of women with long-term mental health problems from their perspective. Consequently little is known about their life experiences, hopes, fears and expectations for the future. Insights into the lives of men and women with long-term mental health problems living in community settings have been provided by Estroff (1985), McCourt Perring (1993) and Barham and Hayward (1995). Their interpretations can usefully be employed as a means of beginning to understand the particular experiences of these women.

The aims of this investigation are as follows:

- To explore the experiences of women with long-term mental health problems who are receiving care and support within the Rehabilitation and Community Care Service in Nottingham. This will include an exploration of the nature of their difficulties both within and outside the service, and the identification of good and poor examples of service delivery.

- To contribute to existing knowledge by seeking to understand the way in which the organization and delivery of mental health services impact on the lives of women with long-term mental health problems.

- To produce findings which can be used to inform both mental health policy and practice.

3.3 Why evaluation ?

This investigation began as a pragmatic evaluation; an attempt to highlight the problems experienced by women with long-term mental health problems in specialist services in order to provide clinicians with the information required to improve and develop services to better meet their needs. As the investigation unfolded however, it became increasingly clear that this pragmatic approach as described by Bulmer (1986) when he talks about different types of policy research which apply to evaluation, could not answer the questions which emerged. Moreover, it became increasingly evident that there were not going to be straightforward answers to the difficulties these women experienced and that a series of recommendations alone would not necessarily provide the means of improving services. The main problem with the approach originally taken stemmed from the inherent difficulties of attempting to investigate the experiences of women with long-term mental health problems as if they, and the psychiatric services that provide them with the necessary support for daily living, exist within a social and policy vacuum. Such an approach therefore failed to acknowledge the much wider issues which impact on both the delivery of psychiatric services in general and on the disadvantaged and inequitable experiences of women in particular.

Consequently the researcher returned to the much broader literature on mental health policy and women's mental health in order to understand how the current system of mental health care has evolved; and to explore how the management of madness generally, and for women specifically, has been conceptualized and explained (See Chapter One). This review thus provides the necessary frameworks within which to consider how the organization and delivery of services can both contribute to, and ameliorate the particular difficulties faced by women with long-term mental health problems.

Such a shift in worldview had inevitable repercussions. These focused primarily on the original choice of an evaluative research approach for this investigation, and whether such an approach was now suitable or appropriate. Indeed the researcher at one point even considered moving away entirely from evaluation to a multi-method research framework as described by Ong (1993). This conflict was resolved in two ways.

Initially considerable time was spent reflecting on what the researcher wanted this thesis to be for and about. In other words, is this thesis about raising awareness and bringing about change in the services provided for women with long-term mental health problems, or is it about trying to understand their particular experiences within the wider policy and social contexts which impact on their lives ? For some months these two views competed. On the one hand the researcher felt very strongly about the impoverished and very difficult lives of women with long-term mental health problems and wanted to present a thesis which could usefully be drawn upon by clinicians wanting to improve and develop services. On the other hand, having considered the wider context within which these women's lives were situated, judgements about the success or otherwise of the service in meeting their needs would be meaningless in a theoretical vacuum. Moreover the researcher did not want to move towards a purely theoretical thesis with little or no direct application to practice. In reality the researcher wanted the thesis to incorporate both elements, that is to make practical recommendations grounded in the data collected, and to contribute to knowledge by seeking to understand the way in which the organization and delivery of mental health services impact on the lives of women with long-term mental health problems. Having thought this issue through the problem remained of whether or not an evaluative research framework was appropriate.

This was resolved by returning to the literature on evaluation to see whether the use of an evaluative research framework could still be justified. This was more difficult than originally envisaged as much of the methodological literature focuses on design and methods with little consideration given to the issues of marrying pragmatics with theory. The recent work of Everitt and Hardiker (1996) however provided a strong justification for remaining with the original choice of an evaluative research approach for this thesis as they believe that evaluations of practice have to be situated within a wider policy and social context.

The argument put forward by Everitt and Hardiker (1996, p25-26) can be summarized as follows. First, they argue that it is politically naive to evaluate practice without taking into account the wider social and political context of that practice, and the policies which both provide opportunities and constrain it. Evaluations that do not acknowledge the wider context, therefore assume that services are isolated endeavours which can be separated out for study. Such evaluations therefore fail to acknowledge that practice is situated within legislative and policy processes and are shaped through dimensions such as class, gender, race and disability. Second, they argue that atheoretical evaluations provide little opportunity to critically appraise the impact of policy and social structures on practice and how this in turn impacts on the continuing and or increasing disadvantage and inequality of those in receipt of it. In addition to the argument put forward by Everitt and Hardiker (1996), the original rationale for choosing an evaluative research framework remains pertinent. For example, much of the existing knowledge about the difficulties and needs of people with long-term mental health problems and their use of services has been gained from researchers working within the broad field of evaluative research. There are therefore considerable advantages in working within an established approach as it affords some degree of protection by the established nature of some of the ideas, debates and arguments; and a range of research methods and instruments which have been widely used. Furthermore, the field of evaluative research is constantly developing and it offered the opportunity to explore some of the more recent and innovative approaches.

3.4 Evaluative research

The interest in evaluative research has grown exponentially over the last three decades as is evidenced in the proliferation of journals, papers and texts devoted to the subject. One of the main themes which emerges from this literature is that there is little consensus amongst and within academic disciplines as to the 'right' approach to take in the evaluation of public and social services. The proposal that effective evaluation must be tailored to the activities being examined appears uncontentious but in practice presents the researcher with a multitude of problems and dilemmas. These dilemmas are highlighted by Prout (1992) in his quest to select a suitable approach for a health promotion project when he describes the struggle to bring together current debates about the theory of evaluative research with the practical demands of a complex project to be evaluated. The dilemmas occur because "theoretically, evaluation methodology presents a confusing, if not contradictory, mosaic of possibilities, rather than a unified and coherent set of principles; and practically because many of the services being evaluated have complex structures with open-ended objectives which are not amenable to traditional evaluation strategies (Prout 1992, p77)".

Although there are no agreed definitions of what evaluative research is and what it should do, there are certain basic characteristics which distinguish it from other types of social research. First, evaluative research is an integral part of policy. Its aim is to discover whether a particular policy is actively accomplishing what it set out to accomplish, that is, does a particular service meet the policy goals (Bulmer 1986). Evaluative research is therefore conducted to aid decision makers in reaching conclusions about continuing a policy, improving a policy, adding or withdrawing specific features of a policy or allocating resources between competing alternatives (Bulmer 1986, Cronbach 1987). Second, evaluative research is deliberately undertaken as a guide to action and has been described as a type of action research (Bulmer 1986). Scriven (1967) for example, distinguishes between two ways in which the findings of evaluative research can inform action. First, the formative use of evaluation to feedback into the process of sustaining and improving a programme during the life of the evaluation. Second the summative use of evaluation in judging the overall merit of the programme at the end of the study. This feedback of evaluative findings into future decision-making suggests that evaluative research has a social rather than a purely technical purpose (Bulmer 1986). Finally, perhaps the most distinctive characteristic of evaluative research is its inherently political nature as it is directly linked with the objectives of a social programme and with managerial aims and objectives (Ong 1993, Greene 1994). These issues will be explored in more depth later in the chapter.

In the mid 1960's evaluative researchers were encouraged to use experimental methods to assess the extent to which programmes attained their goals and emphasis was placed on objectivity and political neutrality (Greene 1994). In the last thirty years however, the philosophy, methodology and politics of evaluative research have changed substantially. This evolution is the result of major debates which have occurred in the evaluation literature during this period. These debates, which have occurred mainly within the disciplines of education and the social sciences, focus on philosophical and methodological issues and on the political nature of evaluation.

Different methodological approaches to evaluative research have been polarized into two warring camps (Beattie 1995). First, sitting within the philosophical framework of positivism, has been the quantitative approach which represents the historically dominant tradition in evaluative research (Greene 1994, Luker 1981). This approach claims to be a scientific method for the objective, neutral and rational assessment of performance, and emphasis is placed on evaluating effectiveness through the accurate measurement of outcome and impact (Cronbach 1987, Prout 1992). The model of experimental design is advocated routinely within this approach and whereas the randomized controlled trial is seen as the ideal design for evaluative studies, quasi-experimental designs are often adopted if randomization is not possible (Bulmer 1986).

Although quantitative evaluative research remains the dominant approach, many researchers in education, health care and social work resented the reduction of complex and multi-faceted services and practices to input and output measures (Prout 1992). Consequently there has emerged a powerful critique of the traditional quantitative approach to evaluation (see Smith and Cantley 1985, Greene 1994), and the subsequent development of alternative approaches. These alternative approaches to evaluative research are less prescriptive, and therefore more appropriate to complex activities such as health care, and more open to the many different viewpoints and interests that are represented there. They pay far more attention to contextual and political factors, such as the adequacy of resources and pressures from competing demands on workers' time. Their general strategy is to examine processes, how and why work was done, as well as the outcomes of particular initiatives (Prout 1992).

Although there is no one philosophical framework into which all these alternative approaches to evaluative research fall, many of the qualitative, ethnographic and naturalistic approaches embrace the tenets of interpretivism. Everitt and Hardiker (1996, p86) suggest that interpretivism "assumes that the social world is fundamentally different from the physical and natural one in that it is made up of people with subjectivities". Interpretivists acknowledge that subjectivity cannot be eliminated by attempts to control it and that values influence both the data collected and their analysis. Examples of these alternative approaches include illuminative evaluation (c.f. Parlett 1981), pluralistic evaluation (c.f. Smith and Cantley 1985), and fourth generation evaluation (c.f. Guba and Lincoln 1989). Many of these alternative approaches rely heavily but not solely on qualitative methods, and it has been argued that these methods can effectively give a voice to the normally silenced (Greene 1994). Qualitative data may also play an essential role in making evaluative findings more usable by providing memorable and powerful images that illustrate major points and findings (Wortman 1983). These alternative approaches to evaluation were initially criticized on both practical and methodological grounds. However this debate has eventually evolved to a detente signalling the important acceptance of these alternative methodologies by some but by no means all evaluators (Smith & Heshusius 1986).

The debate between the qualitative and quantitative modes of knowing is not restricted to evaluative research but has spilled over from similar debates in the social sciences. Wortman (1983) suggests that there are two ways of viewing this debate. First, it is a fight for methodological turf. Given the multidisciplinary nature of evaluative research, it is not surprising that different disciplines advocate the legitimacy of the methods of their discipline as suitable for conducting evaluations.

Second, it represents a useful critique of current, mainstream approaches to conducting an evaluation.

Historically, positivist evaluators ignored the political nature of evaluation as it considered itself to be value-free with a reliance on neutral methods of collecting data (Ong 1993). However, evaluators have now moved from a position in which they saw themselves as technical experts opposed to the evils of politics to a position where it is acknowledged that evaluation itself has political effects (House 1993). Politics are now considered to be an integral aspect of evaluative research and the evaluator has political influence even if she/he does not aspire to it (Bulmer 1986, Greene 1994, Ong 1993). Evaluations are inevitably conducted on public organizations which are the results of political decisions concerning individual and community needs. Consequently evaluative research is integrally intertwined with political decision making about societal priorities, resource allocation and power (Greene 1994). It has also been acknowledged that such research occurs in a context where power, ideology and interests are often more powerful determinants of decision making than evaluative findings (Cook and Shadish 1986).

When judging the overall merit and efficacy of any programme the evaluator has to decide on the criteria to use. However in complex organizations such as health care services there are multiple and often conflicting criteria of merit (House 1993). For example, what is a good outcome for one group may not be good for another. Traditional evaluators have tended to use the goals of an organization as the criteria for judging success, as they believe that those best reflect overall interests. A more recent trend however, has been to engage the clients and grass root workers both in the planning of the evaluation itself and more commonly by eliciting their views as regards the success of the programme. House (1993) suggests that this increasing emphasis on multiple criteria for success and multiple perspectives reflects the change from consensus to pluralism that has occurred in wider society.

Finally there has been a substantial shift from the traditional view held by evaluators that their discipline is value-free, towards the acceptance that evaluative research involves promoting the values and interests of some groups over others (Gubrium and Silverman 1989, House 1993). Indeed Greene (1994) argues that what distinguishes one evaluation methodology from another are not methods, but whose concerns are addressed and which values are promoted. Inevitably the explicit promotion of certain societal and personal values over others in evaluative research cannot be divorced from the political issues already raised. Evaluators who explicitly recognize and explore the values underpinning their research tend to view evaluation as a process of promoting empowerment and the necessary structural change (Greene 1994). House (1993) for example, argues for evaluative research rooted in conceptions of social justice. While social justice is viewed as a central moral concern in evaluation, other concerns include the importance of human rights, equality, liberty and utility (Cook and Shadish 1986).

The combined force of the philosophical / methodological and political debates have resulted in the development and gradual acceptance of a diverse range of alternative approaches to evaluative research (Wortman 1983). Each of these approaches are underpinned by a particular set of philosophical assumptions, integrated with values about the role of social enquiry in social policy and political decision-making. Each approach has preferences with regards to methods of data collection and different means for identifying the criteria for the success of a particular programme, innovation or treatment. The major approaches to evaluative research are summarized in Table 1, the structure of which rests upon the adaptation of a categorization proposed by Greene (1994).

Table 1: Approaches to evaluative research (Greene 1994)

Philosophical framework	**Key values promoted**	**Preferred methods**	**Criteria for success**
Positivism	Efficiency Accountability Effectiveness Cost efficiency	Quantitative: Randomized controlled trials Quasi-experiments Cost-benefit analysis	Defined by policy and decision makers
Pragmatism	Practicality Utility	Mixed: Quantitative and qualitative	Defined by policy and decision makers
Interpretivism	Pluralism Understanding Solidarity Diversity	Mixed: Qualitative and quantitative	Defined by staff and clients. Competing definitions of success accepted and expected
Critical, normative science	Empowerment Social change Equity Democracy	Mixed: Quantitative and qualitative	Defined by clients, their communities and other powerless groups

The debate concerning the 'right' approach for evaluative research has now moved on as many evaluators currently accept that the selection of a suitable approach not only depends upon personal values and preferences but also on the political nature of what is being evaluated. The notion that an evaluation has to be tailored to the activities being examined is therefore more widely accepted. The issues currently being debated in the literature centre around the compatibility of combining a range of methods within an evaluation. Guba and Lincoln (1989) for example, support a mix of qualitative and quantitative methods but argue strongly against mixing approaches to evaluation at the philosophical level. They argue that a researcher cannot simultaneously adhere to the objectivist detachment of conventional science and the subjectivist involvement of interpretivism. Nevertheless, it has been suggested that not only is it acceptable to mix approaches at the philosophical level but that there are benefits from adopting a pluralistic acceptance of multiple ways of knowing (Bryman 1988, Greene 1994). Reichardt and Cook (1979) argue that evaluators should use whatever methods are best suited to the needs of the study even if that entails a combination of qualitative and quantitative methods. They see such a combination as not only extending the scope of the evaluation, but also yielding new insights not accessible by either method alone. Although accepting of this pluralist approach, House (1993) does raise some concerns when he highlights the problems of how disparate philosophies and methods can be melded. He suggests for example, that the issues of pulling together the results from different methods and combining different perspectives and viewpoints have yet to be resolved.

3.5 Evaluative research in mental health care

Evaluative research in mental health care has a comparatively short history (Hafner and Heiden 1996) but the demand for such research has grown particularly in the last ten years. There are numerous reasons for this increase in demand which stem primarily from an ever growing population requiring mental health services within finite resources. Evaluative research in mental health care provides a means for public accountability (Goldberg and Connelly 1982), evidence that services are providing a good quality of care in an efficient and cost effective manner (Shepherd 1988), and a safeguard against the introduction of new, unproven methods of intervention (Nocon and Qureshi 1996). The pressure to improve the quality of care provided by community-based services has been reinforced by recent reports highlighting the perceived failure of some services to provide adequate care (c.f. Richie et al 1994).

The increasing importance attached to evaluative research in mental health care has been demonstrated by the financial support given to a number of studies through the research and development initiatives from the Department of Health, and the setting up of Health Services Research Centres within Universities throughout the United Kingdom (Leff 1991, Lewis et al 1994). Despite this support and interest, and the considerable challenges regarding research design and the opportunity to participate in research whose underlying values are concerned with improving human welfare, evaluative research is frequently viewed as a low status activity (Coulter 1991). It lacks, for example, the glamour and funding power of scientific research. The lure of biological psychiatry for researchers with its more rapid output of publications and enhanced career prospects has resulted in comparatively few researchers working within the field of evaluative research. This has resulted in a lack of recognition of its complexity and importance in academic circles and among decision makers, and the relative under-development of methodology (Hafner and Heiden 1996).

Recently attempts have been made by influential researchers in the mental health field to redress the balance and to improve the quality of evaluative research. This has been achieved primarily through wide dissemination of research findings through publication and conference presentations. The lack of formal guidance on conducting evaluative research has also been acknowledged and several key texts have recently been published which review developments in research design, method and measurement in the mental health field (c.f. Milne 1987, Freeman and Henderson 1991, Tyrer and Creed 1995, Knudsen and Thornicroft 1996).

The methodological developments in evaluative research in mental health care are inextricably bound up with the changes which have occurred in the delivery of mental health services, notably the move from hospital to community-based care. In addition the legislative demands for mental health services which are comprehensive, coordinated, accessible, acceptable, accountable, efficient and effective have influenced and limited the range of approaches taken to evaluation. The ever expanding body of literature in the field can be artificially divided into two parts. First there are the numerous evaluative studies, which taken as a whole, document the move of patients out of long-stay hospitals into community-based care (see section 3.5.1). Second, there is the literature focusing on methodology which reflects changing political priorities and the growing emphasis on public accountability (see section 3.5.2). Although these developments are entwined, they will be explored separately to provide a basis from which to highlight current methodological trends and concerns.

3.5.1 Evaluating the move from long-stay hospitals to community-based care

Bachrach (1996) defines deinstitutionalization as the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based alternatives for the care of people with long-term mental health problems. She suggests that the rationale for pursuing deinstitutionalization which combines elements of idealism and pragmatism, reflects justifiable concern for the well-being of people with mental health problems. The movement encompasses several critically important assumptions, notably that community-based care is intrinsically more humane, therapeutic and cost-effective than hospital-based care (Thornicroft and Bebbington 1989). In theory deinstitutionalization consists of three processes. The release of patients living in psychiatric hospitals to alternative facilities in the community; the diversion of potential new admissions to the alternative facilities; and finally the development of community-based programmes, combining psychiatric and support services, for the care of a non-institutionalized patient population. The focus of the majority of mental health evaluation studies conducted over the past thirty years reflect the assumptions encompassed within the deinstitutionalized movement, and cluster around the three processes identified.

The first group of evaluative studies focus on the process of hospital closure and moving into the community, and the consequences for both the patients and staff involved. A recent review of the studies from the United Kingdom, the United States of America and Italy by O'Driscoll (1993) concluded with the observation that "much of the literature on deinstitutionalization remains anecdotal or polemical, and that there is a relative dearth of well constructed outcome studies to support or refute the validity of current policies". This observation is supported by Braun et al (1981), Leff (1991) and Mitchell et al (1995) who highlight a number of methodological inadequacies in many of the studies which preclude confident conclusions regarding the efficacy of alternatives to continued long-term hospitalization. These methodological inadequacies include biased selection and uninformative sociodemographic and clinical description of patients, no presettlement assessment, the use of measures of questionable validity and reliability, inadequate and limited number of outcome criteria, and insufficient length of follow-up. A recent, ongoing evaluative study which has attempted to overcome many of the inadequacies of methodology associated with earlier research is that being conducted by the Team for the Assessment of Psychiatric Services (TAPS). This is a follow-up study of over 1100 long-term patients discharged from Friern and Claybury hospitals and findings have been published on patients' social networks, the comparative costs of hospital and community care, the clinical and social outcomes for long-term patients one year after discharge from hospital, the characteristics of psychogeriatric patients, social deprivation, and the accumulation of new long-stay patients (c.f. TAPS 1989, Jones and Margolius 1989, Leff et al 1990, Knapp et al 1990, Anderson 1990, Thornicroft et al 1992).

The second group of studies compare community alternatives with inpatient admission for people with acute mental health problems. Comprehensive reviews of the early studies have been conducted by Braun et al (1981) and Keisler (1982) who concluded that there was no evidence to suggest that hospital treatment was superior to the community alternatives, and the need to be removed from home for the purpose of hospitalization was greatly reduced when community-based treatment was the main form of service delivery. These findings have been replicated in a number of reputable and well cited studies which include those that have compared hospital with home care (c.f. Stein and Test 1980, Hoult 1986, Muijen et al 1992, Burns et al 1993a,b), hospital with day hospital care (c.f. Creed et al 1991a,b) and hospital with early community intervention in psychiatric emergencies (c.f. Merson et al 1992). Although these studies have been influential with regards to service delivery there have been criticisms. For example, several of the studies (c.f. Stein and Test 1980, Hoult 1986, Muijen et al 1992) were conducted on innovative service developments which had attracted both additional funding and high quality staff who were motivated towards ensuring the success of the development. Concerns have consequently been raised as to whether the findings of these studies could be replicated in less well resourced facilities (Holloway 1995).

Finally, the third group of studies has focused on the evaluation of a range of community-based facilities and developments for both deinstitutionalized patients and the newer non-institutionalized group. These include studies of integrated, multidisciplinary community-based care (c.f. Wilkinson et al 1995), residential hostels (c.f. Wykes 1982, Gibbons 1986, Hyde et al 1987), community mental health centres (c.f. Patmore and Weaver 1991), day care (c.f. Holloway 1989), and care management (c.f. Holloway 1991, Ford et al 1993).

3.5.2 Studies focusing on methodology

The accrued evidence from the research to date suggests that considerable progress has been made towards developing community-based services. However Steinwachs et al (1992) suggests that understanding is still lacking about ways to organize community services to meet the needs of people with long-term mental health problems. The difficulties of conducting evaluative research within multi-faceted community-based services cannot be underestimated and the methodological issues which have been explored in order to attempt to meet this challenge will now be discussed.

In the field of health services evaluation it has been a traditional practice to distinguish between input or structure, process and outcome evaluation (Morosini and Veltro 1991). The study of input relies on accurate information on factors within the organizational system such as facilities and equipment available, staffing levels, styles of management and characteristics of care givers. Process refers to the actual nature of the service provided, that is, does it meet the clients' needs and are effective treatments being offered ? Finally outcome evaluation should reflect what happens to people as a result of their being involved in a service. Within this model, evaluation may be undertaken from any one, or combination of these areas, although Donabedian (1985) does suggest that looking at any one of these elements in isolation is inadequate.

3.5.2.1 Evaluating input

In the National Health Service, data sources for evaluating input include activity data, 'Korner data' sets, patient information systems, medical audit, skill mix data and case registers (Shepherd 1988, St Leger et al 1992, Wing 1996). The emphasis on evaluating and monitoring input, particularly in governmental policies on deinstitutionalization, has not been accompanied by standardized published measures of input (Brugha and Lindsay 1996). This has been partially remedied by six recently published instruments designed to be used as quality assurance assessments for mental health policy, mental health programmes, out-patient mental health facilities, primary health care facilities and residential facilities (c.f. Janka and Chandrashekar 1993).

3.5.2.2 Evaluating process

There are a number of alternative approaches to the measurement of the process of care, although what constitutes a good quality service is still a matter of debate. Anthony et al (1982) for example, have attempted to list the components of a good rehabilitation programme which could be used as a checklist against which the overall adequacy of the rehabilitation being practiced in a particular setting might be evaluated. These include client involvement in rehabilitation and assessment, direct teaching of skills to clients, individualized client rehabilitation plans, and follow-up of clients in their real life. A number of measures have also been developed to evaluate management practices in long-term care settings. These measures identify a number of dimensions which can be classified under the headings of client-orientated versus institutionally-orientated practice (c.f. Shepherd and Richardson 1979, Garety and Morris 1984, Wykes et al 1982). The limitations of these approaches are that the components or dimensions that are measured have been identified by practitioners and researchers and therefore might not necessarily equate to what the clients might consider to be a good quality service.

Shepherd (1988) argues however that the most systematic approach to process evaluation currently being developed is within the field of needs assessment. The growing literature in this area has explored the issues around how needs can be defined and who should assess them (c.f. Wing and Morris 1981, Bennett 1978, 1980, Shepherd 1984) and several measures have subsequently been developed to assist the move towards services that are more appropriate to the needs of their users. The most well reported of these being the Needs for Care Assessment described by Brewin et al (1987). This measure is based on an individualized assessment of clinical and social problems or deficits in functioning, linked with a schedule that prescribes appropriate actions or care for the defined problems. Several studies have presented their findings on individual needs assessment using this instrument (c.f. Brugha et al 1988, Brewin et al 1988, Compton and Brugha 1988, Pryce et al 1993) along with a detailed critique of the approach (c.f. Brewin and Wing 1993). Two other instruments which have attracted attention are the Camberwell Assessment of Need (Thornicroft 1994), and the Cardinal Needs Schedule (Marshall 1994). These three measures essentially represent a quantitative approach to assessing needs. Hayward et al (1993) however suggest that there should be two distinct but complementary approaches to needs assessment. Namely, the quantitative approach already discussed and a qualitative approach which focuses on what clients and carers say they need. By using stakeholders conferences and focus groups, the qualitative approach aims to define the needs of people with mental health problems from the perspective of users and carers, to identify gaps in the service and to share ideas for future developments. Hayward et al (1993) therefore argue that by combining the most useful elements from both qualitative and quantitative approaches; a more effective, efficient and user friendly service for people with mental health problems should result. This will be achieved by using quantitative measures to gain an estimation of the numbers of people with a particular diagnosis in a given district, and to match this with qualitative information on existing services to give a more accurate picture of the scope, nature, and size of services required.

3.5.2.3 Evaluating outcome

Until recently evaluation in mental health care has focused very much on input and process but has tended to ignore outcomes (Brugha and Lindsay 1996, Thomas 1996). The current emphasis on measuring the outcomes of care derives primarily from the lack of evidence concerning the effectiveness of many treatments and the growing cost of providing services for people with mental health problems (Nocon and Qureshi 1996, Ramon 1996). This has prompted political pressure for evidence to demonstrate the efficiency and cost-effectiveness of services (Coulter 1991). Many of the changes introduced to mental health services, particularly by the NHS and Community Care Act (Department of Health 1990) can be seen as creating an environment which facilitates a focus on outcome as the arrangements are intended to address the users' and carers' needs more directly and effectively than under the previous service-led system (Nocon and Qureshi 1996). It is argued that outcome studies are essential to demonstrate the effectiveness of psychiatric treatments and services both in terms of benefits to patients and providing value for money (Mirin and Mamerow 1991, Sullivan 1996). Consequently the measurement of outcome is currently viewed as one of the more important components of mental health service evaluation (Milne 1987, Morosini and Veltro 1991, Brugha and Lindsay 1996). The work in this field however is still in its infancy (Heiden 1996), and the lack of knowledge on the efficacy of psychiatric interventions has been highlighted by various authors (c.f. Jenkins 1990, Mirin and Mamerow 1991, Attkisson et al 1992).

The need to conduct outcome evaluation studies which adopt a comprehensive, multi-dimensional perspective is a strong theme in much of the current literature (Mirin and Mamerow 1991, Sullivan 1996, Ruggeri and Tansella 1996, Ramon 1996). This development reflects the fact that many people with mental health problems receive complex packages of care within multi-faceted community-based mental health services. It is therefore argued that this care can only be evaluated within a multi-dimensional outcome framework which includes the use of measures to assess a broad range of functional areas from a range of perspectives such as the client, relatives and professional groups. Much of the work to date reflects the central concerns of providing a service which benefits clients within finite resources. This has resulted in the development of outcome tools to measure social functioning, quality of life, client satisfaction, and cost-effectiveness; each of which will now be considered in turn.

3.5.2.3.1 Social functioning

The measurement of the social functioning of clients with mental health problems has become increasingly important. This is because illnesses such as schizophrenia and the major affective disorders in particular are strongly associated with social dysfunctioning, and because the course of the illness, symptomatology and social functioning may vary (Wiersma 1996). Measures of social functioning have therefore been developed as quick and accurate indicators of the severity of mental health problems and are useful in both the tracking of individual patients, and for the initial evaluations of the characteristics of patient populations attending particular services (Jones et al 1995).

Social functioning refers to the performance of social roles that would normally be expected of an individual in his or her habitual social environment. These roles include occupational, household, marital, parental, family and social roles plus leisure activities, general interests and self-care. The majority of social functioning measures assess the adequacy of a client's functioning within these roles although there are some combined measures which include the assessment of quality of life, social support, psychiatric symptomatology, the burden of illness on the family and satisfaction with services (Jenkins 1990).

A large number of schedules and instruments have been developed to measure social functioning. The content tends to be similar in each, although there are differences in the wording, the description, the anchor points, the focus, the scaling, and the client group targeted by the measure (Jenkins 1990, Wiersma 1996). Comprehensive general reviews of social functioning measures include McDowell and Newell (1987), Thompson (1989), Weissman et al (1981), Katschnig (1983), Wing (1989), Morrison and Bellack (1987), and Bowling (1995). More specific reviews include Wallace (1986) and Rosen et al (1989) with respect to schizophrenia. An assessment of social functioning can be obtained from information provided by the client, by a family member, or by a mental health professional. Each source of information has its advantages and disadvantages which influences the reliability and validity of the assessment (Wiersma 1996).

There have been some reservations expressed about the measurement of social functioning including the lack of agreement on social norms, unwarranted assumptions, number of relevant roles and lack of validity (Platt 1981, Katschnig 1983). However, Wiersma (1996) on the basis of his extensive use of such measures in research, argues that these assessments can be performed reliably, that the measures take the sociodemographic backgrounds of patients adequately into account, that the internal and external validity is satisfactory, and they are sensitive to change.

3.5.2.3.2 Quality of life

Over the last two decades increasing emphasis has been placed on quality of life as a crucial outcome variable in evaluating community-based services. Within mental health services this reflects a shift in emphasis from symptom-orientated measures of treatment outcome towards a more holistic approach to care based on the assessment of the well-being of service users (Oliver et al 1995). Conceptually quality of life could cover a wide range of outcome measures such as measures of symptomatology and functional status, however it commonly refers to measures covering patients' perspectives on what they have, how they are doing and how they feel about their life circumstances (Baker and Intagliata 1982, Lehman 1996).

Quality of life has been defined as having subjective and objective components. The subjective component is often referred to as well-being or life satisfaction and is usually assessed by means of satisfaction ratings concerning different life areas. The objective component includes aspects of living conditions such as accommodation, employment, leisure and finance and is usually determined by direct questions to the interviewees concerning the different aspects of their lives (Barry and Zissi 1996). Although increasing importance has been accorded to quality of life as an indicator of outcome, its inclusion in evaluative studies is relatively new (Oliver 1991, Hafner and Heiden 1996, Hansson 1996). In a review of quality of life studies of people with long-term mental health problems, Barry and Crosby (1996) found that the majority of such studies were cross-sectional in nature or involved comparisons between groups in different care settings. Relatively few of the studies reviewed had directly examined the sensitivity of quality of life measures in evaluating change.

To date a number of instruments to measure quality of life have been developed and reviews of measures which have been specifically developed for people with mental health problems have been published by Barry and Zissi (1996), Lehman (1996), and Oliver et al (1996). The accumulated literature acknowledges that considerable work has yet to be done with regards to the reliability and validity of the existing instruments. Scores for example, may be affected by poor insight, recent life events, expectations and personal desires, side effects of medication, cognitive and emotional functioning, and motivation for life improvement (Barry et al 1993, Atkinson 1997). Despite these methodological difficulties, it has been argued that quality of life provides a framework for the better understanding of the very complex needs of clients with long-term mental health problems and the impact of services on their lives (Lehman 1988). It also offers a useful means of incorporating the clients' perspective into the evaluation process (Oliver et al 1995, Barry and Crosby 1996, Barry and Zissi 1996), and there is some evidence to suggest that clients with long-term mental health problems are able to provide reliable responses to a quality of life interview (Lehman et al 1982). As an outcome measure, quality of life is generally used alongside other outcome indices such as symptomatology, social behaviour or social functioning.

3.5.2.3.3 Client satisfaction

The third outcome variable that is receiving increasing attention is that of client satisfaction. This reflects the growing recognition that obtaining feedback from users is an integral part of measuring effectiveness of services and that without such a perspective, evaluation will have limited legitimacy (Knox and McAlister 1995). The increased importance ascribed to the views of users is linked to notions of consumerism, public accountability and the pursuit of quality, all of which assume that involving users is valuable (Knox and McAlister 1995).

The measures currently being developed are concerned with the availability, accessibility and acceptability of services, patient-professional communication, and patients' views about services and/or interventions. The most common methods for evaluating client satisfaction have been reviewed by Lebow (1982) and these include questionnaire surveys, complaints or statements of approval, and estimates of service utilization. Certain reservations have been expressed about the measurement of client satisfaction. First, there are concerns about the reliability and validity of available measures (Kalman 1983). Second, Brandon (1981) argues that the opinions of people with mental health problems are seldom sought because of the widely held view that mental illness deprives an individual of the capacity to make considered and rational judgements, and that patient's views are often only considered useful for making and confirming a diagnosis. Recent evidence however suggests that people with mental health problems are sensitive to verbal and non-verbal elements of the health care process, fairly accurate in distinguishing the quality of provider behaviours, such as courtesy and competence, and that they base their satisfaction ratings on these discriminations (Ruggeri and Tansella 1996).

3.5.2.3.4 Economic evaluation

Finally, economic evaluations are increasingly likely to become component parts of, or supplements to many evaluation studies. This development reflects the aims of central government, the National Health Service, and mental health providers and purchasers to promote cost-effectiveness in treatment and service provision (Knapp 1995). The aim of economic evaluations is not to cut health spending or to pare down costs, but to improve both the efficiency with which health care and other resources are employed and the targeting of those resources on needs and demands. Approaches to economic evaluations combine outcome and costs data in cost-effectiveness, cost-benefit and cost-utility analyses (Knapp 1995). The approach adopted to research is not very different from other evaluations of health care, where it differs is in its tendency to examine a fuller range of cause and effect and add a resource dimension. Although increasing importance has been attached to the economic component of evaluation, there are currently few economic evaluations of mental health care and its impact to date has been relatively small (Knapp 1995, Knapp and Beecham 1996).

These four categories of outcome measurement - social functioning, quality of life, client satisfaction, and cost-effectiveness - are not exhaustive however. An increasing interest has also been shown in the development of tools to measure family burden, staff stress and morale, and the effects of stigma (Wilkinson et al 1995).

3.5.2.3.5 Problems in evaluating outcome

Although outcome measurement is now considered to be one of the key elements in the evaluation of mental health care a number of problems have yet to be resolved. Outcome evaluation implies measurement against accepted criteria so that it is possible to ascertain the degree of the patient's improvement. This is a complex undertaking as the goals of mental health services can be conceptualized in a number of ways. From an epidemiological stance, Wing (1973) argues that the aim of mental health care is the reduction and containment of mental morbidity. More recently Murphy (1992) in her discussion of visionary goals suggests that "a service should aspire to provide individuals with as fulfilling and rewarding a life as possible and provide for the ordinary needs of life - a home, daily occupation, emotional support through friendships and social contacts and recognizes individuals rights as citizens". As criteria for the evaluation of the effectiveness and efficiency of services these goals need to be translated into measurable and accessible realities. In mental health services research however, there are few agreed standards and no accepted method of measuring success (Heiden 1996), and the objectives of many mental health services are insufficiently defined making it difficult to measure outcome (Falloon et al 1987).

Difficulties also exist in the selection or development of appropriate measures of the impact of the intervention, that are reliable, valid, sensitive to change, and specific to the situation concerned (Jenkins 1990). Even with the existence and assiduous use of such measures, attribution of improvement to specific interventions is problematic. A client's clinical symptoms and social functioning for example, is determined not only by the treatment received but also by a multitude of cultural, socio-economic, and interrelational factors (Mirin and Mamerow 1991). A poor quality outcome therefore does not necessarily imply a poor quality of care (Brugha and Lindsay 1996, Ramon 1996).

The timing of outcome measurement is also problematic particularly when the service being evaluated has low level effects such as long-term rehabilitation services, when the start and end of treatment is unclear, or when several treatments are being conducted simultaneously (Nocon and Qureshi 1996). In addition the timing must also take into account that changes in a patient's symptoms or functional abilities are points along a continuum rather than absolutes and that progress may take place over many years (Mirin and Namerow 1991).

The content validity of the measurement of outcome according to different perspectives such as those of the patient, relatives and professionals remains relatively unexplored in the literature. Differences in patients' and professionals' views on service delivery have been reported (Ruggeri and Dall'Agnola 1993), but if the patient's view is not included, then there is the risk that the evaluation may purely reflect the perceptions of the professionals. Moreover the majority of outcome measures rely heavily on standards generated by professionals, thus their content validity according to patient views are questionable (Ruggeri and Tansella 1996).

Finally outcome evaluation is often perceived as a subversive activity and resistance from service providers can pose problems. This resistance may stem from a suspicion that the evaluation is about fault finding , they may fear a reduction in resources , or feel that it is only those who directly care for the clients who can fully understand the complexity of their problems and be the judge of the care provided (Coursey 1977, Coulter 1991, Brugha and Lindsay 1996, Ramon 1996).

3.5.3 Summary of trends

The approach adopted by the majority of evaluative studies of community-based mental health services reflects a bias towards natural science methodology and a positivist research framework in a quest to prove the worth and/or success of a particular service or intervention (Ramon 1996). The adherence to this traditional or orthodox approach to evaluation may reflect the natural sciences background of many of the researchers working within the field. Such researchers argue that there is an ethical and scientific obligation to demonstrate the efficacy of interventions and services (Hafner and Heiden 1991, Kluiter and Wiersma 1996), and that the randomized controlled trial is the most appropriate research design to ascertain the superiority of one intervention over another

(Fraser et al 1995). In addition the funding bodies responsible for the allocation of research grants to evaluative studies favour proposals which adopt a traditional, objective approach to evaluation (c.f. Department of Health 1993d).

Whilst the value of the randomized controlled trial in evaluating specific treatments and interventions is acknowledged, there is a growing consensus that this approach is unsuitable for complex evaluations of community-based services and its limitations have been widely debated (c.f. Coulter 1991, Hafner and Heiden 1991, Morosini and Veltro 1991, Tyrer & Creed 1995, Kluiter and Wiersma 1996). Indeed, Bachrach (1996) has argued that the current preoccupation with statistical analysis and experimental design is often inappropriate or at least premature much of the time. She also criticizes the fact that the allocation of research funding tends to favour the demonstration of technical competence over the appreciation of clinical reality. However, no one alternative approach to the evaluation of community-based mental health services has been advocated to date. Instead there is a growing recognition amongst researchers and practitioners in mental health that qualitative and multi-method approaches to evaluation should be applied more widely, including a focus on the views of users and carers (Goldberg and Connelly 1982, Wortman 1983, Cook and Shadish 1986, Rossi and Wright 1994, Wright et al 1994). This provides a climate for researchers to tailor evaluative studies in mental health care according to the activities being investigated.

3.6 Towards a pluralistic model of evaluation

So far this chapter has explored the methodological background against which this evaluation was developed. The chapter began by justifying the choice of an evaluative research approach. This was followed by an overview of current debates in the broad evaluation literature, that is in education and the social sciences, leading into a focus on specific developments in mental health services evaluation. In particular the shift in emphasis from the dominance of the positivist approach to evaluative research towards the gradual acceptance of alternative approaches has been highlighted. In mental health services research this shift away from a positivist approach is partly a response to the need to include users' views in evaluation as a result of policy imperatives (c.f. Department of Health 1989a; 1995c; 1998a), and partly a response to the failure of quantitative approaches to answer questions about the subjective experience of clients and service providers (Strauss 1994, Ramon 1996). The value of qualitative approaches is not in doubt in mental health services research but this does not mean to say that evaluators know how best to proceed. The review of the literature on evaluative research, both broadly (see section 3.4) and specifically (see section 3.5), has shown that evaluations need to take account of the views of more than one group, and that it is essential to incorporate users' views whilst not ignoring the views of those who provide the service. Thus the complexity of mental health evaluation fits with a pluralistic approach which will now be discussed in more detail.

In developing the methodology a number of evaluation models were critically reviewed to see whether they were suitable for this evaluation. A review of the evaluative literature revealed that there are very many models which differ according to their philosophical orientation and the values which underpin them (see Table 1, section 3.4). They also vary in terms of their comprehensiveness and complexity, and their particular strengths and weaknesses. The advantages and disadvantages of various models have been comprehensively reviewed in the literature (c.f. Coursey et al 1977, House 1978, Robson 1993, Everitt and Hardiker 1996). Building on these reviews, as well as issues raised in the preceding sections, the discussion will now focus on how and why a pluralistic model of evaluation was best suited to this investigation. This justification is set against an appreciation of three other models which had the potential to be adapted and modified for this evaluation. Namely, the welfare model (Davies and Challis 1986), the illuminative approach (Parlett 1981), and fourth generation evaluation (Guba and Lincoln 1989).

The welfare model of evaluation (Davies and Challis 1986) was developed by researchers working in the Personal Social Services Research Unit (PSSRU) at the University of Kent at Cantebury in the mid to late 1970's. Working closely with the Social Services for Kent County Council, a set of experiments (called community care projects) were set up for the care of elderly people at high risk of institutional long-term care. These experiments created structures which provided incentives to improve efficiency. The power to manage resources was devolved to case managers who in turn became increasingly accountable for their practice. The welfare model of evaluation was developed alongside the setting up of these experiments in order to evaluate their success in meeting pre-determined targets. The model is dominated by concepts of efficiency and effectiveness, and focuses on comprehensive measurement of resource use and the clear specification and measurement of outcomes. Although the welfare model is primarily an economic one, it does ground evaluation in a comprehensive analysis of health policy. For example, Wright et al (1994) apply the model to evaluating services for people with learning difficulties. Through a comprehensive analysis of the reorganization of health and social care in Britain in the mid 1980's to early 1990's, they argue that this economic approach is currently pertinent as service providers who are unable to meet consumer demand (as expressed by purchasers) at a price that reflects the best use of resources employed will be driven out of business by more efficient providers (Wright et al 1994, p25).

The welfare model is informed by a positivist methodology. Evaluators working within this field generally seek to remain separate from the practice they are evaluating and make claims of objectivity, neutrality and lack of bias (Smith and Cantley 1985, Greene 1994). Everitt and Hardiker (1996) argue however, that such a stance effectively de-politicizes the research process and the findings of the evaluation. That is, it abstracts the process and the findings from the social and political context in which it takes place. In addition Smith and Cantley (1985, p5) argue that approaches typified by the welfare model, tend to produce findings for a narrow elite audience such as senior managers, and regard organizations as consensual entities rather than places in which different interests and values are played out. For these reasons the welfare model was an unsuitable framework for this evaluation, and more suited to projects requiring an economic dimension.

Having ascertained that models such as the welfare model, and indeed others sitting within the broad rational-technical approach to evaluation, were unsuited to this investigation, models situated within the interpretivist approach were critically reviewed. These included illuminative evaluation (Parlett 1981), fourth generation evaluation (Guba and Lincoln 1989), and pluralistic evaluation (Smith and Cantley 1985). Although there are significant differences between each of these models, they all assume that the social world is different from the physical and natural one and consequently reject the notion of value-free objectivity. These models were considered particularly suitable for this evaluation as they acknowledge the existence of a range of different, and possibly competing and/or conflicting views of success; and that an understanding of practice cannot be separated from its wider context.

Illuminative evaluation (Parlett 1981) was primarily developed by researchers evaluating educational programmes although it has been used more recently in the health field (c.f. Prout 1992). The primary aim of this approach is to illuminate or shed light upon what is going on in practice. In this approach there is no pre-set design, instead the issues to be examined are identified through familiarization with the service / project being evaluated in negotiation with key stakeholders. The research design changes through the course of the evaluation to accommodate an increasing knowledge base. Finally illuminative evaluators do not judge the success or otherwise of the project / service being evaluated. Instead they confine themselves to summing up arguments for and against different interpretations, policies and possible decisions (Parlett 1981).

This notion of negotiation also runs through the fourth generation approach to evaluation described by Guba and Lincoln (1989). Again they argue that it is important to include the views of all stakeholders in an evaluation. They go one step further than illuminative evaluators however, by arguing that it is not enough for different stakeholders to be heard but that they should also be heard by one another. Fourth generation evaluators therefore see themselves as facilitators of a process whereby key stakeholders debate the evidence about their practice so that the conclusions and recommendations of an evaluation are arrived at jointly and are not the sole province of the evaluator. Guba and Lincoln (1989, p41) acknowledge however that consensus may never be reached and suggest that in this sense evaluation is never finished or complete.

Despite the strengths of the illuminative approach (Parlett 1981) and fourth generation evaluation (Guba and Lincoln 1989) such as giving participants a sense of ownership of the evaluation, and highlighting the diverse interests of a range of stakeholders; there have been a number of criticisms of these approaches in the literature (c.f. Adelman 1996, Kushner 1996, Pawson 1996). The criticisms suggest that these approaches are limited when it comes to making pragmatic decisions about the quality of services or programmes being evaluated, and that there is a tendency for evaluators to go around in circles rather than making progress towards a recognizable reality. The pluralistic model of evaluation, described by Smith and Cantley (1985), was eventually selected as it provided a framework to evaluate an evolving community-based mental health service; to include the views of a range of groups, including the women; to look behind the professional rhetoric of success; to explore the process and outcome of service delivery; and to take account of the wider societal and political context which impact on the services and in turn on the women's experiences.

Unlike Smith and Cantley (1985) who were engaged in developing the pluralistic model and had little to build on since they were working within a critique of the rationalist model; the researcher, in common with pluralistic researchers who have built on their work (c.f. Nolan and Grant 1993, Ong 1993) could adapt the pluralistic approach to the requirements of this investigation. This investigation was therefore informed by a pluralist approach, and indeed as the investigation developed the researcher was able to move beyond it by drawing on the work of Everitt and Hardiker (1996) , so that the voices of women with long-term mental health problems were not simply one of many, but the focus, which would not otherwise have been possible.

The key features of the pluralistic model of evaluation will now be discussed together with an exploration of its strengths and weaknesses. The way in which the model was used to inform the design of this investigation and the modifications and developments that were made are explored in chapter four.

The pluralistic approach to evaluative research embodies the following key features. First, the major stakeholders must be identified in order to elicit and compare their views. This comparison includes both their ideological perspectives and the functional strategies they adopt to maintain their stance. Second, the criteria for the success of an innovation, service or treatment are determined by the stakeholders involved. The evaluation must document not only the plurality of notions of success but also the different groups' strategies as they strive to implement their own perspective in their own interests (Smith and Cantley (1985). As a consequence of adopting this stance, the notion of success itself becomes pluralistic rather than unitary (Nolan and Grant 1993). There are a variety of strategies adopted by researchers in their attempts to identify the meanings of success as defined by those responsible for planning, implementing and using the service being evaluated. Smith and Cantley (1985) for example, conducted a set of semi-structured, tape-recorded interviews with a sample of staff and patients' relatives about what they considered to be relevant criteria of success. In contrast Nolan and Grant (1993) conducted an extensive review of the literature relating to respite care to both identify groups of people whose views needed to be taken into account, and the broad criteria against which to evaluate the success of the project. Finally

Ong (1993) used the pluralistic approach to formulate dimensions of the concept of quality of life by interviewing patients and staff, and aimed to arrive at a post hoc definition of success.

The third feature of pluralistic evaluation is the use of multiple methods of data collection which embodies the principles of triangulation. The purpose of this approach is to bring together a range of information sources, data collection methods and data types to verify a single phenomenon, thus strengthening data credibility (Wright et al 1994). In addition, Smith and Cantley (1985, p173) argue that methodological pluralism is vital to overcome the issue that different data sources tend to be interest-bound, that is tied to the interests of one group of participants more than another; and also ideology-bound, that is reflecting one group's perspectives on success rather than another. They therefore suggest that using a range of data collection methods in an evaluation ensures as far as possible that the range of interests, perspectives and ideologies are reflected. It has also been argued that the more an evaluative effort is spread over multiple studies, the greater the place for a mixture of methods (Reichardt and Cook 1979, Saxe and Fine 1979, Cronbach et al 1980). These points are directly relevant to this investigation and will be further discussed in chapter four.

Fourth, Beattie (1995) argues that the pluralistic approach to evaluation involves the researcher in "new and closer negotiating stances with informants - both as individuals and as groups or communities". He suggests that these relationships are new because they were not required by the objective stance of the positivist researcher, nor by those conducting ethnographic research, and that the pluralistic approach crosses the boundary between researcher and researched. By attending to personal accounts around the focus of enquiry, putting informants at their ease, exchanging experiences, and offering advice and support, the researcher attempts to make the evaluation less of an imposition and more of a shared exploration of issues and a search for action. Beattie (1995) suggests that this stance adopted by the researcher arises from the view that pluralistic evaluation is essentially a "dialogical process of enquiry".

The limited methodological debate around the pluralistic approach to evaluative research and the few published studies within the health care field makes it difficult to draw firm conclusions concerning the advantages and disadvantages of the approach. Nevertheless the literature does highlight a number of key issues. These issues are most comprehensively explored by Smith and Cantley (1985) whose study is perceived as a model of pluralistic evaluation by other researchers who have used it (c.f. Nolan and Grant 1993, Ong 1993).

The advantages of the pluralistic approach to evaluative research highlighted by Smith and Cantley (1985) include the following. First, the approach provides a means of evaluating whether the innovation or service is successful or not. This success however, is not judged according to whether or not certain idealized aims are met, but according to the multiple criteria identified by a range of stakeholders. Although identifying multiple criteria for success is a complex undertaking, it does enable the researcher to explore which parts of the service are successful or not and from whose perspective. Smith and Cantley (1985, p 180) suggest that this approach also offers a means of explaining why failures in service provision occur. They argue that "this explanation most often takes the form of an account of which groups have been able to marshall power and resources to pursue their interests, and at what cost to other groups and other forms of service provision". Pluralistic approaches therefore challenge the professional rhetoric of success.

Second, by focusing on the social processes which contribute to the success or failure of a particular service and not just the outcomes; Smith and Cantley (1985, p180) argue that pluralistic evaluations can suggest the way forward for change and development. Explanations grounded in the wider social and political context of which a service is a part, which may or may not include an analysis of conflict and power relationships, can highlight which groups need to be assisted and supported and in what ways. In addition, Smith and Cantley (1985) argue that resistance to change and development is less likely due to the wide range of views elicited rather than a narrow perspective dominated by a limited number of groups or views.

Although the pluralistic approach to evaluative research attempts to overcome many of the criticisms of the dominant positivistic approach, it does have its critics (c.f. Coulter 1991, Ramon 1996). Ramon (1996) for example, argues that pluralistic evaluation is based on the logical assumption that, given the complexity of a service and the incompleteness of any given evaluation measure, it is necessary to use more than one method of evaluation. He doubts however, whether the combination of different methods results in a coherent whole, or whether even triangulation can adequately cover the complexity. He suggests that triangulation can be seen as an insurance policy device, based on the inherent weaknesses of the available repertoire of evaluation methods.

Coulter (1991) acknowledges that the approach is an attempt to accommodate the real world of incremental change. However, she argues that it is a conservative approach because by giving equal legitimacy to a wide range of success criteria, it leaves unresolved the problem of providing directions for change. Smith and Cantley (1985) however, address this notion of conservatism when they argue that although a pluralist evaluation avoids the bias entailed in the selective use of evaluative measures, it may be argued that the emphasis placed on the way in which members themselves perceive a service, introduces a flaw because such an evaluation can assess a service only in its own terms. Defects in a service may well occur because significant groups of professionals, planners, administrators and even consumers are themselves using inappropriate criteria to influence the service. Evaluations should therefore, according to Smith and Cantley, (1985) assess these criteria and thus provide both a radical criticism of the service and suggestions for significant changes and improvements.

Finally Smith and Cantley (1985) note that there is a problem with data exclusion in conducting pluralistic evaluation. The major danger is that in selecting certain groups the researcher may be biased towards one particular set of interests. In their study the views of the elderly patients using the service were not sought, which arguably weakens their evaluation as the views expressed by their carers and the service providers may be very different. The ways in which the criticisms of the pluralistic approach were addressed in this investigation will be discussed in chapter four.

3.7 Conclusion

The arguments in this chapter have been developed to support the choice of a pluralistic model of evaluation as a methodological framework for this investigation. The chapter began by reflecting back on the key issues which were raised in chapters one and two. This served to remind the reader that not only do women with long-term mental health problems have a wide range of particular problems and difficulties, but that an exploration of their experiences within specialist community-based mental health services must take account of the wider societal and political context which impacts on both the organization and delivery of those services.

A critical review of the evaluation literature, drawing broadly from the field of education and social sciences (see section 3.4) and specifically from the field of mental health services research (see section 3.5), highlighted the problems of using orthodox or traditional models of evaluation to explore the complex and evolving nature of community-based mental health services. The review also illustrated the gradual acceptance of alternative models of evaluation such as those situated within the interpretivist research paradigm. These models, such as illuminative evaluation (Parlett 1981), fourth generation evaluation (Guba and Lincoln 1989), and pluralistic evaluation (Smith and Cantley 1985), emphasize the subjectivity of evaluation, acknowledge the importance of including the views of a range of stakeholders, and view evaluation as an empowering rather than a punitive exercise.

The pluralistic model of evaluation developed by Smith and Cantley (1985), was ultimately selected as the most suitable methodological framework for this investigation. This model, which was discussed in section 3.6, provides a framework for the researcher to design an evaluation which will accommodate a complex, evolving community-based mental health service; that will include a range of stakeholder groups, especially women with long-term mental health problems; and that will look beyond the professional rhetoric of success. In addition the pluralistic model is an ideal way of beginning to understand the process of service delivery, and also as a means of saying something meaningful about outcomes in terms of the success or otherwise of the service in meeting the needs of the women from their perspective.

Finally, the researcher, in common with other pluralistic evaluators (c.f. Ong 1993, Nolan and Grant 1994) who have built on the work of Smith and Cantley (1985), has modified and developed the pluralistic model to suit the requirements of this particular investigation. The ways in which this was done will be explored in chapter four, together with a consideration of how the criticisms of the model have been addressed.

Chapter Four

Research Design

4.1 Introduction

The previous chapter developed a set of arguments to support the choice of a pluralistic model of evaluation as the most appropriate methodological framework for this investigation. The purpose of this chapter is to discuss the way in which this model was used to inform the design of this investigation, and to highlight and justify the modifications and developments that were made.

The chapter begins with a description of the long-term mental health service which provided the base for this study. The service is deliberately described in some detail as this provides essential background material which will be subsequently drawn upon later in this chapter, and throughout the rest of the thesis. This is followed by a discussion which focuses on the way in which a pluralistic model of evaluation was used to inform the design of the investigation. Particular emphasis is placed on the complexity of identifying suitable criteria which could be used to judge the success or otherwise of the service in meeting the needs of women with long-term mental health problems. The final part of the chapter discusses how access was gained to the research setting and the ethical considerations that were made.

4.2 Research setting

This evaluation was conducted in the Rehabilitation and Community Care Service (RCCS), one of seven Clinical Directorates which make up the Nottingham Healthcare NHS Trust. The Trust operates within the Nottingham Health Authority catchment area, with an estimated population of 620,000. As a Department of Health designated demonstration service for psychiatric rehabilitation, the RCCS offered a useful and appropriate focus for this evaluation, as mental health professionals had expressed an interest in research in this area and there was a developed awareness of the importance of women's issues within the service. Women care managers had initiated regular meetings to discuss women's issues and consider ways of meeting the particular needs of women clients. One of the residential facilities has a designated women-only house so that women have a choice about sharing their accommodation with male clients. In addition, many female clients in the service are allocated female key workers unless they expressly wish to have a male worker. These positive endeavours offered an opportunity to evaluate services for women in a known centre of good practice.

4.2.1 Aims and values of the service

The RCCS's mission is to enable people with long-term mental health problems to have a high quality of life despite their mental health difficulties, to provide support services, and to reduce the level of their disability. The service has clearly identified a number of core values and aims. The core values include putting service users first, the pursuit of excellence, multi-disciplinary teamwork, valuing staff and making good use of resources (RCCS 1995). The specific aims of the service are outlined in Table 2. These core values and aims were not imposed on the staff by senior personnel, but were developed over time through a process of consultation and negotiation with representatives from all parts of the service.

The shared mission, core values and aims are not reflected in one universally accepted philosophy or model to guide practice within the RCCS. The Strengths model of practice has however, been adopted by many parts of the service. The Strengths model was originally developed as an approach to care management in the United States of America, and its aim is to normalize the helping process and make it an empowering interaction (Rapp & Wintersteen 1989, Prance 1993). The model is underpinned by a number of key principles. First, the focus is on the clients' strengths, interests and abilities, rather than on weaknesses or deficits. Second, clients with long-term mental health problems can learn, grow and change. Third, the client / key worker

Table 2: Aims of the Rehabilitation and Community Care Service (RCCS 1995)

- to provide specialist rehabilitation and community care services in order to achieve the highest quality of life to service users, and to reduce disabilities
- to enable clients to live in homes of their own
- to develop networks of human relationships, to work, and to function at the most independent level possible
- to work closely with all other agencies concerned with the needs of our client group, statutory, voluntary and private, to ensure continuity of care and to facilitate the development of a well coordinated network of services
- to provide a high quality of service which meets the needs of individual clients
- to advocate for the client group and to ensure that there are adequate resources to meet their needs
- to make creative use of resources and to ensure that there are adequate resources to meet their needs
- services will be provided, as far as possible, close to the individual's home environment, and in a manner and locations which do not segregate and which do not stigmatize
- to provide a service in which the service user and staff are valued and involved. The voice of the client and carers, individually and collectively is sought and is influential in decision-making
- to provide a flexible service which responds quickly and smoothly to changes in the needs of individual clients and to changes in the practice of mental health care
- to provide services which are easily accessible to users and which are also sensitive to culture, religion, race, physical disability, age and sex. To promote the service positively to minority groups
- to ensure effective communication, both within the service and with other agencies
- to evaluate and demonstrate the effectiveness of services. To identify shortfalls in resources for the client group and endeavour to develop services to address un-met needs
- to develop quality assurance systems which ensure that high standards of practice are developed and maintained
- to ensure, within available resources, that the numbers, skills and training of staff match the needs of the clients
- to ensure that there is an effective management structure, and that there are coherent, comprehensive and communicated policies and procedures
- to ensure that the physical environments in which care is provided are therapeutic, allow privacy, and are comfortable
- to achieve a balance between the need to take risks in order to achieve change and improvements in services and the need to safeguard vulnerable people

relationship is viewed as the foundation of mutual collaboration. Within this collaboration the client is seen as the director of the helping process. Finally assertive outreach is the preferred mode of working with clients as the community is viewed as an oasis of potential resources rather than an obstacle.

4.2.2 The client group

The majority of clients referred to the RCCS suffer from severe and long-term mental illnesses, such as schizophrenia, although exceptionally individuals with other diagnoses are accepted. A secondary diagnosis of personality disorder or substance misuse is becoming increasingly common. Over the past few years an increasing number of women have been accepted into the service and there has been a fall in the age of the client group (RCCS 1996a).

The criteria for accepting clients into the service are based upon diagnosis, level of disability and duration of illness. Many people who fulfil the criteria receive services from other Directorates, but RCCS works with those with a higher level of un-met need, or where a multiplicity of services are required (RCCS 1996a). For RCCS to be the most appropriate service, the individual concerned should meet the following criteria. First, the majority of referrals will have a diagnosis of functional psychosis, although exceptionally people with other diagnoses are considered. Second, the client must require a multiplicity of services, or residential care, and have high levels of un-met need. Third, clients must have been appropriate for Care Programme Approach for one year or more or had a continuous stay in a psychiatric hospital of six months or more. Exceptionally people are considered sooner if there is clearly a need for continuing care.

Within these criteria certain groups of clients are usually excluded because they are best dealt with by other services. These are persons of school age and younger, persons suffering a mental illness for the first time over the age of 65, persons with a progressive dementia, and persons with persistent violent and threatening behaviour.

4.2.3 Structure of the service

The RCCS was established in 1982 and has evolved primarily from the closure of three long-stay hospitals. Development has been possible through the re-utilization of capital and revenue as the older institutional services were closed, with only one relatively small injection of funding through joint finance (Howat et al 1988). It is now community-based, providing a continuing service to approximately 500 clients with long-term mental health problems. The RCCS is differentiated from Social Services and the private and voluntary sectors in targeting the most disabled client group and by the provision of a comprehensive range of community services. The service now provides an increasingly flexible and responsive range of crisis resolution and respite care in addition to rehabilitation and continuing care. The clients either live in their own accommodation, within the residential services provided by the RCCS, or in a variety of facilities such as hostels, group homes and supported housing provided by the Social Services, the voluntary and the private sector.

The RCCS is headed by a Clinical Director and directly managed by four service managers. The range of services provided by the RCCS are described in detail and are summarized in Table 3.

Table 3: Components of the Rehabilitation and Community Care Service (RCCS 1996b)

Title	Function	Capacity
Community Rehabilitation Teams (4) (Care management)	Assessment, care planning, coordination and monitoring of care. Crisis intervention	478 clients
Community Support Teams (4) (Dispersed Intensively Supported Housing - DISH)	Long-term, flexible outreach care and support to clients living in dispersed ordinary housing.	63 clients
Skills and Practical Activity Network (2 Centres)	Sheltered work, employment rehabilitation, practical skills and training	50 clients at each Centre
Day Centres (2 Centres)	Social rehabilitation and support services	33 clients at each Centre
Residential Care Services: MC TM BH DL	Short term rehabilitation and crisis intervention Long term rehabilitation and continuing care " " " "	28 clients 12 clients 12 clients 12 clients
Residential Partnership Schemes: PC OS OR HL SH	Long term rehabilitation and continuing care	12 clients 12 clients 21 clients 15 clients 11 clients
Medical Services	Four consultant psychiatrists specializing in rehabilitation with supporting junior staff	
Clinical Specialist Services	A nurse specialist and a clinical psychologist	
Community Occupational Therapy Team	Offer support to residential services and assessment and treatment of community clients	
Community Connections Team	Promote community-based activities	No current limit

Community Rehabilitation Teams: Formerly known as the care management teams, this service now comprises four multi-disciplinary teams of community psychiatric nurses, social workers and occupational therapists. The teams specialize in caring for clients who have complex needs and require multiple support services. The aim is to provide seamless care packages for clients both in the community and through in-patient admissions. The clients are allocated a care manager from one of the teams who is responsible for assessing, planning, implementing, monitoring and reviewing their care in line with the Care Programme Approach (Department of Health 1990b).

The care manager is involved in providing direct care, co-ordinating the care provided by other services, and liaising with other agencies such as housing offices, the Department of Social Security and a variety of community-based facilities. The care managers also contribute to many aspects of development work, for example, carer groups, link worker schemes, service structure, minority groups and liaison with voluntary agencies.

Intensive Community Support Teams: Formally known as Dispersed Intensive Supported Housing (DISH), this is a community-based service providing support and rehabilitation to clients living in their own homes. Most of the clients have secured tenancy agreements with Housing Associations, a few own their own homes or rent from the council. The service is aimed at clients who need input of more than one visit per week and up to two visits per day. The service is provided by four multi-disciplinary teams seven days per week and there is an 'on-call' service in operation allowing access to staff in an emergency. The remit of this service is wide and includes monitoring the physical and mental health of clients, giving medication, one to one counselling and family interventions, support for clients wanting to become involved in community activities, and practical help in developing basic daily living skills. Each team has two places available for crisis or respite care at any one time.

Skills and Practical Activities Network (S.P.A.N.): The skills and practical activity network operates from two main centres, one in the city centre and the other on the outskirts. Both centres offer work orientated and other activities based on the philosophy that work together with daily living and other activities, provides a balanced lifestyle. Each centre has a range of workshops and group activities which include printing, upholstery, crafts, woodwork, clerical skills, cookery, gardening, adult literacy, and men and women's groups. The staff include occupational therapists, technical instructors, projects workers and domestic trainers.

Day Centres: The two day centres are open from 8.15 am to 4.30 pm Monday to Friday with occasional out-of-hours activities. Clients attend from one to three days per week but can attend more frequently if the need arises. Emphasis is placed on developing personal, domestic and leisure skills, utilizing community-based facilities wherever possible. The multi-disciplinary teams at both centres provide a range of activities including woodwork, cooking, poetry reading, keep-fit, sports, and men and women's groups.

Residential Care Services: The residential services consist of four community-based units located in different parts of the city. The units differ in terms of the client group they serve and the nature of care provided. The short-term rehabilitation unit (MC) consists of shared town houses where each client has his or her own bedroom. There is one house allocated for women only, the others are mixed. The facility generally caters for younger clients who have not spent long periods of time in hospital. Although the length of stay depends on the individual needs of the client, the majority stay less than a year, many moving into independent accommodation. Two multi-disciplinary teams of staff provide 24 hour care with an emphasis on enabling clients to come to terms with their difficulties and strengthen their skills. The clients are encouraged to remain as independent as possible and are responsible for providing their own meals and contributing to the housework. The unit additionally offers a crisis and respite service. This enables clients during a period of crisis to get away from the immediate pressures of their own environment and obtain support from staff and fellow residents.

The three long-term rehabilitation and continuing care units (BH, TM and DL) provide 24 hour supported care. These units generally cater for clients who have been in hospital for some years, although recent trends indicate a move towards a younger more challenging resident group. The length of stay tends to be longer than that of the short-term rehabilitation unit, and for many clients this is seen as their home rather than a step towards independent living. The emphasis on supported care is reflected in the provision of meals, domestic and laundry services. The clients are however, encouraged to be as independent as possible and the staff encourage involvement in a range of daily activities.

Residential Partnership Schemes: There are five residential partnership schemes offering 24 hour care and support for clients. These schemes cater for clients over 50 years old, many of whom have been in hospital for many years. Two of the schemes are jointly funded by the Nottingham Health Authority and Nottingham Community Housing Association, two by the Anchor Housing Association and Nottingham Healthcare NHS Trust, and the fifth by the Nottingham Health Authority and Nottinghamshire County Council Social Services. All these homes are staffed by multi-disciplinary teams who aim to provide a safe, comfortable, homely environment in which the clients are encouraged to be as independent as possible. The homes all provide single bedrooms with communal sitting and dining areas and one of the homes is registered for people with physical disabilities. Meals are provided and there are staff responsible for cleaning and laundry. The clients are encouraged to attend day or drop-in centres, and there are programmes of recreational events which include outings in small groups.

Clinical Specialist Services: The clinical specialist service currently comprises a clinical psychologist and a clinical nurse specialist. The service is available to all parts of the RCCS and works with clients and staff either individually or in groups. The activities include individual psychological support, staff supervision, staff education, training and research.

Community Occupational Therapy Team: The community occupational therapy team provides a service to clients living in the RCCS residential units and in the community. Their work includes working with clients to develop their practical living skills, running creative activities, and promoting opportunities to use a range of recreational, leisure, educational and sporting facilities in the community.

The Community Connections Team: The day care services within RCCS started a programme of radical and innovative change in 1995 known as the community connections project. This innovation was a response to the growing awareness amongst the staff within the RCCS that, while day centres can provide a valuable haven, they also constrict social networks and inhibit the expression of citizenship in the wider society (Bates 1996). This development consequently places less emphasis on traditional day centre forms of care and more on the development of specifically tailored activities carried out in normal community settings and in partnership with other agencies. The community connections team consists of six key staff who are affiliated to the team from other parts of the RCCS. Each of these staff are responsible for developing access routes into a range of activities within a number of life domains which include education, employment, volunteering, arts, sports and neighbourhood.

4.2.4 Referral routes

All the clients referred to the RCCS have to fulfill the criteria based upon diagnosis, level of disability and duration of illness discussed in section 4.2.2. Referrals are accepted from any of the mental health directorates in the Nottingham Healthcare NHS Trust or from within the RCCS for specific services. There are a variety of referral routes into the service although there is a standard referral letter which has to be completed by the referrer.

The community rehabilitation teams accept direct referrals from the other mental health directorates and from within the RCCS. Once the referral has been received one of the teams is allocated the responsibility of assessing the client to ascertain their need for the particular service provided. The decision to accept or reject a referral rests with the team in consultation with the referrer and the client.

Referrals for support from the community support teams or places in the partnership schemes and the continuing care residential units are assessed by the Continuing Care Panel. The panel is a sub-committee of the Trust's Senior Medical Staff Committee and membership is multi-disciplinary. The panel aims to ensure that the most intensive services are provided to those most in need. Referral to the community support teams crisis and respite facility is made to the manager responsible for the area.

Appropriate referrals are considered from any of the other directorates or from within the RCCS for a placement at the short-term rehabilitation residential unit. Referrals are discussed at a weekly multi-disciplinary allocation meeting with representation from the two unit teams. Requests for the use of the crisis facility are made to the RCCS medical team in normal working hours. Admission to this facility out of hours is made at the discretion of the nurse in charge.

The day care services will accept appropriate referrals from the other mental health directorates and from within the RCCS. The exception is the Community Connections Team who only accept referrals from within the RCCS. Additional criteria for clients requiring day care include: having complex problems requiring support from a multi-disciplinary team, having a named key worker or care manager who will remain in contact with them and has a commitment to ongoing review of care provision, having a plan for integration in the community which includes developing skills in interpersonal relationships and practical skills, and the desire to attend regularly and be part of a user group. If the referral is appropriate the client will either be offered a start date if vacancies exist or placed on the waiting list. Over the first 10 attendances the client will be assessed. This is followed by a review and a decision made as to whether to offer the client a permanent place.

The community occupational therapists only accept referrals for clients within the RCCS. Referrals can be specific for occupational therapy or for an assessment to give the key worker or care manager more information about the client. Referrals are discussed at the team meeting and allocated to an occupational therapist for an initial assessment. The assessment is discussed at the following team meeting where the referral will either be accepted or referred onto a more appropriate facility. The specialist clinical services similarly only accept referrals on behalf of clients and staff within the RCCS.

4.3 Research design

The previous chapter introduced Smith and Cantley's (1985) model of pluralistic evaluation and discussed how and why, with certain adjustments, this approach was ideally suited to this investigation. This section explores the way in which a pluralistic model was used to inform the design of the investigation. The researcher, in common with other pluralistic evaluators (c.f. Ong 1993, Nolan and Grant 1994) who have built on the work of Smith and Cantley (1985), has modified and developed the model to suit the requirements of this particular investigation. The design therefore builds mainly on the work of Smith and Cantley (1985), and has been adapted with reference to Everitt and Hardiker (1996) who place an emphasis on the issues of power within evaluations and on the importance of ultimately making judgements about good or poor practice based on the evidence generated. Although Smith and Cantley (1985) do not ignore these issues, Everitt and Hardiker (1996) are coming from an anti-oppressive stance and have geared their approach to evaluations which involve marginalized groups. Given that chapters one and two of this thesis clearly demonstrate that women with long-term mental health problems are a marginalized group, then their approach is a way of strengthening what pluralism has to offer.

The key principles of a pluralistic approach to evaluation were discussed in the previous chapter together with its limitations. These key principles of identifying stakeholders, identifying success criteria, and methodological pluralism, will now be considered in turn in order to demonstrate how they influenced the design of the investigation. The discussion will also highlight the attempts made to overcome some of the limitations of a pluralistic approach identified in the literature. Although the principles will be considered separately, in reality they are linked. Individually they impact on one another, and collectively on the ultimate design.

At this point in the thesis it is also important to emphasize that it was unrealistic to explore every aspect of a comprehensive service such as the RCCS, and to elicit a complete range of viewpoints. Given the constraints on time and access to stakeholders, it was therefore necessary to make choices about the focus of the evaluation. Such choices invariably reflect the values of the researcher and an effort will be made to make these values explicit.

4.3.1 Identifying stakeholders

The first principle of pluralistic evaluation is that major stakeholders must be identified in order to elicit and compare their views. It was therefore necessary to identify those groups of people within the RCCS and the non-statutory services providing services for women with long-term mental health problems whose interests and views needed to be taken into account. This was achieved by visiting a wide range of services and talking with key service providers. The key groups identified included women with long-term mental health problems; service providers with a range of professional backgrounds within the RCCS; professional and voluntary staff working in a variety of groups, facilities and services outside the RCCS; managers and decision makers; and finally carers and relatives. It is inevitable that the design and resultant findings of the evaluation will reflect the groups selected, and therefore an attempt was made to explore as many viewpoints as possible.

The decision to enable the least powerful groups to predominate in this evaluation was influenced by the work of Mark and Shotland (1985) and Knox and McAlister (1995). They argue that traditionally the power to influence policy decisions concerning developments in services rests with fund holders and senior personnel. Front line staff and clients are consequently perceived as low down within the power hierarchy and their voices are seldom heard. Whilst acknowledging the existence and viewpoints of decision makers, the emphasis placed on eliciting the views of less powerful groups will allow for an exploration of issues that are not normally addressed within a traditional approach to evaluation. The key groups identified therefore were the women with long-term mental health problems and the front line staff working both within the RCCS and in the facilities outside the service.

The women with long-term mental health problems were selected as their views have not been traditionally sought in evaluative studies of this client group. Although reservations have been expressed as to their ability to make a meaningful contribution to research (Kalman 1983, Nocon and Qureshi 1996), there is sufficient evidence to suggest that in a supportive environment they are able to reflect on their past and current lives, identify their difficulties, and make accurate observations about the services they are receiving (Perkins 1996). This choice also reflects the researcher's belief that these women have the same dignity, the same rights, the same aspirations and the same basic needs and desires for positive life experiences as everyone else. It also acknowledges that these women deserve to be treated as individual, complete human beings and as full and valued citizens in their own right.

The front line staff working both within the RCCS and in the facilities outside the service were selected for a variety of reasons. First, although these groups have more status and power than the women with long-term mental health problems, they are relatively powerless within the power hierarchy and their voices are similarly seldom heard in traditional evaluative studies. Second, as a large group of staff with a range of backgrounds, it is likely that their individual viewpoints will be characterized by divergence. This divergence may be reflected in the way that different parts of the service operate and in the way that they perceive the nature of the services. This possible range of viewpoints will allow for an exploration of tensions within this group as they endeavour to meet the needs of women with long-term mental health problems.

In addition to directly eliciting the views of women with long-term mental health problems and front line staff, it was decided to design the evaluation so that the views of managers and decision makers were also reflected. This was important to ensure that the findings were meaningful and acceptable to a range of audiences, particularly to those groups of people who had the power and authority to change or further develop services if required.

Finally,the views of carers and relatives were not included in this evaluation although the absence of their perspective is regrettable. Primarily constraints on time and the difficulties of accessing this group did not allow for their inclusion. Although the researcher acknowledges this limitation, few of the clients within the RCCS live with their relatives and many have little contact with family or friends. Out of all the stakeholder groups identified therefore, this seemed the most appropriate group to omit from the evaluation.

Unlike Smith and Cantley (1985) who used semi-structured interviews to elicit the views of their identified stakeholders, and also to generate success criteria; the researcher modified the process of generating success criteria and exploited the principle of methodological pluralism to ensure that the viewpoints of the range of stakeholders identified were included, albeit in different ways. The ways in which this was achieved will be explored in the next two sections.

4.3.2 Success criteria

The second principle of a pluralistic evaluation is that the criteria against which the success of a service is judged are determined by the stakeholders involved. Thus the notion of success itself becomes pluralistic rather than unitary (Nolan and Grant 1993). For the purpose of this investigation it was therefore necessary to generate success criteria which reflected the views of the identified stakeholders; namely women with long-term mental health problems, front line staff both working within the RCCS and in the facilities outside the service, and managers and decision makers.

As was identified in chapter three, section 3.6, pluralistic evaluators (c.f. Smith and Cantley 1985, Nolan and Grant 1993) have used different strategies for identifying multiple criteria for success. Smith and Cantley (1985) for example, conducted a set of semi-structured interviews with staff and relatives to elicit what they considered to be relevant criteria of success. The limitations of this strategy have been highlighted however by a number of critics (c.f. Coulter 1991, Everitt and Hardiker 1996), and by Smith and Cantley (1985) themselves. Such a strategy may be construed as narrow and parochial in that a service can then only be assessed according to the criteria identified by the stakeholders (Smith and Cantley 1985), and by giving equal legitimacy to a range of success criteria it leaves unresolved the problems of providing directions for change (Coulter 1991). In addition Everitt and Hardiker (1996) argue that this strategy is possibly only relevant when evaluating practice in contexts of consensus. They therefore suggest that this strategy may not be adequate when there are observable conflicts of interest or, even more so, where conflicts of interest are not visible or articulated. The strategy adopted by Smith and Cantley (1985) for generating success criteria was therefore considered inappropriate for this investigation for a number of reasons. First, the generation of success criteria by the stakeholders within the RCCS might limit the scope of the evaluation and consequently make it difficult to make innovative recommendations for change and development. Second, the researcher wanted to adopt a strategy which was broad enough to allow for an exploration and/or the emergence of issues around conflicts of interests. This was particularly important in light of the issues which emerged in chapter one regarding the conflicting nature of mental health policy and the need to explore how this impacts on the organization and delivery of care within the RCCS, and in turn on women with long-term mental health problems.

The strategy adopted by Nolan and Grant (1993) to identify criteria against which to evaluate a respite care service builds on Smith and Cantley's (1985) work and addresses some of the limitations that were identified. Rather than eliciting success criteria directly from the four stakeholder groups identified in the service, Nolan and Grant (1993) conducted an extensive literature review on respite care from each of the stakeholder perspectives. The evaluation guide subsequently developed thus incorporated both user and provider perspectives. Moreover Nolan and Grant (1993) argue that,

> "..... it was not, however, the intention that this guide should form a rigid a priori specification. Rather, it was to reduce the likelihood of difficult questions being ignored........ The study sought not to compare what is with what should be, for this is too prescriptive in a pluralistic context. Rather, the guide was intended to provide a framework within which to compare what is both with what might reasonably be argued could be and with what each of the stakeholder groups thought should be" (Nolan and Grant 1993).

The first stage of identifying possible success criteria for this investigation adopted the strategy described by Nolan and Grant (1993). The broad range of criteria identified for each of the stakeholder groups were drawn from the broad literature on community care, evaluation reviews of mental health care, the views of users generally, and the views of women in the specific literature on women and mental health. These identified criteria then provided a foundation from which to critique the stated aims of the RCCS (previously described in section 4.2.1), and identify a set of criteria to inform the design of this investigation.

To begin it is important to highlight the ways in which the broad aims of community care identified in the mental health policy literature (see chapter one) have been interpreted by clinicians and researchers working within the field of mental health services evaluation. An early epidemiological viewpoint was expressed by Wing (1973) when he identified that the primary aim of mental health care was the reduction and containment of mental morbidity. Huxley (1990) concurs with this view but provides a broader definition which includes an emphasis on the growing interest in social functioning and quality of life (see sections 3.5.2.3.1 and 3.5.2.3.2 for discussion on social functioning and quality of life). For Huxley (1990) the main aim of services for people with mental health problems is,

> "the elimination or reduction of clinical and social disablement and the achievement of optimal quality of life for the suffers and their carers" (Huxley 1990, p1).

From a different, more visionary stance, Murphy (1992) proposes that mental health services should aspire to,

> "provide individuals with as fulfilling and rewarding a life as possible and provide for the ordinary needs of life - a home, daily occupation, emotional support through friendship and social contacts, and to recognize individuals' rights as citizens" (Murphy 1992, p125).

Given the broad nature of these aims, they are unsuitable in their current form as criteria against which to judge the success of the RCCS in meeting the needs of women with long-term mental health problems. This point has also been identified by Hafner and an der Heiden (1996) in their review of the aims of community care. They argue that it is necessary for broad aims such as these to be translated into more specific criteria in order to be meaningfully used in evaluation studies.

The need to move beyond the broad aims of mental health care to develop specific criteria against which to judge the success of community based mental health services has been taken up by a number of clinicians and researchers in the field (c.f. Coursey 1977, Thornicroft and Bebbington 1989, Huxley 1990, Murphy 1991, Hafner and an der Heiden 1996). The key approaches to this issue and the subsequent lists of criteria developed will now be considered in turn. These lists of criteria vary in their complexity and specificity and therefore a greater emphasis will be placed on those that have been most comprehensively developed and explained.

An early attempt to identify success criteria was proposed by Coursey (1977, p14). He suggests that services could be evaluated against the criteria of programme effort, effectiveness, adequacy, efficiency and process. Coursey (1977) does not however, expand very much on these criteria or make it particularly clear what he means by them. Thornicroft and Bebbington (1989) offer a slightly more expansive list of criteria when they suggest that mental health services should be comprehensive in meeting the whole range of psychiatric disturbances; accessible geographically and culturally; and acceptable to clients, their families and neighbours. In addition they argue that interventions should be of proven effectiveness, and must be efficient in cost-benefit terms. Hafner and an der Heiden (1996) identify similar criteria to those already described but also include the integration and co-ordination of services, the acceptance of patients into the community, client satisfaction with services, flexibility in order to meet changing needs, the reintegration of socially disabled people after discharge from hospital, the reduction of social disability, and the maintenance and improvement in the client's quality of life. Although these lists of criteria provide useful indicators, they are not specific enough in their current form to be used as a means of judging services, and together they lack a certain coherence and focus.

A noteworthy attempt to develop a model which can be used as a framework for the production of operational standards of service delivery against which performance can be judged is that proposed by Huxley (1990) in his comprehensive review of empirical research into existing mental health services. The need to create a model arose out of the necessity to have a coherent framework within which to organize the sheer volume of research in this area. The framework describes the fundamental goals of community mental health services, and the underlying principles of service delivery in terms of ultimate aims. These goals, which constitute the elements of the framework, are that services should be: comprehensive, coordinated, accessible, acceptable, efficient, effective, accountable, and evaluated. Huxley (1990) subsequently used this framework as a means of organizing, summarizing and presenting the key research to date on mental health care. From this review he was then able to highlight the main problems with present services, and to suggest goals for future provision. The framework and the goals for future provision identified by Huxley (1990) are summarized in Table 4.

Whilst this framework is undoubtedly comprehensive and coherent, Huxley (1990) does point out that it is not immutable, and that the work of translating the goals for future provision into operational objectives was not undertaken in the book. Thus evaluators wishing to use the framework would still have to develop their own specific criteria. Finally Huxley (1990) argues that while evaluators may select to evaluate services against a few, rather than all of the elements of the framework; the element of effectiveness should always be included as he believes that this is the ultimate goal of mental health provision. As he says, 'an acceptable, accessible, and well coordinated service is of little value if it is not an effective service (Huxley 1990, p3).

Table 4: Goals for provision of mental health services (Huxley 1990)

Comprehensive services
Services should provide comprehensive coverage of an individual client's needs. At any one time, a client may need help with any or all of the following areas: psychological, social, welfare, financial, housing or health. A service should seek to offer a wide range of care options for clients. This may include increasing the volume or scope of services to meet the needs of those unserved or overlooked by existing provision.

Coordinated services
A service should provide a coordinated service to its clients so that they can be referred with ease from one service to another. A service should pass information between agencies to enable a more coordinated approach to care. A coordinated service requires effective communication between the different carers involved in the care of any particular client. Clients requiring long-term care, involving a number of different settings and carers are particularly in need of well coordinated services.

Accessible services
The ideal is that services should be accessible to all those who have mental health problems, and that there are no barriers between carers and those they seek to serve. A service should be geographically accessible, non-stigmatizing, and of appreciable relevance to those in need of help. It should be in a physical setting which is pleasant and welcoming, care should be available outside normal working hours, and clear information concerning what is available to whom and when should be provided.

Efficient services
Services should be technically efficient, and should be targeted towards priority groups. Routine monitoring should be mandatory, and common standards established. Better cost-effectiveness and cost utility analysis is needed.

Acceptable services
Services should provide care options which are not damaging, which offer the least restrictive care in terms of the curtailment of liberty, and which promote self determination on the part of clients. Appropriate care should be non sexist and non racist.

Effective services
Services should provide the most appropriate form of care for each type of need. Effective strategies for providing for people with long-term problems should be part of the service coverage. The best combinations of different treatment elements, including professional and non professional care should be provided.

Accountable services
Services should be accountable to a number of different stakeholders; they should be democratically planned and managed with flexible and responsive mechanisms for decision making.

A very different framework is that offered by Murphy (1991). As was identified earlier, Murphy (1991, 1992) views the aims of community care from a different stance from Huxley (1990) and places a greater emphasis on the rights of citizenship and of the need to enhance the ability of individuals to live independently in as 'normal' a way as possible. Her vision, translated into a framework for both service delivery and evaluation, contains the following elements: consultation and participation; self-determination and autonomy; a normal environment; minimum segregation; protection and asylum; small scale; local; environmental solutions are better than special services;

and alleviation of distress. The framework and goals for mental health services identified by Murphy (1991) are summarized in Table 5.

Table 5: Goals for provision of mental health services (Murphy 1991)

Consultation and participation
Clients should be consulted about their treatment and care, and participate as fully as possible in decisions about their lives.

Self-determination and autonomy
Services should aim to promote individuals' capacity for self-determination and autonomy and to enhance their ability to make realistic choices for themselves. In order for this to be achieved, users need information on future possibilities and options.

A normal environment
Services should be provided wherever possible in ordinary houses and homes rather than in institutions.

Minimum segregation
Individuals should be restricted and segregated from the general community as little as possible. As far as their disabilities allow they should have the opportunity to participate in normal community activities. Promoting a policy of minimal segregation does not, however, preclude the provision of protection from abuse and harm.

Protection and asylum
Services should be able to provide temporary or permanent 'asylum' in the sense of a haven or retreat when a client requires shelter and protection from the pressures of the external world.

Small scale
Ideally services should be provided on a small rather than a large scale. For example the numbers of people living together, or attending a day centre.

Local
Services which are organized locally are usually more accessible and friendly than remote, distant ones.

Environmental solutions are better than special services
Wherever possible it is better to provide a person with the living conditions and equipment to do things for her or himself, rather than providing special services.

Alleviation of distress
Services should have as a primary goal the alleviation of distress, by providing a programme of treatment, care and support based on the unique needs of an individual. Distress does not just arise from the symptoms of mental illness but also from the consequences of the illness as they affect the social and occupational life of the individual. Services should also aim to enhance the individual's own ability to cope with distress.

The frameworks described by Huxley (1990) and Murphy (1991) in particular, identify a range of broad goals which could be developed into specific criteria against which to judge the success or otherwise of the RCCS in meeting the needs of women with long-term mental health problems. The sole use of such goals however, has been criticized by a number of authors who argue that since they have been developed by researchers and clinicians then they will invariably reflect their agendas and concerns, and not necessarily those of service users (Williams 1995, O'Grady 1996, Perkins and Repper 1996). Numerous studies for example, have shown differences in the goals of clinicians and users (c.f. Dimsdale et al 1979, Mitchell et al 1983, Lynch and Kruzich 1986, Shepherd 1994 et al). Clinicians typically define their primary goals in terms of reducing service users' symptoms; the frequency, duration and severity of relapse; professional support; treatment; and monitoring. While service users may also desire freedom from debilitating symptoms, they also place an emphasis on genuine choices; control over their lives; personal fulfillment; help in coming to terms with their problems; assistance with housing, finance, social networks and physical health; to be treated with dignity and respect; and to have the opportunity to achieve the same things as everyone else. It is vital therefore that this discrepancy between the goals of clinicians and service users is reflected in the selected criteria for this investigation.

Not surprisingly, there are few frameworks or lists of criteria which have been developed to reflect the perspective of service users. This situation is gradually changing however with the movement towards additionally evaluating services in terms of the quality of life of service users (Hafner and an der Heiden 1996). One, much cited framework which has led to the identification of goals in terms of users' lifestyles rather than the characteristics of services is that described by O'Brien and Lyle (1987). This framework which is underpinned by the normalisation philosophy (c.f. Wolfensberger 1983), has been important in underlining the rights of service users to make choices on their own behalf and also to receive services sensitively tailored to their needs (Wistow and Barnes 1993). It is based on the idea of five accomplishments which include: community presence, choice, competence, respect and community participation. The framework is summarized in Table 6.

Table 6: Framework for Accomplishment (O'Brien and Lyle 1987)

Community presence
To share with other citizens choices in respect of workplace, leisure, home and education.
Choice
To make choices and benefit from experiences which guide choice among a variety of options in all areas of life.
Competence
To develop competence which will increase independence and social skills.
Respect
To gain respect from other members of the community by being supported in achieving valued social roles.
Community participation
To form friendships and relationships with members of the local community

Although it has been argued that the accomplishment framework provides a substantive set of criteria for judging the quality of services in terms of user needs and preferences (c.f. Wistow and Barnes 1993), it is generally agreed that the framework as it stands is too broad and lacks specificity (Nocon and Qureshi 1996). Furthermore, Murphy (1991) argues that since the framework and the normalisation philosophy upon which it is based was originally focused on people with learning disabilities, it has limitations in the context of mental health services as it fails to take account of the realities of many mental health problems.

The review so far has identified a range of goals for community-based mental health services which could be drawn upon and subsequently refined into specific criteria to reflect the views of the identified stakeholders in this investigation, that is the views of users, service providers, and decision makers. There is however a further dilemma in selecting criteria which stems from the fact that the identified goals tend to view people with mental health problems as an homogenous group. In reality, as was identified in chapter two, people with long-term mental health problems are an extremely heterogeneous group. In addition to differences in terms of diagnosis, duration of contact with services, and disability; there are also numerous demographic distinctions such as age, class, race/ethnicity, and gender (Perkins and Repper 1996). From an evaluation perspective such differences are important as a service is unlikely to serve each of these groups equally well. Given the evidence that community-based mental health services may not provide well for women (see chapter two), it was important to also identify goals which pertain specifically to them. A number of individual authors (c.f. Gadd 1996, Payne 1998), and organizations (c.f. Good Practices in Mental Health 1993, MIND 1993a, the RCN 1996) have specified goals which can be used by services to improve the provision for women with mental health problems, but which can also be used by evaluators to judge the success of their endeavours. These goals have been collated and are summarized in Table 7.

Table 7: Goals for meeting the needs of women with mental health problems

Appropriateness and accessibility: services should -
Develop knowledge and awareness about women as patients.
Respect and support women's difference without making unwarranted assumptions about their requirements, their sexuality or their sameness.
Ensure that women have the option of being cared for by women staff including key workers, care managers, doctors and nurses.
Monitor service provision by gender, especially drug use and ECT treatment.
Provide treatment outside working hours making it possible for women to access the care they need.
Draw attention to unfair or discriminatory practice.
Provide child care arrangements that enable women to use the services they need and that avoid the separation of mother and child.
Consult with women who use the mental health services, with women who belong to local women's groups and committees.
Promote links and network with women's agencies and groups which support and complement the local health provision for women.
Ensure that treatment responses include counselling, therapy, specific support groups and practical help, specifically targeted on issues that affect women such as sexual abuse and domestic violence.
Develop alternatives to hospital admission, e.g. Small safe houses for women in crisis, respite care and other support services.

Making services safe for women: services should -
Respond to overt and covert sexual harassment and abuse, complaints should always be taken seriously.
Develop and implement sexual harassment and abuse policies.
Provide training in countering abuse.
Promote safety through designated 'women only' spaces, and outlawing mixed sex sleeping and bathroom areas.
Listen to and accept as legitimate the experiences of women who use services.

Recognizing issues affecting particular groups: services should -
Be aware and respond appropriately to the needs of black and ethnic minority women, women in secure settings, bisexual and lesbian women, women with long-term problems, older women, women who have been abused, women with physical disabilities, women in rural areas, women as mothers, and women in carer roles.
Ensure professional interpreting is available for ethnic minority women.

Equity: services should -
Ensure equal access to services according to need

The goals outlined in Table 7 give an overall indication of how services can best meet the needs of women with mental health problems. Although the literature reviewed does highlight that the issues of particular groups of women must be taken into consideration, there remains a lack of evidence about what women with long-term mental health problems want from community-based services. In an attempt to fill this gap, Perkins (1996) interviewed 24 women with long-term mental health problems to elicit their views. Table 8 highlights the key findings of Perkins' (1996) study and provides a range of broad goals which could be developed as specific criteria against which to judge the RCCS. Many are similar to those described in Table 7, but a greater emphasis is placed on the women's particular vulnerabilities, their potential to be marginalized in community settings, and the longevity of their problems.

Table 8: Goals for meeting the needs of women with long-term mental health problems (Perkins 1996)

Women-only space and choice of women staff
An adequate range of services must include women-only facilities of all types, including groups, day facilities, supported accommodation and in-patient facilities, as well as the option of having a woman worker.

Safety
Minimizing the dangers of harassment, sexual abuse and violence must be a priority. As well as women-only facilities, appropriate measures include providing personal alarms, and help and support in reporting any abuse to the police. Harassment and violence should always be taken seriously, and a woman should be available for the victim to talk to. There should be a clear policy on action to be taken in the event of harassment or abuse.

Supporting social networks
Services should actively help women keep in touch with their social networks. This will involve making available welcoming visiting arrangements, childcare and help with parenting. Advocacy in childcare proceedings may also be needed, as well as residential and day facilities that can accommodate mothers with their children.

Choice
Services should let women decide what sort of treatments they want, ensuring access to services 24 hours a day, providing both domiciliary and non-domiciliary services, and facilitating engagement in non-segregated work, social activities and accommodation within relevant communities.

Access to someone who listens
Services should acknowledge the importance these women place on developing a caring, therapeutic relationship with someone who understands.

Recognizing diverse communities and aspirations
Community support services must recognize that these women are a diverse group. The different cultures and communities they come from must be understood, and supports must be provided to ensure access to relationships, activities and facilities within these communities.

Longevity of problems
Services must understand that disabilities experienced by this group of women may go on for a very long time: time-limited help of any kind denies this reality and therefore the help that such women need.

So far this section has reviewed a wide range of goals for community based care which reflect the perspectives of the key stakeholder groups which have been identified for this investigation. Reflecting back on the aims of the RCCS presented in section 4.2.1,Table 2, it can be seen that a number of these goals have been included. The aims of the RCCS appear to represent an attempt to include goals which reflect current mental health policy, and those which address the users' agenda. Although the aims of the RCCS are comprehensive, they are unsuitable as criteria against which to judge the service in terms of its success in meeting the needs of women with long-term mental health problems in their current form for a number of reasons. First, as was identified in section 4.2.1, the aims of the RCCS were developed over time in consultation with decision makers and service providers from all parts of the service. The aims therefore reflect their views but not necessarily those of service users. In addition there is little specific reference to gender issues and/or the specific needs of women. Second, as Wistow and Barnes (1993) point out, important differences in values and interests may be concealed within generalizable and apparently unchallengeable commitments to such concepts as quality of life, consumer choice, participation and risk assessment. These differences may exist not only between the decision makers and service providers who devised the aims, but also between them and the service users. For example users may wish to take greater risks than service providers with their own safety in the community. O'Grady (1996) illustrates this point by arguing that the introduction of powers of supervised discharge (Department of Health 1995a) will inevitably bring into the open the sharp divide between the wishes and aspirations of users, carers and society; leaving mental health professionals with the daunting task of accommodating very different perspectives on choice and risk.

Having reviewed a wide range of goals for community-based mental health services from a range of perspectives, and critiqued the stated aims of the RCCS; the researcher was left with the dilemma of having to specify criteria against which to judge the success of the RCCS in meeting the needs of women with long-term mental health problems. Although a pluralistic approach to identifying multiple criteria from a range of perspectives was illuminating, the approach proved limited when it came to making judgements about whose views should predominate in situations where criteria for success cannot be agreed or where there is evidence of conflict. For this reason the researcher drew on the work of Everitt and Hardiker (1996) because their approach to evaluation is underpinned by an anti-oppressive stance and therefore foregrounds the voices of marginalised groups, in this case women with long-term mental health problems. Although Everitt and Hardiker (1996) are wary of placing the evaluator in the position of 'judge', they nevertheless argue that evaluations are about making judgements on the basis of evidence about good and poor practice. This is not to deny that this investigation will produce many 'truths' of practice, and that each of the stakeholder groups may see the practice differently and value it in diverse ways; but that ultimately judgements have to be made concerning the specific criteria for this evaluation, and whether the subsequent evidence generated constitutes good or poor practice.

Given the diversity of the services provided within the RCCS, and the need to place some boundaries around the focus of this evaluation; a decision was therefore made to select a range of criteria drawn from the literature reviewed in this section and the aims of the RCCS. Whilst these criteria reflect the interests of all three stakeholder groups, particular emphasis has been placed on the perspectives of women with long-term mental health problems. As has been previously argued (see section 4.3.1), the views of these women have not generally been given priority in evaluative studies of long-term users, and this was an opportunity for their voices to be heard. In compiling this range of criteria, the researcher was keen to avoid being too rigid. To do so would be to paternalistically set the stakeholders' agenda of importance, rather than taking into account their different experiences and enabling them to highlight those issues which are important to them. Instead the following criteria were used as a framework within which to pose a series of questions which would provide the basis for informing the investigation. These criteria included effectiveness, equity, comprehensiveness, responsiveness, acceptability, choice, respect, safety, alleviation of distress, and knowledge. This framework and the corresponding questions are set out below.

Knowledge
Are service providers aware of the particular problems and difficulties experienced by female users ?

Equity
Do women with long-term mental health problems have equal access to a range of services according to their needs compared to men ?

Comprehensiveness
What specific services are provided for, and used by women with long-term mental health problems ?
What links and networks exist between the RCCS and alternative provision for women in the wider community ?

Effectiveness
What impact does the RCCS have on optimizing the quality of life of women with long-term mental health problems, and reducing their social disabilities ?
Are services flexible and responsive to changes in the needs of women with long-term mental health problems ?

Acceptability
Are the existing services acceptable to women with long-term mental health problems ?

Choice
How much information are women given regarding the care options available to them ?
How much choice do women have regarding the services they receive and the life decisions they have to make ?

Alleviation of distress
What attempts are made to alleviate distress experienced by women ?
How much emphasis is placed on developing caring therapeutic relationships ?

Safety
Are efforts made to protect women from abuse and harm ?

Respect
Are the women supported in achieving valued social roles ?

4.3.3 Methodological pluralism

The third principle of pluralistic evaluation considered was that of methodological pluralism. The advantages of being able to use a range of data collection methods and to move beyond one single study to a series of studies was exploited in the following ways.

First, not only were the perspectives of the three groups of stakeholders reflected in the evaluation criteria, but they were also reflected in the choice of data collection methods and measures selected for this evaluation. Particular methods and measures were selected for example, because they had been devised by clinicians and would therefore primarily reflect their interests. These included standardized instruments for measuring quality of life and social functioning. Conversely qualitative methods were also used to enable both service providers and women with long-term mental health problems to set the agenda of what is and what is not important or problematic rather than giving their opinions on predetermined issues. In addition attempts were made to explore the questions identified in the evaluation framework using more than one method of data collection in order to strengthen and verify the credibility of the data collected.

Second, it would have been very difficult to explore each of the evaluation criteria in one large study. Instead it was decided to design a series of six studies which looked at different aspects of the services provided from a range of perspectives. Collectively therefore, this series of six studies explore the broad range of evaluation criteria and questions identified. The six studies are presented in chapters five to nine. They are each presented as discrete studies with aims; a description and justification of the design and methods of data collection selected; a clear description of the procedure adopted and approach taken to analyzing the data; presentation of findings; and finally a discussion which seeks to understand the findings within the context of existing knowledge about women with long-term mental health problems. The collective findings of the six studies will be discussed in chapter ten with reference to the evaluation criteria and questions. The six studies are:

- A description and comparison of men and women with long-term mental health problems using the RCCS.

- An exploration of the provision for women with long-term mental health problems within the RCCS.

- An exploration of the provision for women with long-term mental health problems outside the RCCS.

- An investigation into the effectiveness and responsiveness of services provided for women with long-term mental health problems.

- An exploration of the service providers' perspective.

- An exploration of the women with long-term mental health problems' perspective.

4.4 Gaining access to the research setting

In a recent evaluative study of services for people with learning difficulties, Wright et al (1994) emphasize that gaining access to the research setting can be complicated, difficult and time consuming. Time spent fostering positive relationships with staff and clients is essential as the successful completion of the evaluation cannot be achieved without the cooperation and active support of all those people involved. In this evaluation the need to involve people from the beginning was vital for a number of reasons. First the RCCS had been the focus of several large scale research projects since its inception. There was therefore a possibility that staff and clients may feel 'over-researched' and reluctant to become involved in yet another project. Second, some of the data were to be collected by the staff and their help would be needed in gaining access to clients.

The strategies used to gain access to the staff and clients within the RCCS and associated services acknowledged the hierarchies of power and consent. Thus formal access was first negotiated with senior personnel prior to approaching front-line staff and clients. In addition a range of formal and informal strategies were adopted, many of which continued throughout the duration of the evaluation.

Formal access into the RCCS was gained from the Clinical Director in January 1993. In this meeting the objectives of the evaluation and the data collection timetable were discussed. This was followed by meetings with the four RCCS service managers to plan the most appropriate means of gaining access to key groups of staff within the service. A period of six months from July 1993 was spent meeting groups of staff in a variety of formal settings which included the monthly care managers' meeting, the monthly community support teams' meeting and the RCCS research forum. These meetings were used to explain the objectives of the evaluation and the proposed data collection timetable, and to discuss the feasibility of staff becoming involved in collecting some of the data. A great deal of discussion was generated in these meetings and the evaluation was greeted enthusiastically by some staff and with reservations by others. The reservations primarily revolved around the amount of time that they would need to spend gathering data, and concerns around gaining the informed consent of vulnerable clients. These expressed concerns were addressed in two ways. First, attendance at key care manager meetings, the RCCS research forum and the RCCS sexuality forum continued throughout the duration of the evaluation. This enabled the researcher to give regular feedback about progress, and provided an opportunity for staff to discuss any continuing concerns. Second, all the care managers were visited individually to gain their cooperation and to answer questions concerning their involvement in the evaluation. Although these strategies were very time consuming and frequently stressful, they did provide an excellent opportunity to sell the research and to get to know the staff within the service.

A major investment of time was also made in general relationship building throughout the RCCS and associated services. This involved a regular informal programme of visiting and meeting staff. Again this programme was very time consuming but ultimately proved to be very valuable in gaining the support of the staff. As Wright et al (1994) point out, this work involves a lot of sitting around, drinking coffee and talking. It did however pay dividends in terms of cooperation, large amounts of help and friendship. The importance placed on continually negotiating access with the staff enabled the researcher to become reasonably integrated into many parts of the service. This had the added benefit of gaining an appreciation of the internal politics of the service from the viewpoint of a variety of service providers.

4.5 Ethical considerations

Formal ethical approval was granted for the evaluation in August 1993 by the Nottingham University, Highbury and General Hospitals Ethics Committee. In addition a number of principles were adopted whilst conducting the evaluation to safeguard the rights of all the people who were involved. The ethical guidelines discussed by Hopkins (1989) formed the basis of these principles although additional consideration was given to aspects of the evaluation involving clients with long-term mental health problems.

The general ethical principles adopted included the following. First, permission and approval was sought from the Clinical Director of the RCCS and the other consultant psychiatrists prior to looking at clients' medical notes. Similarly consent was sought from the relevant team leaders before reading nursing, social work or psychology reports on clients. Second, the wishes of staff concerning their involvement in the evaluation were respected. No pressure was placed on staff to provide information or to facilitate access to clients if they expressly wished not to. The staffs' workload was also acknowledged and meetings were frequently rearranged to accommodate study leave, annual leave, sickness or work demands. Third, staff were given the opportunity to amend observations of meetings or transcripts of interviews to ensure accuracy. Fourth, it was acknowledged that the researcher is in a powerful position in some respects particularly through the possession of a lot of detailed and often sensitive information. Efforts were made to ensure anonymity and confidentiality.

A high priority was attached to safeguarding the rights of the clients with long-term mental health problems involved in this evaluation. Wright et al (1994) note that the lower an individual's place is in the hierarchy of power, the more difficult it is for them to refuse consent to be involved. In addition the issue of informed consent is a very complex one particularly with clients known to have emotional or cognitive deficits (Davis & Mahon 1984). The procedures adopted to ensure that clients willingly participated in the evaluation and had an understanding of what that participation involved is explained fully in chapter seven.

4.6 Conclusion

The purpose of this chapter was to discuss the way in which a pluralistic model of evaluation was used to inform the design of this investigation, and to highlight and justify the modifications that were made.

The chapter began with a description of the RCCS, which provided the setting for this investigation. The service was deliberately described in some detail as it provided background information which was drawn upon in this chapter, and will be subsequently drawn upon throughout the remainder of this thesis. This description illustrated that the RCCS is a complex and comprehensive service which has formal and informal links with a variety of statutory, non-statutory and voluntary agencies throughout the Nottingham district. This, together with the wide range of professional and non professional staff involved in providing a service for women with long-term mental health problems made it an ideal base from which to conduct the evaluation. The service has clearly identified a number of core values and aims although there is an assumed homogeneity with little reference to gender. The service has also operationalized the definition of people with long-term mental health problems in its criteria for entry into the service. There is an acknowledged interest amongst service providers about working towards meeting the needs of women with long-term mental health problems.

The second section of this chapter discussed how the key principles of a pluralistic approach to evaluation influenced the design of this investigation. The section began by identifying the groups of stakeholders whose views needed to be sought and reflected. The stakeholder groups selected included women with long-term mental health problems, service providers with a range of professional backgrounds within the RCCS, professional and voluntary staff working in a variety of facilities outside the RCCS, and managers and decision makers.

The discussion then moved on to explore the complexity of identifying suitable criteria which could be used to judge the success or otherwise of the RCCS in meeting the needs of women with long-term mental health problems. The evaluation criteria and questions subsequently selected reflected the interests of the key stakeholder groups identified. It is important to reiterate at this stage that these criteria were not intended as a rigid specification but a means of highlighting the key issues that will be explored in this investigation. Furthermore they are sufficiently broad to allow the particular interests and agendas of each of the stakeholder groups to emerge. Finally the perspectives of the stakeholder groups were not only reflected in the evaluation criteria but in the range of data collection methods and measures selected.

The process of gaining access to large numbers of service providers working in geographically disparate services was also explored. This process was continuously demanding of both time and emotional energy, although the efforts were rewarded by the support and cooperation of both staff and clients. Finally, the importance of safeguarding the rights of staff and clients in the evaluation was highlighted in the ethical considerations made. The general ethical principles which underpin this evaluation were briefly discussed but will be explored in more detail as they apply to each of the six studies.

The six studies which make up this evaluation are presented in the next five chapters. Each of the studies focus on different aspects of the services provided for women with long-term mental health problems from a range of stakeholder perspectives. Some of the studies focus more on the perspective of one particular group of stakeholders than another and this will be made explicit. Although the findings of each study will be discussed separately, the collective findings will be discussed with reference to the identified evaluation criteria in chapter ten.

Chapter Five

A Description and Comparison of Women and Men with Long-Term Mental Health Problems using the Rehabilitation and Community Care Service

5.1 Introduction

The aim of this study is to describe and compare the socio-demographic and psychiatric characteristics of women and men with long-term mental health problems using the Rehabilitation and Community Care Service (RCCS) together with their use of services. This investigation of gender differences within a large client group will not only add to the evidence available for this population, but will also serve to highlight issues that require further investigation in the other five studies which make up this evaluation.

5.2 Method

Using a cross-sectional design, socio-demographic, psychiatric and service usage data were collected on all clients in the RCCS. These data were supplemented by an assessment of the clients' social functioning. A cross-sectional design involves the collection of data at one point in time. The design is especially appropriate for describing the status of phenomena or for describing relationships among phenomena (Polit and Hungler 1991, p243). Such a design is particularly appropriate for this study as it would allow for a comprehensive description of the clients within the RCCS and a comparison between the men and the women. The purpose of this study is therefore descriptive rather than exploratory as a cross-sectional design does not allow for an assessment of change over time nor an exploration of the extent to which the services meet the needs of the clients (Spear et al 1995).

5.2.1 Sample

Data were collected on all RCCS clients registered with the service on 1/1/94. The list of clients was obtained from the RCCS database which identified that on 1/1/94 there were 480 clients in the service.

5.2.2 Data collection tools

Evaluative studies which describe clients with long-term mental health problems typically include data on their socio-demographic and psychiatric characteristics, and the services they receive (c.f. Thornicroft et al 1992, Ford et al 1993, Spear et al 1995). In addition an assessment of social functioning is often included as this provides a more reliable indicator of the severity of a client's mental health problems and social disability than a diagnostic label (Wiersma 1996). The decision to collect data on the socio-demographic, psychiatric and service usage characteristics of all the clients in the RCCS together with an assessment of social functioning was therefore made in order that the findings of this study could be compared to similar studies of this client group.

5.2.2.1 Socio-demographic, psychiatric and service use

There is no universally accepted data collection tool for assessing the socio-demographic characteristics, psychiatric diagnoses and past and current psychiatric history, and the service use of clients with long-term mental health problems. Typically mental health evaluative studies devise their own tools in order to collect such data, for example Leff et al (1996). A selected review of studies which have described the characteristics of clients with long-term mental health problems suggests that the range of information gathered is similar across studies although the emphasis placed on certain characteristics varies according to the focus of the study (c.f. Thornicroft and Breakey 1991, Thornicroft et al 1992, Ford et al 1993, Spear et al 1995). In planning the precise information required for this study it was decided to gather data on the range of characteristics typically included in mental health evaluative studies with an emphasis on issues of particular relevance to women such as number of children and domestic arrangements.

A data collection document was designed which was in three parts, Forms A, B, and C. Socio-demographic data which included the age, sex, marital status, ethnicity, current accommodation, and work arrangements of clients were recorded on Form A (see appendix A). Psychiatric data were recorded on Form B (see appendix B). These data included psychiatric diagnosis and past and current psychiatric history. The clients' current use of services were recorded on Form C (see appendix C).

5.2.2.2 Assessing social functioning

Section 3.3.2.3.1 highlighted the current emphasis which is placed on the assessment of a client's social functioning in mental health evaluative studies. Since Wallace (1984, 1986), Rosen et al (1989) and Bowling (1995) have reviewed a large number of measures to assess the social functioning of clients with long-term mental health problems, this review focuses on the criteria that were used to select the most appropriate measure for this study. The criteria were derived from those suggested by Platt (1985), Rosen et al (1989), and Polit and Hungler (1991).

A list of measures which had been developed for clients with long-term mental health problems was gained from Wallace (1984, 1986), Rosen et al (1989), Bowling (1995) and from those used in the mental health evaluative studies reviewed in Section 3.3. Those measures which had been specifically developed for use in a variety of day or residential settings rather than a community-based setting, for example the Social Behaviour Schedule (Wing 1989), were eliminated. Table 9 lists the remaining ten measures. They all possess demonstrated reliability, validity and a well developed scoring system. Evidence of the psychometric qualities of the measures was found in key publications describing the measure, in subsequent studies which focused on the reliability and validity of measures, and in comprehensive reviews such as that by Bowling (1995).

Table 9: Social functioning measures

Global Assessment of Functioning (GAF), (American Psychiatric Association 1987)
Global Assessment Scale (GAS), (Endicott et al 1976)
Social Behaviour Schedule (SBS), (Wykes and Sturt 1986)
Katz Adjustment Scales, (Katz and Lyerly 1963)
Social Adjustment Schedule, (Weissman and Paykel 1974)
Social Behaviour Assessment Schedule, (Platt et al 1980, 1983)
Life Skills Profile (LSP), (Parker and Rosen 1989)
Rehabilitation Evaluation (REHAB scale), (Hall and Baker 1983)
Social Role Performance Schedule (SRPS), 3 versions, (Wing 1989)
WHO Psychiatric Disability Assessment Schedule (WHODAS), (WHO 1988)

The assessment of social disability should be based on the actual performance of activities, actual manifestation of behaviours, or actual execution of tasks over a certain period such as over the last month (Platt 1985). Some measures however, include an assessment of symptomatology or quality of life (Bowling 1995). As the intention in this study was to focus on social functioning, global measures such as the Global Assessment of Functioning (American Psychiatric Association 1987), the Global Assessment Scale (Endicott et al 1976), and the Katz Adjustment Scale (Katz and Lyerly 1963) were excluded.

The practicalities of administering a particular measure were also carefully considered. The amount of time required to complete the remaining measures varied from ten to sixty minutes. This factor obviously had to be taken into account as an hour long assessment on each of the clients within the RCCS would be very time consuming. In addition some of the measures required a trained rater. The decision to use a measure which took no longer than thirty minutes to complete by an untrained rater was made as it was planned to elicit the support of care managers and key workers to complete the assessments. The only two measures which met the criteria were the Life Skills Profile (Rosen et al 1989) and the REHAB scale (Hall and Baker 1983).

The Life Skills Profile (Parker and Rosen 1989) (see appendix D) was ultimately selected as the most suitable measure of social functioning in this study for two reasons. First, the questionnaire can be completed in only fifteen minutes by untrained raters such as care managers or key workers. Second, the measure has been previously used in evaluative studies within the RCCS (c.f. Ford et al 1995, Repper and Perkins 1995). These studies provide a basis for putting the results into context. In addition some of the staff were familiar with the content and administration of the measure.

The Life Skills Profile (Parker and Rosen 1989) was developed in response to the authors' difficulties in finding a measure of social functioning which met seven main requirements. First, the authors wanted a measure which focused on those aspects of functioning that affect survival and adaptation in the community. Second, the measure should assess broad areas of functioning of relevance to service providers and give estimates of key disabilities. Third, the measure should be able to be completed by both mental health professionals and lay persons such as relatives or carers. The questions and scoring therefore needed to be free from jargon and simply expressed. Fourth, the emphasis should be on assessing observable behaviours rather than relying on self-reports. Fifth, it should meet appropriate standards of reliability and validity. Sixth, each question should focus on a single distinct behaviour rather than attempt to generalize. Rosen et al (1989) give the example of "fail to wash" rather than "poor hygiene". Finally, the scores should be derived in such a way that the result would be both understandable and relevant to service providers and clients.

The developed measure has 39 items designed specifically to assess general levels of functioning and disability. It is simple and jargon free, and can be completed by professional or non professional staff in approximately 15 minutes. The 39 items fall into five key dimensions which Rosen et al (1989) suggest are highly relevant to people with long-term mental health problems. These are dimensions of self-neglect, turbulence, seclusion, inappropriateness and irresponsibility. The resultant five scales however have been labelled as self-care, non-turbulence, social contact, communication and responsibility. This positive emphasis reflects Rosen et al's (1989) belief that to focus on strengths rather than deficits would be more helpful to clients and to the raters. Rosen et al (1989) and Parker et al (1991) report evidence of the reliability and validity of the Life Skills Profile.

5.2.3 Procedure

Data collection took place over a six month period from 1/1/94. Form A was completed by contacting the clerical officer responsible for managing the RCCS database who accessed the relevant information. Most of the data were obtained from this source and supplemented by data from the clients' medical case notes in some instances.

Form B was completed by contacting the Information Department at the Nottingham Healthcare NHS Trust which is responsible for managing the Psychiatric Case Register. Data were obtained on 200 clients from the Psychiatric Case Register, the data on the remaining clients were obtained from the medical case notes.

Form C and the Life Skills Profile (Parker and Rosen 1989) were designed to be completed by service providers who knew the clients. Every care manager, relevant key worker and a large number of residential homes were contacted to assist in completing the forms. The majority of service providers completed the forms alone once the format had been explained and an example completed under supervision. A number of forms were completed with the service providers if they were unsure about the format or were reluctant or not motivated to complete the forms alone. A pigeon hole was obtained at the RCCS administrative offices where completed forms could be left for collection.

5.2.4 Analysis

The process of analyzing the data followed the sequential steps suggested by Polit and Hungler (1991). Data were analyzed using the Statistical Package for the Social Sciences (SPSS), version 6.1 for the Apple Macintosh Computer.

Much of the data from data collection forms A, B and C were coded through pre categorization (see appendices A, B, and C). The data obtained from the open-ended questions were coded after all the data were collected as it was difficult to anticipate the breadth of information that was obtained.

The Life Skills Profile (Parker and Rosen 1989) has five scales labelled to reflect functional strengths as well as disabilities. The sores reflect that orientation, so that a high score for each scale or for the total Life Skills Profile would indicate high function or low disability. Each of the 39 items are phrased so that the most functional rating is the left-hand anchor point, and the most dysfunctional rating is the right hand anchor point, so that scores for each item are assigned as 4 (extreme left anchor), 3 or 2 if intermediate and 1 (if extreme right anchor). Scale scores are generated by summing anchor scores as follows:

'Self-care' is the sum of scores for items 10, 12, 13, 14, 15, 16, 23, 24, 26, 30.

'Non-turbulence' is the sum of scores for items 5, 6, 25, 27, 28, 29, 32, 34, 35, 36, 37, 38.

'Social contact' is the sum of scores for items 3, 4, 20, 21, 22, 39.

'Communication' is the sum of scores for items 1, 2, 7, 8, 9, 11.

'Responsibility' is the sum of scores for items 17,18, 19, 31, 33.

The total Life Skills Profile score is the sum of all item scores. The scores for each of the scales and the total score were calculated as the completed measures were returned. The scoring was double checked to ensure accuracy.

A codebook was then prepared which listed the variable name to be entered onto the data file, the variable labels, and the codes assigned to the various aspects of each variable (see appendix E). A data file was created for the data to be entered and analyzed. Each column was labelled with the variable name listed in the codebook (see appendix E), and the codes were entered directly from the original data collection tools. Two procedures were adopted to check the entries for any mistakes. First, the data entered were visually double checked. This was a time consuming exercise but worthwhile as several mistakes were identified and rectified. Second, a check was made for outlier or wild codes. Again the few mistakes identified were rectified. It was not necessary to allocate a number to code missing data as SPSS, version 6.1 automatically uses (.) for missing values.

Some of the raw data entered into the data file needed to be transformed. All of the transformations are documented in the codebook (see appendix E) and were included in the data file as additional variables. Two types of transformation were carried out. First, certain categories within individual variables were combined. This was done when the numbers in some categories were low. Care was taken during this transformation to ensure that the new categories remained exclusive and exhaustive. Examples of variables which were transformed in this way include marital status, employment status and living arrangements. Second, a number of new variables were created by summarizing the raw data from several variables into one variable. For example, the seven variables about the clients' contact with the outreach services were transformed into one variable which contained the number of outreach services used.

The principle analysis was undertaken in two stages. In the first stage the data were summarized, explored and described in order to highlight major trends and differences. This preliminary analysis is considered vital in order to identify patterns and trends in the data (Bryman and Cramer 1995) which can later be confirmed by formal statistical testing (Kinnear and Gray 1995). The second stage was used to confirm the trends and differences identified in stage one using a range of formal statistical tests.

5.3 Results

Polit and Hungler (1991) suggest that researchers almost always find that their data set has missing information on some variables. They also argue that if the sample is large and the number of missing cases on a specific variable is small, then the missing data should not cause a problem. In this study the amount of missing data was small: Form A was completed on all 480 clients; Form B was completed on 458 out of 480 clients (22 missing forms); and Form C and the Life Skills Profile (Parker and Rosen 1989) was completed on 460 out of 480 clients (20 missing forms).

The results of this study will be presented as follows. First, the socio-demographic and psychiatric characteristics of the men and women using the RCCS will be described together with their use of services. Second, the differences between the men and the women using the RCCS will be presented.

The description of the socio-demographic and psychiatric characteristics of the men and women using the RCCS together with their use of services will be presented using frequency distributions, measures of central tendency and measures of dispersion as appropriate. All the percentages have been rounded up or down to the nearest whole number. Efforts have been made to summarize the results in order that the most important and relevant findings are highlighted. A complete set of the results can be seen in appendix F.

The socio-demographic characteristics of the 480 clients closely resembled the users of other similar community care services (c.f. Sturt et al 1982, Meltzer et al 1992, Muijen et al 1992, Ford et al 1993). The majority of clients were male (66% men, 34% women), unemployed (98% men, 99% women), and a high proportion had never worked (35% men, 50% women). Most of the clients were white (89% men, 90% women), single (81% men, 62% women), and lived alone (83% men, 77% women). Although a relatively high proportion of the clients had children (16% men, 29% women), few clients had dependent children (5% men, 10% women). Of the clients who did have dependent children, only 2 men and 6 women were directly responsible for their care. Table 10 summarizes the socio-demographic results.

Similarly, the psychiatric diagnosis and psychiatric history of the 480 clients resembled the users of other community care services (c.f. Sturt et al 1982, Meltzer et al 1992, Muijen et al 1992, Ford et al 1993). The majority had a primary diagnosis of some form of psychosis (men, schizophrenia 72%, major affective disorder 14%; women, schizophrenia 68%, major affective disorder 15%), had been involved with the psychiatric services for many years, and had experienced multiple psychiatric admissions (men, mean = 3.4, SD=3.1; women, mean = 3.6, SD=2.8). A high proportion of the clients were prescribed major tranquillizers (64% men, 65% women) or a combination of psychotropic medication (13% men and women). A relatively high proportion had a chronic physical health problem (29% men, 34% women), (c.f. Koran et al 1989, Attkisson et al 1992). Finally, the results indicate that a large number of the clients had reported histories of substance misuse (21% men, 15% women), violence towards people or property (40% men, 22% women), and being detained in prison or a Special hospital (17% men, 8% women), (c.f. Pepper et al 1981, Harris and Bergman 1984, Drake and Wallach 1989, Bachrach 1996). Table 11 summarizes these results.

Table 10: Socio-demographic characteristics of men and women using the Rehabilitation and Community Care Service on 1/1/94 (N=480)

Variable	Men		Women	
Clients in the service	66%	316	34%	164
Age: Mean (SD)	48.3	(14.9)	51.1	(15.3)
Range	63.0	(19-82 yrs)	65.0	(21-86 yrs)
Marital status: Single	81%	257	62%	101
Married	6%	18	7%	12
Cohabiting	-		1%	1
Separated	2%	6	2%	3
Divorced	10%	32	18%	29
Widowed	1%	3	11%	18
Currently or previously married	19%	59	38%	63
Living arrangements:				
Living alone	83%	250	77%	121
Living with partner, family, friends or children	17%	53	23%	37
Ethnicity: White	89%	282	90%	148
Afro Caribbean	7%	23	5%	8
Asian, African, other	4%	11	5%	8
Employment history: Never worked	35%	107	50%	79
Currently unemployed	98%	309	99%	162
Clients who have children	17%	50	30%	47
Clients who have dependent children (under 18 years)	5%	14	10%	17
Where the dependent children live:				
With the client	14%	2	35%	6
With relative, in care, adopted	86%	12	65%	11

Table 11: Psychiatric history and characteristics of men and women using the Rehabilitation and Community Care Service on 1/1/94 (N=480)

Variable	Men		Women	
Primary diagnosis: Schizophrenia	72%	218	68%	106
Major affective disorder	14%	41	15%	23
Other	14%	44	17%	26
Age at first contact with the psychiatric services				
Mean (SD)	27.5	(10.3)	28.9	(11.4)
Range	4-64	(60yrs)	3-70	(67yrs)
Number of psychiatric admissions:				
Mean (SD)	3.4	(3.1)	3.6	(2.8)
Range	19	(0-19)	15	(0-15)
Duration of longest admission (months)				
Mean (SD)	46.3	(93.3)	51.1	(111.3)
Range	671	(0-671)	594	(0-594)
Total duration of admissions (months)				
Mean (SD)	54.2	(98.1)	57.9	(113.1)
Range	671	(0-671)	594	(0-594)
Currently prescribed psychotropic medication:				
Major tranquillizers	64%	194	65%	103
Minor tranquillizers	1%	2	2%	3
Anti-depressants	5%	16	8%	9
Combination of psychotropic medication	13%	38	13%	20
None	17%	52	15%	24
Currently detained under Section of the Mental Health Act (Sections 2, 3, 37 or 41)	5%	15	3%	5
Reported chronic medical condition	29%	88	34%	54
Reported history of alcohol, drug or solvent abuse	21%	63	15%	23
Reported violence towards people or property	40%	122	22%	34
Reported history of prison or special hospital	17%	50	8%	13

The results of the assessment of social functioning completed by the staff within the RCCS using the Life Skills Profile (Parker and Rosen 1989) are consistent with studies that have used the measure with a similar client group (c.f. Rosen et al 1989, Parker et al 1991, Ford et al 1995, Repper and Perkins 1995). As might be expected, many clients had multiple social disabilities. For example the scores in the self care sub-category suggest that many of the clients have a tendency to neglect their physical health, have limited cooking and budgeting skills, and neglect their personal hygiene. The relatively high mean scores in the non-turbulence sub-category suggest that the clients were not particularly disruptive or disturbed although many have some problems living with others, are prickly and take offence easily. This result possibly reflects the mean age of the clients (men 48.3, s.d =14.9; women 51.1, s.d.=15.3) as violence and turbulence are more likely in younger clients (c.f. Rosen et al 1989). The difficulties identified in the communication sub-category scores include slight difficulties in conversation, reduced eye contact, a slightly odd appearance and somewhat intrusive behaviour. These poor communication skills might explain the scores in the social contact sub-category which suggests a group of clients who consistently withdraw from social contact, show a lack of warmth towards others, have few interests or hobbies which they do regularly, rarely attend social activities outside the mental health services, and experience considerable difficulties in making or maintaining friendships. Finally, the scores in the responsibility sub-category suggest that the clients usually cooperate with the mental health service staff but are slightly unreliable about taking their medication without supervision. The scores for the men and the women in each of the sub-categories were very similar and there were no significant differences identified. The results are summarized in Table 12.

Table 12: Social functioning of men and women using the Rehabilitation and Community Care Service on 1/1/94 (N=480)

Measure	Sub-category	Men Mean score (SD)	Women Mean score (SD)
Life Skills Profile (Parker & Rosen 1989)	Self-care (max. score 40)	28.9 (6.3)	29.7 (6.3)
	Non-turbulence (max. score 48)	40.2 (6.1)	40.5 (6.1)
	Social contact (max. score 24)	14.2 (4.6)	14.4 (4.1)
	Communication (max. score 24)	18.9 (3.6)	18.9 (3.6)
	Responsibility (max. score 20)	16.1 (2.8)	16.3 (3.2)
	Total score (max. score 156)	118 (16.8)	119.7 (17.0)

The multiple psychiatric and social disabilities experienced by both the men and the women was reflected in the nature of psychiatric services they received. The majority of clients received regular key worker support from either the Community Rehabilitation Teams or from the Community Support Teams within the RCCS (95% men, 98% women). The inability of many clients to live independently in their own accommodation, either as a result of their poor social functioning or because of a deterioration in their psychiatric symptomatology, was reflected in their use of residential services. For instance, 18% of men and 9% of women were in-patients, and 28% of men and 31% of women lived in accommodation which provided either professional or non professional support over 24 hours. Finally, a considerable number of clients received support from a variety of day care and outreach services such as the RCCS day centres (33% men, 24% women), the Skills and Practical Activity Network (17% men, 12% women), and a range of voluntary organizations, self-help groups and drop-in centres (13% men, 8% women). The results are summarised in Table 13.

Table 13: Service use of men and women using the Rehabilitation and Community Care Service on 1/1/94 (N=480)

Variable	Men		Women	
Use of residential services:				
Hospital	18%	55	9%	15
Accommodation with either professional or non professional support as part of housing	28%	86	31%	49
None	53%	162	60%	94
Use of RCCS day centres	33%	99	24%	38
Use of Skills and Practical Activity Network (SPAN)	17%	52	12%	17
Use of voluntary organizations, self-help groups and drop-ins	13%	39	8%	13
Key worker support from Community Rehabilitation Teams or Community Support Teams	95%	288	98%	138

The preliminary analysis of the data suggested a number of differences between the men and the women which were confirmed by formal statistical testing. The chi-square (X^2) statistical test was selected to analyze the nominal dependent variables. The independent sample t-test was used to analyze the interval dependent variables. To ensure that the data contained within each of the variables did not violate the assumptions of the independent sample t-test the following precautions were taken. First, the Levene test for homogeneity of variance was conducted. Second, means and medians were compared to ensure the distribution was symmetrical.

The identified statistically significant differences between the men and the women using the RCCS on 1/1/94 are presented in Table 14. A complete set of the statistically significant and non significant results can be seen in appendix F. The overall picture which emerges suggests that the past and current experiences of the men and women were very different.

The lives of many of the men, for example, appear to have been relatively turbulent. They were more likely to have a history of violence towards people or property (40% men, 22% women, $X^2=16.49$, df=1, p=<0.001), more likely to have spent time in prison or a Special hospital (17% men, 8% women, $X^2=6.08$, df=1, p=<0.05), and there was a trend towards them being more likely to have a history of substance misuse (21% men, 15% women, $X^2=2.71$, df=1, p=0.09). The similarity of these gender differences to those existing in the general population such as greater male arrests, substance misuse and violence have been commented upon by Lewis (1992). This suggests that there is a need to look beyond illness related factors to explain these gender differences such as differential community tolerance or differential gender role expectations. For instance, greater fear by the lay public of men with mental health problems (Rabkin 1980) might contribute to the more frequent imprisonment of men. This fear might also explain the fact that the men were more likely to be in-patients (18% men, 9% women, $X^2=6.05$, df=2, p=<0.05), and more likely to be receiving support from one of the RCCS day centres where their mental state and behaviour could be monitored (33% men, 24% women, $X^2=3.78$, df=1, p=<0.05).

In contrast to the men, many of the women's life experiences appear to be characterized by domestic responsibilities, both current and in the past. There was a difference in marital status between the sexes with a significantly higher proportion of the women having been married or being currently married (38% women, 19% men, $X^2=22.20$, df=1, p=<0.001). The women were more likely to be divorced (18% women, 10% men, $X^2=37.68$, df=5, p=<0.01) and to have subsequently experienced the loss and stability of a partner and family home. The women were also more likely to have children (29% women, 16% men, $X^2=10.92$, df=1, p=<0.001).

Whilst the social functioning of the women and the men in the study did not differ, women were under-represented amongst those receiving a high level of input from the services. The men were more likely to be attending one of the RCCS day centres (33% men, 24% women, X^2=3.78, df=1, p=<0.05) or be in-patients than were the women (18% men, 9% women, X^2=6.05, df=2, p=<0.05).

Table 14: Differences between the men and the women using the Rehabilitation and Community Care Service on 1/1/94 (N=480)

The women were more likely to be currently or previously married
(38% women, 19% men, X^2=22.20, df=1, p=<0.001)

The women were more likely to be divorced
(18% women, 10% men, X^2=37.68, df=5, p=<0.01)

The women were more likely to have children
(29% women, 16% men, X^2=10.92, df=1, p=<0.001)

The men were more likely to have a history of violence towards people or property
(40% men, 22% women, X^2=16.49, df=1, p=<0.001)

The men were more likely to have spent time in prison or a Special hospital
(17% men, 8% women, X^2=6.08, df=1, p=<0.05)

The men were more likely to be in-patients
(18% men, 9% women, X^2=6.05, df=2, p=<0.05)

The men were more likely to attend one of the RCCS day centres
(33% men, 24% women, X^2=3.78, df=1, p= <0.05).

Although not statistically significant, the differences between the men and the women approached significance in the following area:

The men were more likely to have a history of drug, alcohol or solvent abuse
(21% men, 15% women, X^2=2.71, df=1, p=0.09

5.4 Discussion

The results of this study suggest that the 480 clients receiving care within the RCCS on 1/1/94 closely resemble the users of other similar community-based services. Although little new was found, these results will contribute to the available body of knowledge about this client group. There is a danger however, of simply highlighting, yet again, a similar and familiar set of issues. Whilst not wishing to ignore the many difficulties experienced by the men, this discussion will therefore focus primarily on the key issues of concern for women that were identified. These issues include the women's roles as wives and mothers, and the under-representation of women in some parts of the service.

The comparison between the men and the women in the RCCS found that the women were more likely to be currently or previously married or cohabiting, to be divorced or to have had children than the men. These findings replicate those of earlier studies (c.f. Cheadle et al 1978, Test and Berlin 1981, Seeman 1983, Test et al 1990, Conning and Rowland 1991), and have been explained by the later onset of illness in women and their superior social skills in forming and sustaining relationships (Conning and Rowland 1991). Cheadle et al (1978) suggest that the high divorce rate amongst these women reflects the toll that a serious and prolonged mental illness makes on personal relationships.

There is little recognition that women with long-term mental health problems may desire the valued roles of wife or mother, especially since other roles, such as worker, are often not available (Sayce 1997). Marriage, and increasingly cohabitation, is one of the social norms in society. The societal pressures for women to get married include family continuity, inheritance and security, although the desire to find happiness, companionship and a role in life inevitably plays a part (Smith 1987). The impact of marriage however, is far greater on women than men. There is evidence that marriage is more likely to be beneficial to the physical and psychological well-being of men, and detrimental to the physical and psychological well-being of women (McRae and Brody 1989). The reasons for the detrimental effects of marriage on some women as compared to men are complex. Explanations include the low status afforded to the role of housewife, the multiple roles married women are expected to fulfill such as wife, mother, homemaker and lover, and the isolation of being at home alone with young children (Carmen et al 1981, Smith 1987). These difficulties are compounded if the woman is living in poverty, with little social support and few friends that she can confide in (Brown and Harris 1978). In addition, domestic violence, which is a pervasive social problem, can have lasting physical and psychological effects (Gorman 1992).

It is perhaps inevitable that so few women with long-term mental health problems, many of whom will have married prior to the onset of illness, remain married. Not only will many of them experience the pressures already discussed but will have the many additional stresses associated with their illness. For these women separation and divorce not only brings economic hardship (Faugier 1992), but often the loss of a home, the custody of children, and the one remaining role that defined them as 'normal' in the eyes of society.

This hardship and loss is again reflected in the literature on motherhood. Whilst for some women, motherhood is primarily a positive experience, others experience the loss of any identity other than that of mother, loss of contact with other adults, tiredness and loss of confidence (MIND 1992). Although women with long-term mental health problems may value and desire the role of motherhood, previous studies have suggested that parenting places a huge burden on them (Test and Berlin 1981, Miller and Finnerty 1996). They face enormous barriers to child rearing at every stage. For example, the absence of consistent support in parenting (Miller 1992, Blanch et al 1994), often results in the child being removed from the mother at birth or at a later stage for adoption. The women often lose touch with any children they manage to have and may be offered no help to deal with the bereavement this represents (Apfel and Handel 1993, Sayce 1997). In this study 29% of the women had had children at some stage in their lives and had inevitably experienced some of the difficulties described.

Many women with long-term mental health problems, however, have not had the opportunity to become wives, mothers or workers. 62% of women in this study had never married, 71% did not have children, and 50% had never worked. This lack of opportunity stems from the disabling nature of their mental health problems, and the prolonged periods of hospitalization which many of the older women in particular have experienced. Curtis and Barnes (1994) suggest that as such women get older they feel the loss of missed opportunities and the lives they might have had more keenly. These feelings are often exacerbated when they start losing their physical strength and health and thus become increasingly dependent on others. They thus lose their capacity to care for others, even fellow patients, and subsequently an important source of their identity.

The description of the services used by the clients in the RCCS, showed that the majority of women (98%) received regular key worker support from either the Community Rehabilitation Teams or from the Community Support Teams, and that many made use of a range of residential facilities, day care services and informal drop-in centres and self-help groups. There were significantly less women than men however, in the in-patient units and in the two day centres. This finding is consistent with that of Perkins and Rowland (1991).

It is possible that the women may have declined the available support because it did not meet their needs. The previous discussion has highlighted a number of particular issues for women which are not necessarily shared by the majority of male clients. Alternatively the women may have found that the services were unacceptable. For example they may have been put off using services because of their orientation towards men (Perkins and Repper 1996), and a previous study has suggested that many sheltered or supported work projects are so male dominated that they are not a pleasant place for women to work (Perkins and Rowland 1991). Many women may find these male dominated environments threatening, they may feel unsafe and fear harassment and possible abuse (MIND 1993a, Nadelson 1993). Finally, it is possible that the men's behaviour is forcing services to focus on them. In this study a high proportion of the men had a reported history of substance abuse (21%) and violence towards people or property (40%). Nadelson (1993) argues that public and professional concern about male behaviours, especially violence related to alcohol misuse, leads to the development of services for men that are also used for women but are less effective for them. Consequently, more attention may be paid to men, because of the threat of violence, than to equally disabled, but less threatening women.

Although this study has highlighted some key issues of concern for women, the interpretation of such findings is inevitably speculative. The cross-sectional design of the study was ideally suited for the description and comparison of a large group of clients, but did not allow for further detailed exploration. The women's roles as wives and mothers, and their under-representation in parts of the RCCS will therefore be investigated in more depth in the remaining five studies which make up this evaluation.

The final part of this discussion explains some of the problems that were experienced in collecting the data for this study. Although the majority of data were collected within six months of 1/1/94, there were problems in gathering the psychiatric data in particular.

It proved very difficult in the early stages of the study to get an accurate list of all the clients who were receiving care from the RCCS on the 1/1/94. The list which was held on the database contained a number of inaccuracies. For example, recent acceptances into the service had not been entered, and clients who had died or who had been discharged were still being included in the numbers. This problem was overcome by checking the clients who were on three individual care managers' case loads and checking up on the remainder with the service manager. There remained a number of anomalies however, such as clients who had not been allocated a care manager and who did not receive any direct services other than outpatient appointments, but who remained within the service.

The Psychiatric Case Register at the Nottingham Healthcare NHS Trust proved to be much more difficult to access than was envisaged. Despite a number of telephone calls and letters the data that were requested did not materialize until six months after the initial contact. There appears to have been problems with low staffing levels, new staff who did not know how to access the system, and the problems of the computer being out of action.

The completion of Form C and the Life Skills profile (Parker and Rosen 1989) proved to be the most time consuming activity. A large number of service providers completed the forms willingly and reasonably quickly. About a third of the staff who were originally asked to provide data failed to complete the forms for a number of reasons. These included pressure of work, lack of interest in the research, and objections to the nature of the information being requested. Alternative means of completing the forms were then adopted which involved visiting a large number of residential homes, day centres, and outreach services to persuade willing key workers to provide the information. This proved a successful way of gathering much of the data although it was very time consuming.

5.5 Conclusion

The aim of this study was to describe and compare the socio-demographic and psychiatric characteristics of men and women with long-term mental health problems using the RCCS together with their use of services. Using a cross-sectional design, data were collected on all 480 clients registered with the service on 1/1/94.

The socio-demographic and psychiatric characteristics of the clients were similar to those described in previous studies of this client group (c.f. Sturt et al 1982, Meltzer et al 1992, Muijen et al 1992, Ford et al 1993). The results of the assessment of social functioning completed by the staff within the RCCS using the Life Skills Profile (Parker and Rosen 1989) revealed that many clients had multiple social disabilities in areas such as self care, communication skills and social contact. These findings were again consistent with studies using the measure with a similar client group (c.f. Rosen et al 1989, Parker et al 1991, Ford et al 1995, Repper and Perkins 1995).

A number of differences between the men and women were confirmed by formal statistical testing. The men were more likely to have a history of violence towards people or property, more likely to have spent time in prison or special hospital and more likely to have a history of substance misuse. In contrast the women were more likely to have been married at some stage in their lives, to be divorced and to have had children. The women were also under-represented amongst those receiving a high level of input from the services.

In the discussion it was acknowledged that the exploration of the women's roles as wives and mothers, and their under-representation in parts of the service was inevitably speculative. These issues, amongst others, will be investigated further in the remaining five studies which make up the evaluation. Finally some of the practical problems of gathering this comprehensive data set were discussed.

Chapter Six

Services Provided for Women with Long-Term Mental Health Problems

6.1 Introduction

This chapter presents two studies whose shared purpose was to explore the extent and adequacy of services for women with long-term mental health problems throughout the Nottingham district. The first study focuses on services provided within the Rehabilitation and Community Care Service (RCCS), and the second on the range of services provided outside the RCCS. To some extent this distinction between services within and outside the RCCS is artificial as it implies a demarcation in service provision. For example, the implication that specialist medical and psychiatric care provided by professional staff is solely delivered within the RCCS, and social care is provided solely by non-professional staff within the outside services. In reality the boundaries between social and health care for this client group are becoming increasingly blurred as service providers recognize that these clients require a range of health and social services to facilitate their integration into community settings (Bachrach 1996). The decision however, to separate the two groups of services for the purpose of this study was made for two reasons. First, this evaluation is focusing on clients who are receiving care under the auspices of the RCCS and their contact with other agencies is primarily arranged through this service. Second, the work of the staff within the RCCS is guided by a set of core values and aims (see 4.2.1) which are not necessarily shared by outside facilities and agencies.

These two studies will contribute to the overall evaluation by adding to the limited evidence regarding the extent to which community-based services are either provided for or used by women with long-term mental health problems, and exploring how consistently women's needs are identified and considered when planning and delivering services. Each of the two studies will be presented separately and the discussion will focus on drawing links between the results of each.

6.2 Study 1: Provision for women with long-term mental health problems within the Rehabilitation and Community Care Service

This study has two aims. First, to identify the current provision for women with long-term mental health problems within day care, residential and outreach services provided by the RCCS. Second, to explore staff's awareness of the particular problems experienced by women with long-term mental health problems.

6.2.1 Method

Using a cross-sectional survey design, data were collected on the provision made for women with long-term mental health problems, and the problems experienced by these women, by interviewing staff working in all the component parts of the RCCS. A survey was particularly suited to this study as the approach allows for both a description and an exploration of the issues being investigated (Robson 1995). The decision to interview staff rather than distribute questionnaires was made because personal interviews usually result in a high response rate (Polit and Hungler 1991), and it provided an opportunity for the researcher to both encourage participation and to clarify the questions if necessary (Robson 1995).

6.2.1.1 Sample

Data were collected from small groups of staff working in all 16 parts of the RCCS. This included 5 in-patient residential units, 2 day centres, the 2 parts of the Skills and Practical Activity Network, 5 residential partnership schemes, the Community Rehabilitation Teams, and the Community Support Teams. All staff, qualified and unqualified, were invited to participate but in practice when groups were held only a proportion were free to join in. The qualified staff consisted of nurses, occupational therapists and social workers. The number of staff in each group ranged from two to eight and a total of fifty six staff participated; this constituted approximately 20% of the RCCS staff. The data were gathered from groups of staff rather than from individuals to maximize the quality of data collected and to minimize bias.

6.2.1.2 Data collection tool

An interview schedule with a series of open-ended questions was designed to gather information about the nature of the service provided, the specific needs of the women with long-term mental health problems using their service, the ways in which the service endeavoured to meet these needs, and any problems experienced in either the uptake of their service by women or in the implementation of facilities or policies concerning women (see appendix G for an example of the interview schedule). Open-ended rather than closed questions were used so that the staff were given the opportunity to respond in their own words and to expand on the issues raised in the interview.

6.2.1.3 Procedure

The team leaders of all 16 parts of the RCCS were initially contacted by letter in February 1994. The letter explained the purpose of the study and informed them that they would be contacted within one month to ascertain their willingness to take part. A follow up telephone call gained the cooperation of all 16 parts of the service, and visits were arranged to interview the staff.

The timing of these visits were planned to maximize the number of staff available to take part, usually after the handover period in the middle of the day or as part of a regular staff meeting. All of the services were visited between March and June 1994. The interviews with each group of staff were conducted informally and efforts were made to encourage each member to contribute. All the responses were recorded by the researcher on the interview schedule during the meeting to ensure accuracy. The length of the interviews ranged from twenty to fifty minutes, those involving more staff generally took longer.

6.2.1.4 Analysis

The group interviews produced a wealth of qualitative data as the staff were verbally expressive and cooperative. It was therefore necessary to select a strategy for analyzing the data which imposed some structure on the mass of information, was consistent with the aims of the study, and which was a valid representation of the views of the staff. This was a complex undertaking as there are no clear and accepted set of conventions for the analysis of qualitative data which correspond to those observed with quantitative data (Robson 1995).

The first decision made was whether the data should be quantified to some extent. There are varying degrees to which qualitative data can be quantified. At one end of the continuum, the data can be converted to a numerical system and analyzed statistically. Content analysis, for example, often involves the complete quantification of data (c.f. Cavanagh 1997). At the other end of the continuum, there is no quantification as the purpose of analysis is interpretation and theory building. An example of this approach to analysis is that of grounded theory described by Glaser and Strauss (1967). In between there are quantitative methods for introducing some checks into qualitative analysis.

For this study, it was decided to develop a strategy which combined the quantification of the data with a qualitative analysis. Such a strategy would assist in making sense of the large amount of data, would give greater protection against bias, and would retain the richness of the material generated. The following procedural steps were taken in the analysis of the data. These steps derive from an amalgamation of suggestions made by Polit and Hungler 1991, Maykut and Morehouse (1994), and Robson (1995).

First, a list of three core categories was generated from an initial reading of the interviews. These core categories reflected both the aims of the study and the questions in the interview schedule and included services provided for women, strategies for dealing with issues outside the remit of the service, and special needs or problems of women with long-term mental health problems. All the data were then coded into one of the three categories.

Second, the content of each of the core categories was reviewed. It was not necessary to develop sub categories for two of the core categories, services provided for women and strategies for dealing with issues outside the remit of the service, as the content was easily described under one heading. The third core category, needs and problems of women with long-term mental health problems, however contained a wealth of material which was sub categorized to enhance the messages it conveyed. These categories included a vulnerability to abuse and exploitation, nervousness or wariness of men, low confidence and self esteem, difficulties in finding an appropriate role in life, physical health issues and the minority of women in the service. The data within the core category were then recoded so that they fell into one of the sub categories.

Third, a matrix was developed from the coded data. This matrix was used to identify patterns in the data and also as a means of measuring the frequency that data occurred in each of the core and sub categories. In this way actual numbers were generated (see appendix H for copy of the matrix).

6.2.2 Results

The results of this study will be presented in two parts. The first part focuses on the staff's awareness of the particular problems and needs of women with long-term mental health problems. The second part describes the efforts made by staff within the RCCS to meet these women's needs. These efforts include the strategies they adopted to deal with issues outside the remit of the service, and the services provided within the RCCS for women.

The staff working within the RCCS gave a wide range of responses indicating varying levels of understanding of the women's problems and needs. This might be expected given the complexity of the service and the varying backgrounds of the staff working within it. Although responses varied in terms of quantity and depth, there was consistency in the information given which allowed an overall picture of the problems experienced by women with long-term mental health problems to be built up.

Vulnerability to abuse and exploitation: Twelve groups of staff identified that these women were vulnerable to abuse and exploitation both within the mental health services and in the wider community. Examples were given of women who had experienced physical and verbal abuse and neglect in childhood and those who were currently experiencing abusive relationships with their male partners. Their vulnerability to such exploitation was frequently commented upon, as such women are often coerced into sexual relationships that they do not necessarily want. The geographical locality of some of the services appeared to increase the vulnerability of some of the women, and verbal abuse directed at them by the general public, particularly towards their appearance, was common.

Within the inpatient residential units there was evidence of further exploitation of these women, particularly by the male clients. This exploitation took various forms. The negative attitudes of the male clients towards the women included derogatory comments about their appearance and dress, and an expectation that the women would do the clearing up and housework in the units. In addition several of the staff gave examples of women who had either been harassed and pestered by the male clients for money and cigarettes, or women who had sex with male clients in return for cigarettes and friendship. One group of staff felt that protecting women from such exploitation can conflict with ideas of integration which was viewed as a positive experience particularly for men.

Nervousness or wariness of men: Four groups of staff identified that many women with long-term mental health problems are nervous or wary of both male clients and male members of staff. This nervousness was attributed to two main factors. First, many of the older women had lived in institutions for many years being cared for in single sex wards run by female staff. As a result many had restricted contact with men in the past and are unused to relating to and living with men. Second, this nervousness may stem from their history of sexual and physical abuse by men. Consequently some of the women find it difficult living in residential units or attending the day centres which are dominated by men.

Low confidence and self esteem: Four groups of staff identified that women with long-term mental health problems are lacking in self confidence, have a low self esteem and poor assertiveness skills. Their lives are characterized by a lack of stability, loneliness, few friends, difficulties in establishing and maintaining meaningful relationships, and little family support. Their confidence and self esteem is further undermined by the side effects of their medication such as weight gain, dribbling, shaking, poor skin and a reduction in libido.

Difficulties in finding an appropriate role in life: Six groups of staff commented on the difficulties that many of these women had in finding an appropriate role in life. They gave examples of women mourning the loss of children they had never had, and the traditional role of motherhood, and the loss of opportunities to care for others. Such women feel that they have missed out on these opportunities because of their illness. Consequently the women often flock over staff's babies and children and want to hear about staff's lives. They also demonstrate their desire to care for others by doing things for other, particularly male, clients such as washing up or making tea.

Physical health issues: A number of physical health issues were identified. These issues centered around the women's general neglect of their physical health, rather than particular physical problems. There were examples of the erratic practical management of menstruation and unsafe sex practices. The women were often reluctant to heed advice about contraception and safe sex or to attend clinics for help in managing the menopause or for breast and cervical screening.

The minority of women in the services: A frequent observation was that there was a minority of women with long-term mental health problems in the RCCS. This was attributed to a number of factors. First, the number of women referred to the service was low, possibly because they were not seen to be the most in need as they often presented with less problematic behaviour than the men, or had the daily living skills required for independent living, which men lacked. Second, male dominated services were off putting for women either because the male culture was perceived as unwelcoming or because the available help and support did not meet their needs. Finally the younger women in particular are often difficult to engage in the service as they are more likely to have families requiring care or caring for them. A breakdown of the number of women found in different parts of the RCCS during this study was illuminating (see Table 15).

The explanations provided by staff for fewer women referred to the RCCS might explain their very low numbers in the inpatient residential units and day centres. This does not explain, however, the greater numbers of women found in two of the five residential partnership schemes. This may be due to the older age group of the clients in these particular services. The staff working within the Skills and Practical Activity Network suggest that the preponderance of male clients reflects the service's primary focus on work, and the stereotyped view that male clients are sent to work to get better, whereas women tend to get directed into domestic pursuits. This stereotyping was additionally reflected in the activities undertaken by the clients. The crafts, art and catering classes were mainly attended by women, whereas the woodwork, gardening and upholstery classes were dominated by men. A recent supported education initiative between the Skills and Practical Activity Network and a local college of further education recruited 55 clients, of whom only 7 were women.

Table 15: Number of women with long-term mental health problems in different parts of the Rehabilitation and Community Care Service

Part of the Service		Capacity	Women	Men
Residential care services:	MC 1	14	3	11
	MC 2	14	6	8
	TM	12	2	10
	BH	12	2	10
	DL	12	2	10
Residential partnership schemes:	PC	12	7	4
	OS	12	9	3
	OR	12	4	12
	HL	15	7	8
	SH	11	4	7
Day centres (2 centres)		33 clients at each centre	30%	70%
Skills and Practical Activity Network (2 centres)		50 clients at each centre	25%	75%
Community Support Teams:	Team 1	63 clients in total	25%	75%
	Team 2		25%	75%
	Team 3		50%	50%
	Team 4		50%	50%
Community Rehabilitation Teams (4 Teams)		478 clients in total	30%	70%

The staff working within the Community Support Teams expressed the view that they received few referrals for women because of the perception within the RCCS that their service solely revolves around developing the clients' daily living skills. The other aspects of their work such as one to one counselling, group work and family interventions are seldom acknowledged. Thus they receive more referrals for men as they are seen as most in need of support with regards daily living skills.

Although the lack of women referred to the RCCS was acknowledged and a variety of explanations for this were given, the staff overwhelmingly expressed an interest and a willingness to attract more women to the service.

The majority of staff did not feel that they had encountered women with needs they felt unable to address. These needs were usually met within the facility, and almost all the services felt that the women had care managers who would ensure that gender specific needs were met. There was evidence that some women were referred to agencies outside the RCCS, although the agencies identified were those known to be very accommodating to the needs of people with long-term mental health problems such as drop-in centres run by the Social Services. There were two innovative examples, however, of efforts to use mainstream services. The first involved a well attended, ongoing support group for women with long-term mental health problems run by staff from the Skills and Practical Activity Network using the facilities of a local Health Centre. The group not only benefitted from the physical environment of the Centre, but also invited the primary health care staff to give talks on physical health issues such as contraception, healthy eating and the value of exercise. The second example was the transfer of an established women's group run by RCCS staff from a meeting place in one of the day centres to the local Women's Centre. Although the women expressed initial reservations about the change, several informal visits to the Centre to meet with the staff and view the facilities, together with discussions within the group, assisted in relieving some of their anxieties. The move was ultimately successful and the women appreciated meeting in a facility away from the mental health services.

A number of services within the RCCS provided specific facilities for women. These are summarized in Table 16.

Table 16: Specific services for women within the Rehabilitation and Community Care Service

One women-only house provided by a residential rehabilitation unit
A choice as regards the sex of their key worker offered by five services to female clients
Gender awareness workshops provided for all staff working in RCCS as part of a continuing education package
Equal opportunities policies drawn up in four services
A 'women's group' run by seven services. Purpose varied, included increasing social contact, sharing experiences, discussing problems, discussing women's issues, hair and beauty.
Monthly meeting of a sexuality forum for staff with discussion topics including contraception, medication and pregnancy, childcare, working with couples, lesbian relationships, and sexual abuse
Specific support and practical help in managing childcare, establishing and sustaining relationships, becoming independent, and building up confidence and self esteem provided by five services
A sexual harassment policy developed in two services
Raising the awareness of local events for women through posters and discussions within one registered home
One women-only woodwork group run by a day centre
Emphasis placed on increasing the numbers of women participating in a range of traditionally male orientated activities such as woodwork, upholstery and gardening in two day centres. Extra support given to women to access male dominated workshops by female workshop leaders.
Flexible start and finishing times to accommodate childcare in two day centres

6.3 Study 2: Provision for women with long-term mental health problems outside the Rehabilitation and Community Care Service

This study has two aims. First, to identify organizations, groups and agencies outside the RCCS who offer services to meet the particular needs of women with long-term mental health problems. Second, to investigate the extent to which these services are used by women with long-term mental health problems.

6.3.1 Method

Using a cross-sectional survey design, data were collected by distributing a postal questionnaire to organizations within the Nottingham district who provided a service to women generally or were known to provide a service to women with long-term mental health problems. A postal questionnaire was selected as the most appropriate data collection method for this study as it is an efficient way of collecting a large amount of data, at low cost, in a short period of time (Robson 1995). An effort was made to minimize the disadvantages of using postal questionnaires, such as low response rates and the respondents uncertainty about or misunderstanding of questions. These efforts will be discussed in sections 6.3.1.2 and 6.3.1.3.

6.3.1.1 Sample

A list was compiled of statutory and non statutory services, organizations, groups and agencies for people with mental health, physical and social problems in the Nottingham area excluding those services provided by the RCCS. Details of these organizations were obtained from the District Health Authority, the Nottingham Health Information Centre, the organization Good Practices in Mental Health, the Self-Help directory, and information provided by staff within the RCCS. All those organizations who provided a service for women generally or were known to provide a service for women with long-term mental health problems were included in the sample. The resultant sample of 49 organizations included mental health centres, private registered residential homes, drop-in centres, self-help groups, voluntary organizations and information and support networks.

6.3.1.2 Data collection tool

A questionnaire with a series of open-ended questions was designed to gather information on the client group the particular organization served, their approach towards women with long-term mental health problems, what they already provided for these women, and the help they might need to meet such women's needs (see appendix I for an example of the questionnaire). The use of open-ended questions throughout allowed for both the collection of factual information, and for the respondents to elaborate on particular issues they considered to be important. The wording and structure of each question was kept as simple and as unambiguous as possible to avoid any confusion or misunderstanding. The questionnaire was also designed to be completed in a relatively short period of time to increase the likelihood of it being completed and returned.

6.3.1.3 Procedure

All 49 organizations in the sample were sent a questionnaire by post with a covering letter explaining the purpose of the study. A stamped addressed envelope was enclosed for the return of the questionnaire. The initial mailing was in February 1994 and non-respondents were sent further questionnaires in March and July 1994. A number of non-respondents were followed up by a telephone call in August 1994.

6.3.1.4 Analysis

The approach taken to analyze the qualitative data in this study was the same as that described for the previous study in section 6.2.1.4. Such an approach combines the quantification of the data with a qualitative analysis. The following procedural steps were taken in the analysis of the data.

First, a list of five core categories was generated from an initial reading of the returned questionnaires. These core categories reflected both the aims of the study and the nature of the responses that were received. The core categories included the organizations' awareness of the particular problems experienced by women with long-term mental health problems, specific provision made for women, the extent to which services are used by women with long-term mental health problems, the role of services in meeting the needs of women with long-term mental health problems, and facilitating the use of services. All the data were then coded into one of the five categories. It was not necessary to develop sub categories. Second a matrix was developed form the coded data (see appendix J for copy of the matrix). As in the previous study (see section 6.2.1.4), this matrix was used to identify patterns in the data and also as a means of measuring the frequency that data occurred in each of the core categories.

6.3.2 Results

38 organizations returned completed questionnaires out of a sample of 49, a response rate of 77%. The returned questionnaires included 6 from registered charities, 10 from voluntary organizations and self-help groups, 7 from registered residential homes, and 15 from projects funded by Nottingham County Council, the Social Services, or the District Health Authority. The results of this study will be presented in five parts: the organizations' awareness of the particular problems experienced by women with long-term mental health problems, specific provision made for women, the extent to which services are used by women with long-term mental health problems, the role of services in meeting the needs of women with long-term mental health problems, and facilitating the use of services by women with long-term mental health problems.

The organizations' awareness of the particular problems experienced by women with long-term mental health problems

18 of the organizations surveyed were unable to identify any particular problems that women with long-term mental health problems might experience. The remaining 20 organizations identified a

range of problems which included the minority of women using their services or being referred; isolation, loneliness and lack of family support; vulnerability to violence and exploitation; difficulties in looking after children and fears of them being taken into care; low self worth and self esteem; and difficulties in interpersonal relationships. Many of these difficulties were compounded by poverty, unemployment, poor housing and lack of transport.

Specific provision made for women

20 of the organizations provided services specifically for women, the remainder were open to men and women. 11 of the organizations which provided services for both sexes, endeavoured to meet women's needs on an individual basis. 6 organizations stated that they did not provide any specific services for women. The specific provision made for women by these organizations is summarized in Table 17.

Extent to which services are used by women with long-term mental health problems

32 of the 38 organizations were prepared to offer a service to women with long-term mental health problems if they were able to use the help on offer. Two of the organizations who were unable to offer a service to these women stated that their aim was to cater for women who were not in touch with statutory mental health service provision, and that their organization was not geared up to meet the complex needs of people with long-term mental health problems who were already engaged in the mental health services. Although most of the services had open access, three services offering formal counselling or psychotherapy screened users before accepting them and stated that where appropriate they would refer women with long-term mental health problems on to 'more appropriate services'.

Table 17: Specific provision for women in organizations outside the Rehabilitation and Community Care Service

One women-only registered residential home

Fifteen women's groups offering a range of services including awareness sessions on domestic violence, free creches, support, increasing social contacts, friendship, coping with living apart from children, talks, outings and social activities, telephone contact, coping with having a hysterectomy, coming to terms with sexual abuse.

Refuge and support to victims of domestic violence provided by one charity

Fourteen services providing information and advice on welfare rights, services for women, getting health needs met, making complaints about services, improving physical health, coping with widowhood, and problems with alcohol

A lesbian group run by two organizations

Sessional work offered by prostitute outreach workers in one service

Support and practical help for young mothers provided by three organizations

Organized sessions and workshops on the menstrual cycle and pre-menstrual syndrome, safe sex and contraception, the menopause, healthy eating, being a mother and coping with children, addictions, and self-image provided by one service.

Women-only space and facilities provided by eight organizations

Priority given to women living in poverty or from ethnic minority groups in three organization

Breast screening provided by one service

Two organizations providing support and advice to Asian women

Social care and support to homeless women provided by one organization

In practice 25 of the 38 organizations were aware of women with long-term mental health problems using them. In organizations which were open to men and women, the women were inevitably in the minority. For example, the women made up approximately 20% of the clients using the residential facilities and the drop-in centres. An additional 5 organizations did not know whether they were used by such women because of the very specific nature of the help offered, such as coming to terms with sexual abuse, coping with domestic violence, and help with childcare. For this purpose they did not need to know about their clients mental health problems, and rarely knew whether women with long-term mental health problems were using their facilities. Each of these 5 organizations stated that they did not ask women for their mental health history, and respected the women's rights to keep this information private.

The role of services in meeting the needs of women with long-term mental health problems

Where it was known that women with long-term mental health problems used the service, it was commonly assumed that the care manager was coordinating their care. 21 of the services described themselves as being one part of an overall package of care provided for these women coordinated by the care manager.

The remaining organizations saw themselves as providing a specific service which was related to the clients' position or role as women. These services were therefore not necessarily tailored to meet their needs as women with long-term mental health problems. The Women's Centre for example, had attempted to run discussion groups for women with long-term mental health problems but found that their usual format did not work due to the anxiety and disability of the group. They have subsequently found that providing space for such women to use the Centre as required works better. Similarly the facilitator of a range of health related workshops attended by a group of women with long-term mental health problems found the sessions very difficult. She described feeling 'very out of her depth', and felt that the women learnt very little and became very anxious. On reflection this facilitator felt that teaching methods such as discussion and shared learning were inappropriate for such women. She concluded by commenting that she would benefit from some training with regards to the particular needs of these women.

Facilitating the use of services by women with long-term mental health problems

12 of the services were unsure about how to facilitate access for women with long-term mental health problems, possibly as a result of lack of information and/or training as regards their particular needs. These difficulties are demonstrated by the special efforts which the Women's Centre, for example, needed to make in order for women with mental health problems to be able to use them. The need for information and training as regards the particular needs of women with long-term mental health problems was emphasized by 4 services, and the desirability of working more closely with the mental health services as part of an overall package of care was highlighted by 13 services. 9 of the services commented that few if any women with long-term mental health problems are referred to them, possibly because the women themselves or their care managers are not aware of the service, or because the service is perceived as being orientated towards men.

6.4 Discussion

As was discussed in chapter one there are a number of themes underlying government policies in the development of community care. In particular it has been argued that policies should be needs led rather than service led, and that the best way of meeting this objective is by the replacement of large psychiatric hospitals with a flexible and relevant range of local alternative services in the community (Culhane 1996). A number of policy documents issued from the mid 1970's (c.f. Department and Health and Social Security 1975, House of Commons 1985, Griffiths 1988, Department of Health 1989a, 1990a, 1995b) have proposed major changes in the delivery of health and social care, and spelt out the need for closer cooperation between the National Health Service, Social Services Departments and the voluntary sector. The dividing line between health and social care is no longer clear cut as an increasing number of agencies are examining opportunities to address issues of mutual concern particularly where closer collaboration will result in a more effective and a more 'seamless' service for users (Nocon and Qureshi 1996).

The concept of seamless service provision which meets the needs of a particularly vulnerable group of clients was explored in these two studies whose shared purpose was to explore the extent and adequacy of services for women with long-term mental health problems throughout the Nottingham district. This discussion will begin by considering the findings of each of the studies separately. It will then move on to consider the findings as a whole by focusing on the commonalities between the findings.

The first study sought to identify the current provision for women with long-term mental health problems within the RCCS, and to explore the staff's awareness of the particular problems experienced by such women using their services. The picture which emerged suggests that the current provision for women is very patchy. The many examples of good practice, for example, the women-only residential unit, sexual harassment policies and women's groups, were dependent on the initiative of staff in different parts of the service. There was no evidence of an overall plan or policy to ensure a universally high level of attention to women's needs. Similarly, some of the staff groups interviewed were able to clearly identify a range of problems experienced by these women, whereas others were unable to identify any particular difficulties other than those associated with their mental health problems and/or social disabilities. Such staff felt that women's gender specific needs could be met via the ordinary individual care planning process. There was some recognition of the potential role of local community services for women, but little evidence of knowledge concerning what services exist and how to access and support them. Staff tended to refer women to those outside agencies known to be accommodating to their particular difficulties and needs. Where RCCS staff had actively worked together with non-mental health women's organizations, such as the local Women's Centre, the results had been particularly favorable in ensuring disabled women had access to ordinary facilities.

The second study sought to identify organizations outside the RCCS which could offer services to meet the needs of women with long-term mental health problems, and investigated the extent to which these services are used by such women. A wide range of organizations were identified which could be accessed by women with long-term mental health problems themselves or their care managers to address specific areas of need in a 'normal' non-stigmatized manner. These organizations were generally committed to providing a service for these women as part of an overall support system, but recognized that few such women make use of their services. It appeared that many of the organizations had little knowledge of the needs of women who experienced such difficulties and therefore how access to their services could be ensured. Some of the organizations were not aware that women with mental health problems might be using their facilities, an issue which was raised by agencies where women referred themselves rather than where the care manager organized their attendance. This raises the question of whether these services might have been more useful for women with long-term mental health problems if their difficulties were declared and efforts made to support them appropriately in their use of these services.

The commonalities between the findings of these two studies include the varying levels of understanding of the particular problems experienced by women with long-term mental health problems, the patchy service provision and the low numbers of women referred to the services, and the existence of boundaries between health and social care.

First, a number of service providers within the RCCS and in the outside organizations were able to identify the particular problems experienced by women with long-term mental health problems.

These problems included a vulnerability to abuse and exploitation, a wariness of men, low confidence and self esteem, difficulties in finding an appropriate role in life, and difficulties in interpersonal relationships and parenting. Many service providers however, were unable to identify any particular problems other than those associated with their mental health problems. This reinforces the views of Test and Berlin (1981), Perkins (1991), and Nadelson (1993) when they argue that women with long-term mental health problems are often perceived as 'genderless' and subsequently invisible when compared with the more demanding male clients. This lack of understanding of these women's problems, particularly in services which are dominated by men, has huge implications. The future development of services which are appropriate, safe and attractive to women depends on a common understanding of the particular difficulties they experience in both their personal lives, and in their contact with specialist long-term mental health services and services provided by the Social Services and voluntary and private organizations.

Second, the findings suggest that special provision for women with long-term mental health problems in both the specialist long-term mental health services and other services provided by the Social Services and voluntary and private organizations is patchy and that few women are either in contact with such services or referred to them. Although there was some evidence of good practice, the lack of an overall strategy to ensure that even provision for women was available and that all staff receive adequate training regarding gender issues possibly reflects the problems associated with the increasing fragmentation of community-based services. Such fragmentation is the inevitable consequence of multiple agencies providing for people with long-term mental health problems but is exacerbated by the lack of formalized links between specialist long-term mental health services and other organizations, and the dispersed geographical location of services. Services are no longer managed centrally with the result that many develop their own philosophies of working and there are few agreed guidelines concerning practice. Consequently there is a lack of clarity about what particular organizations, agencies, services and professions actually provide

(Bachrach 1996, Lucas 1996).

Third, although the findings of these two studies suggest that there is a blurring between the health and social care provided for women with long-term mental health problems, there remains a barrier between the specialist long-term mental health services and the services run by the Social Services and the voluntary and private sectors. There was some evidence of good practice where efforts had been made to introduce women with long-term mental health problems receiving care within the RCCS, into alternative services. However the evidence of such collaboration was scarce even though many staff in alternative organizations expressed an interest in working more closely with the mental health services as part of an overall package of care. The existence of these boundaries may simply reflect the historical legacy of mental health care. For example, caring for clients with long-term mental health problems in community-based settings is a fairly recent development and it may take time for such barriers to be overcome so that clients can have access to a range of health and social care dependent on need. Alternatively, Lucas (1996) argues that rivalries between mental health professionals and the voluntary and private sectors remain. For example, he suggests that the assumption that workers in the voluntary sector are little more than interfering amateurs is not conducive to the development of cooperative working and a seamless network of services. This argument is reinforced by one of the staff groups within the RCCS who suggested that input from outside organizations can conflict with the treatment a client is receiving within the mental health services.

The issues raised in this discussion suggest that efforts must be made to overcome the problems associated with the inevitable fragmentation of the wide range of services available for people with mental health problems to ensure that women with long-term mental health problems have access to roles, relationships, activities and facilities in the communities of their choice. The women would then move beyond a physical presence in communities to genuinely become a part of them. Within this framework, the main role of services would be to facilitate and support such access, to enable women to live the lives they wish.

Culhane (1996) and Lucas (1996) have both suggested strategies whereby specialist mental health services can work more collaboratively with their colleagues in the Social Services and the voluntary and private sectors to develop and access a range of services for people with long-term mental health problems. In addition Perkins and Repper (1996) argue that access does not apply solely to opportunities outside the health care system, but applies equally to the mental and physical health services themselves. In this context, access relates not simply to help to get into and engage in services, but also to making services attractive and acceptable to the people who need them.

The provision of comprehensive support for women with long-term mental health problems has to be seen as a collaborative affair which brings together the expertise and experience of different people, organizations and the women themselves. However, such collaboration rarely just happens, and needs to be actively promoted, fostered and supported (Perkins and Repper 1996). These two studies have highlighted a degree of separateness between the services provided by the RCCS and those provided outside by other organizations, and amongst the staff working within the two groups of services. The gap can only be bridged by acknowledging that access is a two way process and that close liaison between mental health workers, other organizations and women with long-term mental health problems is vital.

The final part of this discussion reviews the process of collecting the data for these two studies. The interviews with the groups of staff within the RCCS produced a wealth of interesting data. The majority of staff were willing to participate and in some instances made a special effort to attend the interviews by coming in on a day off or staying behind at the end of a shift. Although these group interviews were time consuming to both conduct and organize, they also provided an opportunity to meet with and get to know staff. This was particularly beneficial for the later stages of the evaluation when the support of staff was vital in gaining access to clients.

There were some difficulties in the postal questionnaire survey of organizations outside the RCCS. The initial mailing of the questionnaire produced a poor response rate, and the 77% response rate eventually achieved was the result of two further mailings and several telephone contacts. Although the majority of respondents had taken the survey seriously and had given considered and full responses to the questions asked, a minority of respondents gave minimal answers. These minimal responses inevitably affected the overall quality of the data collected. Such difficulties with postal questionnaires have been well documented (c.f. Polit and Hungler 1991, Robson 1995).

6.5 Conclusion

This chapter presented two separate studies whose shared purpose was to explore the extent and adequacy of services for women with long-term mental health problems throughout the Nottingham district.

Within the RCCS the response to the women's particular problems and needs took the form of initiatives within individual facilities rather than an overall plan to ensure that necessary provision was available and that staff received adequate training in this area. There was some recognition of the potential role that organizations outside the RCCS could play in providing services for women with long-term mental health problems, but little evidence of knowledge of the range and function of such organizations, and how to access and support them.

Surveying organizations, groups and agencies outside the RCCS who offered services to meet the particular needs of women with long-term mental health problems identified a wide range of facilities which could be accessed by women with long-term mental health problems to address specific areas of need. These facilities were generally committed to providing a service to these women as part of an overall support system. However the organizations were aware that these women rarely used the available facilities, and they were unsure about how to improve access.

These two studies together raise three issues. First, there was no common understanding of the needs, experiences and wishes of women with long-term mental health problems. Second, the special provision made for such women was patchy. There were some examples of good practice but no overall strategy to ensure even provision throughout the RCCS and the organizations outside the service. Third, there was little evidence of a seamless network of services providing both health and social care for women with long-term mental health problems.

Chapter Seven

An Investigation into the Effectiveness and Responsiveness of Services Provided for Women with Long-Term Mental Health Problems

7.1 Introduction

This study has two aims. First, to compare the effectiveness and responsiveness of services provided over time for men and women with long-term mental health problems. Second, to ascertain recipients' views of the extent to which existing services meet their needs by evaluating the quality of life and satisfaction with services of men and women with long-term mental health problems.

The key evaluation criteria addressed in this study are effectiveness and responsiveness. These criteria form part of the evaluation framework presented in section 4.3.2 and were drawn from the stated aims of the Rehabilitation and Community Care Service (RCCS) outlined in section 4.2.1. Namely, the RCCS aims to achieve the highest quality of life for users and reduce disabilities, and to provide a flexible service which responds quickly and smoothly to changes in the needs of individual clients.

The importance of including the criteria of effectiveness in evaluation studies has been emphasised by Huxley (1990, p3) who argues that "an acceptable, accessible, and well coordinated service is of little value if it is not an effective service". Although a range of outcome measures have been developed to assess the effectiveness of services (see chapter three, section 3.5.2.3), this study will focus on social functioning and quality of life as these reflect the stated aims of the RCCS.

The decision to explore the responsiveness of the RCCS to the changing needs of clients was influenced by the work of Perkins and Rowland (1991). Their study of a similar long-term care service suggests that services are less responsive to the changing needs of women with long-term mental health problems when compared to men. Finally this study not only aims to evaluate effectiveness and responsiveness on the basis of the criteria identified, but also attempts to represent the views of different groups of stakeholders. The views of the clients with long-term mental health problems are represented, and also those of the service providers working closely with such clients.

7.2 Method

In order to explore the effectiveness of the RCCS for women with long-term mental health problems, as well as its responsiveness to their needs, a longitudinal study was designed to assess the service input and outcome for a sample of 31 men and 10 women. The initial socio-demographic and psychiatric characteristics, level of social functioning, satisfaction with services, and quality of life of this sample was assessed at their time of entry into the RCCS and one year later, and their use of all services was monitored over this time.

This design reflects the current view in mental health evaluative research that outcome studies can be a very useful means of demonstrating the effectiveness of services in terms of benefits to clients (Mirin and Mamerow 1991, Sullivan 1996). The use of data collection tools to assess a broad range of functional areas from a variety of perspectives (clients and service providers), acknowledges that outcome studies which are conducted in complex community-based mental health services should be comprehensive and multi-dimensional (Ramon 1996, Ruggeri and Tansella 1996). Finally, the decision to gather descriptive data by monitoring the clients' use of services during a twelve month period was an attempt to identify some of the extraneous variables that may have some bearing on the outcomes themselves. This acknowledges that it is difficult enough to determine changes in clients lives, but to state with any certainty that they are due to identified interventions or services may be even more so (Nocon and Qureshi 1996).

7.2.1 Sample

It was originally planned that a sample of 30 consecutive men and 30 consecutive women accepted into the RCCS would give sufficiently meaningful numbers for this study. It was estimated that this number would take approximately one year to accumulate. The study commenced on 1/1/94 and all clients accepted into the RCCS from this date were included in the sample.

In reality the number of clients accepted into the RCCS from 1/1/94 was lower than expected and it took 20 months to accumulate a sample of 31 men and 10 women for inclusion in the study. The sample of 31 men was recruited out of 41 men accepted into the RCCS from 1/1/94 - 31/8/95. Of the 10 men not recruited, 3 refused to take part, 6 were considered by their care managers or key workers to be too unwell, and 1 was discharged. The sample of 10 women was recruited out of 18 women accepted into the RCCS over the same period. Of the 8 women not recruited, 6 refused to take part and 2 were considered by their care managers or key workers to be too unwell. Although there were fewer women in this sample than men, this does reflect reality. In RCCS as a whole there are less female clients than male (see section 5.3), and this is a feature of similar long-term care services (c.f. Sturt et al 1982, Meltzer et al 1992, Muijen et al 1992, Ford et al 1993).

7.2.2 Data collection tools

7.2.2.1 Socio-demographic, psychiatric and service use

The socio-demographic characteristics, psychiatric diagnosis and past and current psychiatric history, and the service use of the men and women in the sample were assessed using the data collection document designed for the study presented in chapter five (see section 5.2.2.1). The document consists of three parts, Forms A, B and C (see appendices A-C).

7.2.2.2 Assessing social functioning

Social functioning was measured using the Life Skills Profile (Parker and Rosen 1989), (see appendix D). This measure was the most appropriate for this study for the reasons already discussed in chapter five, section 5.2.2.2.

7.2.2.3 Assessing quality of life

A number of instruments have been developed to measure the quality of life of people with long-term mental health problems and these have been comprehensively reviewed by Bowling (1995), Lehman (1996), Oliver et al (1996), and Barry and Zissi (1997). Table 18 lists the instruments which were considered for use in this study.

Table 18: Quality of life instruments

Community Adjustment Form (Stein and Test 1980)
Lancashire Quality of Life Profile (Oliver 1991)
Oregon Quality of Life Questionnaire (Bigelow et al 1991)
Standardized Social Schedule (Clare and Cairns 1978)
Quality of Life Checklist (Malm et al 1981)
Satisfaction with Life Domains Scale (Baker and Intagliata 1982)
Quality of Life Interview (Lehman 1988)
Quality of Life Scale (Heinrichs et al 1984)
Quality of Life Index for Mental Health (Becker et al 1993)

The three most comprehensive instruments are the Oregon Quality of Life Questionnaire (Bigelow et al 1991), the Quality of Life Interview (Lehman 1988), and the Lancashire Quality of Life Profile (Oliver 1991) which is based on Lehman's work. All three instruments cover similar domains of quality of life, have acceptable psychometric properties, and have been extensively used with typical examples of people with long-term mental health problems (Lehman 1996). The remaining six instruments have had much more limited usage and / or are less comprehensive.

Bowling (1995), in her review of quality of life instruments, asserts that there are currently no 'gold standards' for quality of life measurements. That is, there are no absolute standards against which to calibrate and compare the instruments. In the absence of an absolute standard, she suggests that the ultimate choice of which instrument to use should be guided by its internal consistency, logical coherence and utility. The Quality of Life Interview (Lehman 1988) was ultimately chosen for this study for the following reasons. First, the instrument has been widely used in the United States of America and in the United Kingdom with samples of clients with long-term mental health problems (c.f. Lehman 1983, Lehman et al 1982, 1986, Simpson et al 1989, Postrado and Lehman 1995, Barry and Crosby 1996). The combined data from these studies, notably from Lehman (1983) and Lehman et al (1982, 1986), have provided valuable information on the instrument's reliability and validity. Second, many clients with long-term mental health problems have difficulties in task perseverance and comprehension (Lehman 1996). The structured interview format is therefore ideally suited to this client group who may find completing a questionnaire alone a daunting task. In addition Oliver (1991) suggests that many clients find such interviews intrinsically therapeutic and empowering because they focus on areas which are important to them. Third, this instrument is a means of exploring the clients' quality of life from their perspective. Although doubts have been raised about the limitations of instruments that rely on a single respondent (Sainfort et al 1996), and about the ability of clients to put forward their point of view, Lehman et al (1982) in a study of people with long-term mental health problems living in supported accommodation in Los Angeles showed that they were able to provide reliable responses to the Quality of Life Interview. Finally, the researcher was able to access the training required to administer the instrument from senior researchers who were familiar with it.

The Quality of Life Interview (Lehman 1988) was first developed for use in a survey of people with long-term mental health problems living in supported accommodation in Los Angeles (Lehman et al 1982). Subsequently the instrument was used to compare the quality of life experiences of people with long-term mental health problems living in hospital and community settings in New York (Lehman et al 1986). Although the Quality of Life Interview (Lehman 1988) has undergone a series of modifications since it was originally developed, there is a core version (c.f. Lehman 1991). This core version contains a global measurement of life satisfaction as well as measures of objective and subjective quality of life in eight life domains: living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, and health. The sections on each life domain are organized so that information is first obtained about objective quality of life and then about level of life satisfaction in that area. Objective data are obtained by asking direct questions about clients' lives, and subjective data are obtained by the clients rating their satisfaction on a seven point interval scale from 'terrible' to 'delighted'.

A number of studies using the Quality of Life Interview (Lehman 1988) have shortened or modified the core version (c.f. Simpson et al 1989, Barry and Crosby 1996). Such modification or shortening of the instrument is possible as Lehman (1991) has recommended a number of steps which can be taken. This includes omiting particular objective quality of life indicators if such data have been obtained from other sources, and omiting entire life domains (both objective and subjective quality of life indicators) that are not of interest to the investigation.

The Quality of Life Interview (Lehman 1988) was shortened and modified for use in this study using the steps recommended by Lehman (1991). The modified version retains the same basic structure as the original core interview and includes objective and subjective quality of life indices in seven life domains together with a global measurement of life satisfaction. The following indicators have been omitted: the work and school life domain (both objective and subjective quality of life indicators); type of current living situation, length of time at current residence, residential stability, homelessness, quality of living circumstances, types and adequacy of financial supports, monthly spending money, number of nights in jail during the past year, physical and role functioning, and pain (objective quality of life indicators). These indicators were ommitted for several reasons. First some of the data were already being collected, for example type of current living situation. Second, some of the indicators were not especially relevant, for example questions about work and school were inappropriate when the majority of clients entering RCCS are unemployed and none are still at school. Third, there was a need for the interview to be as short as possible whilst retaining the essence, making it easier to administer. This was to maximize the likelihood of it being completed with clients who may be experiencing some psychotic symptoms and whose concentration span is limited. Finally four questions about the clients' satisfaction with the services they were currently receiving were added. A copy of the modified Quality of Life Interview (Lehman 1988) can be seen in appendix K.

7.2.2.4 Monitoring service use over time

A data collection document was designed to record descriptive data about the clients' use of health, social, educational and other services over a twelve month period, and the rationale for such services being changed or remaining the same. See appendix L for a copy of the document.

7.2.3 Procedure

The study commenced on 1/1/94 and all clients accepted into the RCCS from this date were included in the sample. Data were collected over a period of 32 months from 1/1/94 to 31/8/96.

The names of clients accepted into the RCCS from 1/1/94 together with the name of their allocated key worker or care manager were obtained by contacting the four RCCS service managers on a monthly basis. Each of the key workers or care managers were then contacted by telephone to discuss the most appropriate way of approaching the clients for inclusion in the study. The majority of clients were approached initially by their key worker or care manager, the remainder were contacted directly by letter which gave brief details of the study. Each client approached was given an opportunity to refuse to participate in the study if they wished and were assured that a refusal would not affect the services they were currently receiving in any way.

Once a client agreed to participate in the study an arrangement was made to interview them using the Quality of Life Interview (Lehman 1988). The interviews took place within two months of the client being accepted into the RCCS and were conducted either in the client's home or in the residential or day care services. Prior to the interview the purpose of the study was explained to the client using an information sheet (see appendix M), and their signed consent was obtained (see appendix N). Efforts were made to ensure that these interviews were conducted in an unthreatening manner and extra time was allowed for informal conversation before and after the interview. The length of the interviews ranged from 45 to 90 minutes. After each interview, Forms A and B were completed using the client's case notes, and Form C and the Life Skills Profile (Parker and Rosen 1989) were completed by the client's care manager or key worker. The clients were interviewed again twelve months later using the Quality of Life Interview (Lehman 1988), and Forms A, B, C and the Life Skills Profile (Parker and Rosen 1989) were completed as before.

The clients' use of services was monitored during the twelve month period between the two interviews. Data about the clients' use of health, social, educational and other services were obtained by contacting the appropriate care manager or key worker monthly by telephone. These data, together with the rationale given for services being changed or remaining the same, were documented in detail using the data collection form designed for this purpose (see appendix L).

7.2.4 Analysis

The quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS), version 6.1 for the Apple Macintosh Computer. Forms A, B, C and the Life Skills Profile (Parker and Rosen 1989) were coded and scored as previously described in section 5.2.4. The Quality of Life Interview (Lehman 1988) was coded and scored using the instructions given in the instrument's manual (c.f. Lehman 1991).

A codebook was then prepared which listed the variable name to be entered onto the data file, the variable labels, and the codes assigned to the various aspects of each variable (see appendix O). A data file was created for the data to be entered and analysed. Each column was labelled with the variable name listed in the codebook, and the codes were entered directly from the original data collection tools. Once entered the data were double checked to eliminate any mistakes. Some of the data entered into the data file needed to be transformed. All of the transformations are documented in the codebook (see appendix O) and were included in the data file as additional variables. The transformations were only done on a small number of the categorical variables and involved the collapsing of certain categories within individual variables. This was done because the numbers in some categories were low.

The analysis of the quantitative data was undertaken in two stages. In the first stage the data were summarized, explored and described in order to highlight major trends and differences. The second stage was used to confirm the trends and differences identified using a range of formal statistical tests. The statistical tests used in this study are presented alongside the results in section 7.3. Significance was set at the conventional 5% level.

The descriptive data about each of the client's use of health, social, educational and other services was plotted on a large two dimensional matrix. The horizontal rows represented one dimension, the client; and the vertical columns represented the second dimension, changes in service use in each of the twelve months of the study period. The data plotted on the matrix included changes in service use, the rationale given by the key workers for services being changed or remaining the same, and any other reported events in the clients' lives. This process was a useful means of reducing and summarizing the large amounts of descriptive data gathered. The structure of the matrix also assisted in the task of identifying patterns in the data, and as a means of measuring the frequency that changes and events occured.

7.3 Results

The results of this study will be presented as follows. First, the socio-demographic characteristics, the psychiatric diagnosis and history, the social functioning and quality of life of the sample of men and women entering the RCCS from 1/1/94 will be described together with their use of services. The second part focuses on the key events in the clients' lives and their use of services over the twelve month study period. Finally, the client outcome after twelve months in the RCCS will be presented.

7.3.1 Characteristics of the sample

Forms A, B and C, the Life Skills Profile (Parker and Rosen 1989), and the Quality of Life Interview (Lehman 1988) were completed for all clients in the sample (10 women, 31 men) within two months of their entry into the RCCS. There were no missing data.

The description of the characteristics of the men and women entering the RCCS from 1/1/94 together with their use of services, are presented using frequency distributions, measures of central tendency and measures of dispersion as appropriate. All the percentages have been rounded up or down to the nearest whole number. Efforts have been made to summarize the results so that the most important and relevant findings are highlighted. The preliminary analysis of the data suggested a number of differences between the men and women which were confirmed by formal statistical testing. The chi-square statistical test was selected to analyse the nominal dependent variables. The Fisher's exact statistical test was used as a substitute for the chi-square test when one or more of the expected frequencies fell below five. The independent sample t-test was used to analyse the interval dependent variables.

The clients had a younger mean age (men 33 years, women 34 years) than the clients in RCCS as a whole (men 48 years, women 51 years). This might be expected given that all the clients in the sample were beginning their patient careers in the long-term care services as compared to many of the existing clients in the RCCS who had been in contact with such services for many years. All the clients were unemployed and receiving benefits, they were predominately white (87% men, 90% women) and lived alone (87% men, 80% women). The women however, were more likely to be currently or previously married (50% women, 16% men, X^2 =4.70, df=1, p=<0.05), and have children (50% women, 16% men, X^2 =4.70, df=1, p=<0.05). Of the five men and five women with children, none were directly responsible for their care. All of the children were either being cared for by relatives, were in care or had been adopted. Table 19 summarizes the socio-demographic results.

Table 19: Socio-demographic characteristics of men and women entering the Rehabilitation and Community Care Service from 1/1/94. (N=10 women, 31 men).

Variable	Men	Women
Clients accepted into the RCCS	76% 31	24% 10
Mean age (SD)	33 yrs (10.8)	34 yrs (9.6)
Currently or previously married	16% 5	50% 5
Living arrangements:		
Living alone (inc. hospital, hostel)	87% 27	80% 8
Living with partner, friends or family	13% 4	20% 2
Ethnicity: White	87% 27	90% 9
Afro-caribbean, Asian	13% 4	10% 1
Currently unemployed	100% 31	100% 10
Employment history: Never worked	19% 6	30% 3
In receipt of benefits	100% 31	100% 10
Clients with dependent children (under 18 years)	16% 5	50% 5
Where the dependent children live:		
With relative, in care or adopted	100% 5	100% 5

The majority of clients had a primary diagnosis of some form of psychosis (men, schizophrenia 64%, major affective disorder 26%; women, schizophrenia 40%, major affective disorder 40%), and had experienced multiple admissions (men, mean=5.0, SD=4.8; women, mean=4.7, SD=2.7). A high proportion of the clients were prescribed major tranquillizers (74% men, 60% women), and had a reported physical health problem (29% men, 30% women). Finally the results indicate that a higher proportion of the clients in this sample as compared to the RCCS clients as a whole had a reported history of drug or alcohol abuse (45% men, 20% women), and a history of violence towards people or property (65% men, 20% women). The men were significantly more likely to have a history of violent behaviour than the women (65% men, 20% women, Fisher's exact, p=<0.05). Table 20 summarizes these results.

Table 20: Psychiatric diagnosis and history of men and women entering the Rehabilitation and Community Care Service from 1/1/94. (N=10 women, 31 men)

Variable	Men		Women	
Primary diagnosis: Schizophrenia	64%	20	40%	4
Major affective disorder	26%	8	40%	4
Other	10%	3	20%	2
Age at first contact with the psychiatric services:				
Mean (SD)	23yrs	(7.8)	20.4 yrs	(4.2)
Range	36	(13-49yrs)	13	(15-28yrs)
Number of psychiatric admissions:				
Mean (SD)	5.0	(4.8)	4.7	(2.7)
Range	25	(0-25)	10	(1-11)
Duration of longest admission (months):				
Mean (SD)	13.8	(19.6)	23.3	(33.1)
Range	92	(0-92)	94	(2-96)
Total duration of admissions (months):				
Mean (SD)	25.1	(32.9)	41.7	(55.5)
Range	160	(0-160)	167	(3-170)
Currently prescribed psychotropic medication:				
Major tranquillizers	74%	23	60%	6
Anti-depressants	10%	3	-	
Combination of psychotropic medication	10%	3	30%	3
None	6%	2	10%	1
Currently detained under Section of the Mental Health Act	26%	8	10%	1
Reported chronic medical condition	29%	9	30%	3
Reported history of drug or alcohol abuse	45%	14	20%	2
Reported history of violence towards people or property	65%	20	20%	2
Reported history of prison or Special hospital	16%	5	20%	2

The mean social functioning scores for this sample as measured by the Life Skills Profile (Parker and Rosen 1989) were slightly higher than those reported by Rosen et al (1989), Parker et al (1991) and Repper and Perkins (1995). The mean scores were also slightly higher than those achieved by the RCCS clients as a whole in the study presented in chapter five. One possible explanation may be that this relatively young group of clients were not exhibiting the features of institutionalization which often occurs as a consequence of prolonged periods of hospitalization or living in rigid, authoritarian community residential accommodation. The features of institutionalization include apathy, lack of initiative, loss of interest and apparent inability to plan for the future, submissiveness, and a deterioration in personal habits and standards generally (Barton 1959, Ryan 1979). Although many of the clients in this sample had experienced a number of hospital admissions, they would have returned to the community between admissions. Living in the community would have enabled these clients to retain contact with the outside world, retain skills in budgeting, cooking and shopping, they would have their own possessions around them, and there would have been considerable societal pressure for them to maintain their self care and personal appearance. The absence of prolonged periods of institutional living coupled with their relative youth, may therefore explain the relatively high social functioning scores which these clients achieved. This does not however, explain the high mean scores in the non-turbulence category. Given the high reported history of violence towards people or property in this sample (65% men, 20% women), and the evidence that such young clients often exhibit violent and aggressive behaviour (c.f. Pepper et al 1981, Lamb 1982, Bachrach 1996), it is suprising that the mean scores were not lower.

Although the mean social functioning scores are higher than might be expected, they do however suggest that many of the clients had multiple social disabilities. The lower than maximum scores on all scales indicate that these would include a tendency to neglect physical health, limitations in self care skills, poor communication skills, problems in maintaining friendships and a lack of social contact outside the mental health services, and a tendency to be unreliable about taking prescribed medication or cooperating with mental health service staff. The mean scores for the men and the women in each of the sub-categories were very similar and there were no statistically significant differences identified. The results are summarized in Table 21.

Table 21: Social functioning of men and women entering the Rehabilitation and Community Care Service from 1/1/94. (N=10 women, 31 men).

Measure	Sub-category	Men Mean score (SD)	Women Mean score (SD)
Life Skills Profile (Parker & Rosen 1989)	Self-care (max. score 40)	31.3 (5.7)	31.0 (6.8)
	Non-turbulence (max. score 48)	39.8 (6.8)	43.1 (5.0)
	Social contact (max. score 24)	13.9 (2.6)	15.0 (3.3)
	Communication (max. score 24)	20.6 (2.6)	21.9 (2.5)
	Responsibility (max. score 20)	17.7 (2.6)	17.7 (2.1)
	Total score (max. Score 156)	123.6 (13.2)	127.5 (15.3)

The results of the Quality of Life Interview (Lehman 1988) suggest that the clients' quality of life as measured by the objective indicators appeared to be very restricted, (see Table 22). The findings replicate those of previous studies which have explored the objective indicators of quality of life of people with long-term mental health problems (c.f. Lehman et al 1982, Mulkern and Manderscheid 1989, Sullivan et al 1991, Barry et al 1993). These studies have also suggested that such findings indicate that the objective quality of life of clients with long-term mental health problems is lower than the general population.

Many of the clients were socially isolated with few sources of support in the community. Only 48% of the men and 30% of the women for example, went anywhere to meet people other than a mental health service of some kind. A high proportion of the clients however, stated that they had close friends who were not family members (58% men, 90% women), and had someone to talk to or confide in if they had problems (68% men, 90% women). Few of the clients were educated beyond G.C.S.E. level. Of the clients who had been involved with the police during the previous two years (42% men, 40% women), a high proportion had been formally charged with commiting an offence (54% men, 50% women).

Few of the clients engaged in active leisure activities, and none were employed at the time of the interview. The activities that the clients were regularly involved in revolved around those necessary for basic survival or those requiring little effort or contact with other people. For example, during the week prior to the interview the majority of clients had been shopping for food (90% men, 90% women), had cooked themselves a meal (71% men, 80% women), had watched television (84% men, 90% women), or had listened to the radio (81% men, 90% women). Few of the clients however had taken part in leisure activities in the week prior to the interview which would bring them into contact with people outside the mental health services or would provide a pleasurable alternative to the humdrum of daily living. For example, few clients had been to the cinema (13% men, no women), played a sport (32% men, no women), been to a library (10% men, 10% women), had a walk in a park (29% men, 20% women), or been to a social gathering of any kind (39% men, 10% women).

There were no statistically significant differences between the men and the women on any of the objective quality of life indicators. It is noteworthy however, that a higher proportion of the women stated that they had close friends and someone they could confide in. This replicates the findings of Ritsher et al (1997) who suggest that personal relationships are more central to the lives of women with long-term mental health problems than men.

Table 22: Quality of life as measured by objective indicators of men and women entering the Rehabilitation and Community Care Service from 1/1/94 (N=10 women, 31 men).

Objective indicators	**Men**	**Women**
Activities undertaken in previous week:		
Cinema or theatre visit	13% 4	-
Watched television	84% 26	90% 9
Shopping	90% 28	90% 9
Visit to cafe or restaurant	45% 14	70% 7
Visit to pub	58% 18	70% 7
Read a book, newspaper or magazine	74% 23	80% 8
Listened to the radio	81% 25	90% 9
Prepared a meal	71% 22	80% 8
Played a sport	32% 10	-
Attended a meeting or social gathering	39% 12	10% 1
Visited a park	29% 9	20% 2
Visited a library	10% 3	10% 1
Availability of a person to confide in	68% 21	90% 9
Somewhere to go to meet people other than a mental health service	48% 15	30% 3
The existence of close friends who are not family members	58% 18	90% 9
Currently unemployed	100% 31	100% 10
Qualifications: None	52% 16	20% 2
CSE / GCSE / O levels	42% 13	60% 6
Vocational	3% 1	20% 2
A levels	3% 1	-
Involvement with police over last two years	42% 13	40% 4
Nature of contact with police: Witness	8% 1	25% 1
Suspect	38% 5	25% 1
Charged	54% 7	50% 2

In general, the self reported levels of satisfaction as measured by the subjective indicators of the Quality of Life Interview (Lehman 1988) were higher than those found in similar studies (c.f. Lehman 1988, Simpson et al 1989, Postrado and Lehman 1995, Repper and Perkins 1995), but the pattern of satisfaction was similar. The clients appeared to be most satisfied with their living situation and least satisfied with their financial situation. This latter finding is to be expected since all the clients were unemployed and all were in receipt of benefits. There were no statistically significant differences between the men and the women on any of the subjective quality of life indicators. These results are summarized in Table 23.

Table 23: Quality of life as measured by subjective indicators of men and women entering the Rehabilitation and Community Care Service from 1/1/94 (N=10 women, 31 men)

Measure	**Subjective indices**	**Men** **Mean**	**(SD)**	**Women** **Mean**	**(SD)**
Quality of Life Interview (Lehman 1988)	Living situation: Home Neighbourhood	 4.6 4.8	 (1.2) (1.0)	 5.2 5.2	 (1.2) (0.7)
	Leisure	4.3	(1.1)	4.6	(0.6)
	Family relations	4.4	(1.2)	4.7	(1.6)
	Social relations	4.3	(1.2)	4.9	(0.9)
	Finances	3.6	(1.7)	3.6	(1.2)
	Personal safety	4.4	(1.6)	5.2	(0.8)
	Satisfaction with services	4.6	(1.4)	4.1	(0.7)
	General life satisfaction	4.1	(1.4)	4.5	(1.3)

The majority of clients (71% men, 80% women) were accepted into the RCCS via a referral to one of the residential units. This route into the RCCS was the most common during the period of this study as the Community Rehabilitation Teams were generally saturated. The teams were accepting referrals for clients once they were established within the RCCS but were only accepting a limited number of referrals for clients wishing to remain living independently in the community (RCCS 1996a). Within two months of the clients being established within the RCCS, 81% of the men and all of the women had an allocated key worker from either one of the Community Rehabilitation Teams or from one of the Community Support Teams. A minority of clients were in receipt of RCCS day care services (29% men, 10% women) or were in contact with the RCCS occupational therapy team (16% men, 20% women). Very few clients were in contact with the day care facilities run by the Social Services (3% men, 20% women), or were taking part in the training or educational initiatives within the RCCS (10% men, 10% women). None of the clients were receiving support or help from the voluntary sector. This pattern of service use might be expected given that the clients had only been in contact with the RCCS for a few weeks and their needs for particular types of service input and support had yet to be fully assessed. This pattern also replicates the findings of previous studies of younger clients with long-term mental health problems (c.f. Pepper et al 1981, Lamb 1982, Prevost 1982, Bachrach 1996). There were no statistically significant differences between the men and women in terms of their service use. See Table 24 for a summary of the service use of clients entering the RCCS.

Table 24: Service use of men and women entering the Rehabilitation and Community Care Service from 1/1/94 (N=10 women, 31 men)

Variable	**Men**		**Women**	
Use of residential services:				
Hospital	71%	22	80%	8
Accommodation with either professional or non professional support as part of housing	3%	1	-	
None	26%	8	20%	2
Key worker support from Community Rehabilitation Teams or Community Support Teams	81%	25	100%	10
In receipt of RCCS day care services	29%	9	10%	1
In receipt of Social Services day care facilities	3%	1	20%	2
In receipt of educational and/or training initiatives	10%	3	10%	1
In contact with RCCS occupational therapy team	16%	5	20%	2
In contact with voluntary, charity or self-help organization	-		-	

7.3.2 Key events in clients' lives and service use over the twelve month study period

The information gathered from service providers about the progress of the clients over this period was illuminating both in terms of the clients' personal experiences, and the service response to their individual changing needs. The findings presented here arise from descriptive data collected on all 10 of the women in the sample, and 29 out of the 31 men. The descriptive data on 2 of the men were not included in the analysis as it was not complete, one of the men died six months after being interviewed and the other was remanded in prison five months after being interviewed.

Clients' experiences

22 of the men and 8 of the women were admitted into the RCCS via one of the short-term rehabilitation residential services. The aim of this placement is for the multi-disciplinary staff teams to work with the clients to develop the necessary skills and confidence required for independent living. During this period of assessment and rehabilitation, plans are made for moving into alternative accommodation. This might involve applying to housing associations or the local authority housing department for independent accommodation, applying for supported housing provided by the Social Services, charitable organizations or the private sector, or alternatively considering long-term residential care provided within the RCCS. The remaining 7 men and 2 women were admitted to the RCCS via the Community Rehabilitation Teams. All of these clients were living in their own homes on entry into the service.

During this period 13 of the men (45%) and 5 of the women (50%) were reported as experiencing a relapse in their psychotic symptoms. The pattern of reported events which preceded relapse of psychotic symptoms and subsequent readmission or transfer was very different for the men and the women. Of the 13 men who relapsed, 8 men had not been taking their prescribed psychiatric medication. The reasons given for the mens' refusal to take the medication included a dislike of the side effects, a reluctance to see themselves as mentally ill, and in one case concerns about a lowering of libido and an inability to maintain an erection. Although the reasons for not wanting to take the medication were understandable, such lack of compliance is commonly associated with a relapse in psychotic symptoms (c.f. Hogarty et al 1974). In addition 8 of the men who relapsed had been verbally or physically aggressive to either staff or their family. Of these 8 men, 6 were reported as regularly misusing either drugs or alcohol. Of the 5 women who had a relapse of psychotic symptoms, only 1 had been reluctant to take medication. This women generally took her medication as prescribed while she was on the residential unit. She refused however, to take any when she went on leave to stay with her boyfriend as she didn't want him to know that she was on precribed medication for her mental health problems. None of the women who relapsed were verbally or physically aggressive towards others, and none were misusing drugs and/or alcohol.

A closer examination of the clients' personal experiences during the twelve month period again revealed interesting differences between the men and the women. All of the ten women were reported as having experienced one or more independent life events during this period. Independent life events are those which are both outside the control of the client and cannot be altered by controlling their illness (Ventura et al 1992). Table 25 summarizes the life events experienced by these women.

Only 6 of the men were reported as having experienced one or more independent life events during this period. Two of the men were bereaved, two had relationship difficulties, one was concerned about his mother's deteriorating physical and mental health, and one had been refused access to see his children.

Table 25: Life events experienced by the women (N=10)

Women	Life events
Woman 1	• Partner becoming increasingly abusive • Partner pressurizing her not to take medication
Woman 2	• Family argument and rift • Anniversary of baby's death • Broken limb requiring hospital admission • Other physical illness requiring hospital admission • Family pressure to reconcile with abusive father
Woman 3	• Pregnancy and delivery • Baby fostered and then put forward for adoption • Breakdown of relationship with partner
Woman 4	• Major accommodation move • Adopted baby, now adult, wants to see her
Woman 5	• Breakdown of relationship with partner due to his threatening behaviour and misuse of alcohol.
Woman 6	• Termination of pregnancy
Woman 7	• Bereavement • Breakdown of abusive relationship
Woman 8	• Breakdown of abusive relationship
Woman 9	• Concerns about partner's health
Woman 10	• Parents away on holiday • Re-establishing relationships with old friends

In addition to the many independent life events experienced by the women, a higher proportion of the women experienced three or more changes in their accommodation during this period than the men (50% women, 14% men). Although many of the moves may have been necessary to provide the level and type of support the women needed, the process of moving can be a difficult and disruptive one. Perkins and Repper (1996) suggest that moving involves a series of life events such as leaving friends and family, changing leisure and spare time activities, and coping with a new set of roles and expectations. The stress from these life events can manifest themselves in a deterioration in ability to cope with every-day situations, behavioural disturbance, exacerbation of cognitive and emotional problems, and acute personal distress.

Service response

A number of different approaches were adopted by the staff within the RCCS to meet the varying and different needs of the men and women in this sample. A number of the approaches appeared to reflect a set of well used routine procedures used to manage the problems commonly experienced by these clients. These procedures are illustrated in the ways in which the staff managed clients who were experiencing a relapse in their psychotic symptoms, and the way in which clients were prepared for discharge into independent accommodation from the residential units within the RCCS. In addition there was some evidence that staff attempted to meet the individual needs of both the men and women. These attempts are illustrated by the efforts made by staff to encourage clients to engage in a variety of activities both within the RCCS and in the wider community.

All of the 13 men and 5 women who were reported as experiencing a relapse in their psychotic symptoms during the period of this study were either admitted or readmitted to the residential units within the RCCS or transferred to the in-patient acute psychiatric services. The specific criteria used for deciding whether to transfer a client to the acute psychiatric services rather than providing the necessary care within the residential services was difficult to determine from the information provided by the staff. It did appear however, that clients who were aggressive and/or physically violent, and those who were perceived as a risk to themselves were more likely to be transferred. A number of clients who were transferred to the acute psychiatric services (8 men, 1 woman) were described as 'difficult to manage' by the staff. These clients occupied much staff time and detracted from the rehabilitative work they were doing with other clients. None of the clients who were transferred were discharged from the RCCS and the allocated care manager remained in regular contact with both the client and the staff throughout the admission.

Of the 22 men and 8 women admitted to the residential units on entering the RCCS, 12 men and 5 women had moved into independent or supported accommodation after twelve months. The plans for these moves followed a similar pattern for both the men and the women and involved collaboration between the client, the residential key worker, the allocated care manager and the Community Support Teams who provided consistant support for the client before and after discharge. Although the majority of clients benefitted from such input, some disliked the intensive support provided by the Community Support Teams in particular. 2 of the women and 3 of the men resented the regular visits made by these teams on their discharge, particularly when the focus of such visits revolved around their budgeting and self care skills and a perceived monitoring of the cleanliness of their accommodation. The withdrawal of such support was a decision taken by the multidisciplinary team and the visits continued in each case for several weeks after the client had requested that they stop.

The key workers and care managers spent considerable time and energy in an effort to encourage clients to become involved in a range of activities both within the RCCS and in the wider community. The key workers and care managers not only provided encouragement but in many instances practical support such as accompanying the client to the activities or providing transport. Despite these efforts very few of the clients were involved in any meaningful activity by the end of the study period.

18 of the men in the sample were not willing to become involved in any regular activity. The reasons given for this included a lack of interest, a dislike of organized group activities and the fact that some of the men did not see themselves as mentally ill. The remaining men were involved in a relatively narrow range of activities. These included pleasurable activities such as sport, photography and art; organized groups with an emphasis on managing and coping with symptomatology such as the Hearing Voices Network; and finally vocational activities such as adult literacy classes or voluntary work.

6 of the women in the sample were not involved in any regular activities. The reasons given by the staff for their lack of involvement were very similar to those of the men although 2 of the women were very embarrassed about their physical appearance and worried about what other people might think of them. The activities which the remaining 4 women were involved in included voluntary work and sports such as keep-fit classes and riding. Finally one of the women spent every week day in a local drop-in centre run by volunteers because the registered home where she lived did not allow her to remain there during the day.

7.3.3 Client outcome after twelve months in the Rehabilitation and Community Care Service

Changes over the twelve month study period in social functioning, quality of life and use of services were compared for the women and the men. After twelve months in the service there were some missing data on a small number of clients. This consisted of two uncompleted Form C's (service use), and five uncompleted Life Skills Profiles (Parker and Rosen 1989) and Quality of Life Interviews (Lehman 1988). It was not possible to collect these data as one of the clients had died, one was in prison, and three were in-patients who were too unwell to be interviewed. Only those clients with a complete data set were included in the analysis of changes in social functioning and quality of life over the twelve month period (N= 10 women, 26 men). Changes in service use were analysed using a slightly larger sample as data on only two clients were missing (N=10 women, 29 men).

The categorical variables, which included the objective quality of life indicators and the service use data, were analysed using the chi-square and the Fisher's exact statistical tests as appropriate. A two-way multivariate analysis of variance (MANOVA) was carried out on the social functioning scores and the subjective quality of life scores to compare the baseline results for the women and men with outcomes after twelve months in the RCCS. Each client therefore served as their own control in the study permitting a direct comparison of levels of functioning and quality of life on entry into the RCCS and after twelve months. Separate MANOVA's were used for the set of subjective quality of life indicators and the set of social functioning sub-categories with 'time' being regarded as a within subjects factor and 'sex' as the between subjects factor. If one or more of the three F scores for the MANOVA were statistically significant, a two-way repeated measures analysis of variance (ANOVA) was subsequently carried out on each of the subjective quality of life indicators and social functioning sub-categories to determine which sub-categories were associated with significant effects.

The social functioning scores of the men and the women as measured by the Life Skills Profile (Parker and Rosen 1989) on entry into the RCCS and after twelve months in the service are presented in Table 26. A MANOVA across the two assessment points indicated that there was not a significant change in the scores over the twelve month period (F=1.12, df=5,30, p=0.37), and there was no interaction between sex and time (F=0.26, df=5,30, p=0.92). The MANOVA however did indicate that there was a significant difference between the scores achieved by the men and the women (F=4.54, df=5,30, p=<0.01). An examination of the scores in Table 21 suggests that overall, women tend to have higher scores than men. That is, better social functioning. However, an ANOVA performed on each of the sub-categories produced only one significant finding, the women had significantly higher social contact scores than the men (F=5.70, df=1,34, p=<0.05). Such a finding suggests that overall the women were more likely to show warmth towards others, engage in outside interests, and make and maintain friendships than were the men. This finding again replicates the findings of Ritsher et al (1997).

Table 26: Changes in social functioning after twelve months in the Rehabilitation and Community Care Service (N=10 women, 26 men)

Measure	**Men** **(Mean and SD)**		**Women** **(Mean and SD)**	
Life Skills Profile (Parker and Rosen 1989)	**Baseline**	**After 12 mths**	**Baseline**	**After 12 mths**
Non turbulence	40.1 (6.8)	40.4 (5.9)	43.1 (5.0)	43.3 (4.2)
Social contact	14.3 (2.4)	12.9 (2.6)	15.0 (3.3)	15.4 (2.7)
Self care	31.9 (5.1)	29.9 (5.3)	31.0 (6.8)	31.5 (4.4)
Communication	20.6 (2.5)	19.9 (2.9)	21.9 (2.5)	21.7 (2.8)
Responsibility	17.5 (2.8)	17.1 (2.1)	17.1 (2.1)	17.7 (1.8)
Total score	124.7 (13.5)	121.4 (14.3)	127.5 (15.3)	129.6 (10.8)

The care and support received by the clients within the RCCS during the twelve month period was not particularly evident in changes in the objective indicators of the Quality of Life Interview (Lehman 1988). The results suggest that the clients' quality of life as measured by the objective indicators had improved slightly in some areas and deteriorated in others. The only statistically significant difference identified was that the women were more likely to attend a social gathering after twelve months in the service than on entry (Fisher's exact, p=<0.01). See Table 27 for a summary of the results.

Table 27: Changes in quality of life as measured by objective indicators after twelve months in the Rehabilitation and Community Care Service (N=10 women, 26 men)

Objective indicators	Men		Women	
	Baseline	After 12mths	Baseline	After 12mths
Activities undertaken in previous week:				
Cinema or theatre visit	4% 1	15% 4	-	-
Watched television	89% 23	89% 23	90% 9	100% 10
Shopping	89% 23	69% 18	90% 9	90% 9
Visit to cafe or restaurant	39% 10	50% 13	70% 7	60% 6
Visit to pub	58% 15	54% 14	70% 7	70% 7
Read a book, newspaper or magazine	77% 20	73% 19	80% 8	90% 9
Listened to the radio	81% 21	89% 23	90% 9	90% 9
Prepared a meal	69% 18	73% 19	80% 8	60% 6
Played a sport	31% 8	23% 6	-	10% 1
Attended a meeting or social gathering	46% 12	35% 9	10% 1	80% 8
Visited a park	31% 8	31% 8	20% 2	30% 3
Visited a library	12% 3	8% 2	10% 1	-
Availability of a person to confide in	69% 18	81% 21	90% 9	90% 9
Somewhere to go to meet people other than a mental health service	54% 14	50% 13	30% 3	40% 4
The existence of close friends who are not family members	65% 17	50% 13	90% 9	70% 7
Involvement with police over last two years	46% 12	39% 10	40% 4	20% 2

The quality of life of the men and the women as measured by the subjective indicators of the Quality of Life Interview (Lehman 1988) on entry into the RCCS and after twelve months in the service are presented in Table 28. A MANOVA across the two assessment points indicated that there was not a significant difference in the scores achieved by the men and the women (F=0.85, df=9, 25, p=0.57), and there was not a significant change in the scores over the twelve month period (F=1.53, df=9, 25, p=0.19). The MANOVA however did indicate that there was a trend towards an interaction between time and sex (F=2.17, df=9, 25, p=0.06). An ANOVA performed on each of the subjective quality of life indicators produced the following significant findings. First, whilst there was not a significant difference between the men and women in their satisfaction with the neighbourhood they were living in, there was a significant change in the scores over the twelve month period (F=5.42, df=1,33, p=<0.05), and a significant interaction between sex and time (F=5.42, df=1,33, p=<0.05). This indicated that the women were significantly less satisfied with the neighbourhood they were living in after twelve months in the service, whereas the men's level of satisfaction remained the same. Second, there was a significant change in the scores achieved on the social relations indicator (F=8.34, df=1,34, p=<0.01), that is, both the men and the women were less satisfied with the quality of their social relationships after twelve months in the service. There was not, however, a significant difference between the men and women on this indicator, nor a significant interaction between sex and time.

Table 28: Changes in quality of life as measured by subjective indicators after twelve months in the Rehabilitation and Community Care Service (N=10 women, 26 men)

Quality of Life Interview (Lehman 1988)	Men Baseline	After 12 mths	Women Baseline	After 12 mths
General life satisfaction	4.1 (1.4)	4.2 (1.3)	4.5 (1.3)	4.7 (0.9)
Living situation: Home	4.6 (1.1)	4.8 (1.1)	5.2 (1.2)	5.3 (0.7)
Neighbourhood	4.8 (1.0)	4.8 (1.0)	5.2 (0.7)	4.5 (0.8)
Leisure	4.3 (1.1)	4.3 (0.9)	4.6 (0.7)	4.3 (0.9)
Family relations	4.4 (1.2)	4.3 (1.2)	4.7 (1.6)	4.5 (1.2)
Social relations	4.3 (1.3)	3.8 (1.0)	4.9 (0.9)	4.2 (1.1)
Finances	3.5 (1.7)	3.9 (1.6)	3.5 (1.2)	4.6 (1.2)
Personal safety	4.4 (1.6)	4.8 (1.2)	5.2 (0.7)	4.8 (1.0)
Satisfaction with services	4.6 (1.4)	4.5 (1.5)	4.1 (0.7)	4.8 (1.0)

Table 29 summarizes the changes in service use of the men and women after twelve months in the RCCS. The biggest change was in the use of residential services as a higher proportion of the men and women were living independently after twelve months as compared to the proportion in hospital accommodation on entry into the service. This change is perhaps inevitable as the majority of clients were in the short-term residential services whose primary focus is intensive rehabilitation and the resettlement of clients into independent accommodation in the community. It is noteworthy however, that with the exception of key worker support from the Community Rehabilitation Teams and Community Support Teams, few of the clients were benefitting from the range of day care and outreach services offered within the RCCS, by the Social Services or from voluntary organizations. There were no statistically significant differences in service use between the men and the women or over time.

Table 29: Changes in service use after twelve months in the Rehabilitation and Community Care Service (N=10 women, 29 men).

Variable	Men		Women	
	entry	after 12mths	entry	after 12 mths
Use of residential services:				
Hospital	76% 22	45% 13	80% 8	40% 4
Accommodation with either professional or non professional support as part of housing	3% 1	7% 2	-	20% 2
None	21% 6	48% 14	20% 2	40% 4
Key worker support from Community Rehabilitation Teams or Community Support Teams	79% 23	93% 25	100% 10	100% 10
In receipt of RCCS day care services	31% 9	24% 7	10% 1	20% 2
In receipt of Social Services day care facilities	3% 1	3% 1	20% 2	20% 2
In receipt of educational and/or training initiatives	10% 3	7% 2	10% 1	10% 1
In contact with RCCS occupational therapy team	14% 4	7% 2	20% 2	20% 2
In contact with voluntary, charity or self-help organization	-	3% 1	-	-

7.4 Discussion

The purpose of this study was to investigate the effectiveness and responsiveness of the services provided within RCCS for women with long-term mental health problems. The longitudinal design provided an opportunity not only to describe the clients as they entered the service and measure outcome after twelve months, but also to explore the clients' experiences throughout the study period. The previous section has presented the results of the study under three discrete headings and throughout comparisons have been drawn between the men and the women and significant differences have been highlighted. This comparison is important as previous studies have suggested that women with long-term mental health problems are often disadvantaged in mental health services when compared to men (c.f. Bachrach 1984, 1985, Perkins and Rowland 1991). The discussion however, will focus on exploring the particular issues for women which have emerged from this study. Although it is acknowledged that the men are equally needy with a wide range of gender specific problems, a detailed exploration of their issues is outside the remit of this study. There was also a possibility that a consideration of the problems of the male clients highlighted in this study may detract from those of the women.

The discussion is divided into three parts. First, the key findings pertaining to the women will be discussed together with the service providers' responses to their varying and individual needs. The second part will critically evaluate the design of the study. This will include some observations on the usefulness of outcome studies, a critique of the methods used, and a consideration of the practical problems encountered in gathering the data. Finally, the difficulties of assessing the effectiveness and responsiveness of the RCCS in meeting the needs of women with long-term mental health problems will be discussed.

7.4.1 Key findings

The women in this study, along with the men, share many of the characteristics of a group of clients commonly referred to as young adult chronic patients (c.f. Pepper et al 1981, Lamb 1982). These young clients are different to older clients because they are still struggling to be like their mentally healthy contemporaries to whom stable relationships, education and employment are an accepted part of adult life. Such hopes for a 'normal' adult life is one of the intended benefits of community orientated rather than hospital orientated mental health care. However this benefit does have implications for these clients. For example, their persistent lack of success in achieving goals that are socially appropriate for their age does set them apart from their contemporaries and consequently they constantly have to experience the pain of being different and of failure. In addition, their reluctance to see themselves as different or to define themselves as mentally ill frequently functions as a barrier to accepting treatment. They are therefore often reluctant to acknowledge the need for regular and continuous medication, reluctant to accept a range of mental health services and are frequently resistant to seeing themselves as particularly vulnerable to the effects of alcohol and/or recreational drugs. Much of the literature which describes these young clients however, treats them as a homogeneous group and the differences between the men and the women are not comprehensively addressed (c.f. Pepper et al 1981, Lamb 1982, Prevost 1982, Wintersteen and Rapp 1986, Bachrach 1996). By drawing comparisons between the men and the women in this study important differences were identified. The women for example, were more likely to be currently or previously married and have children, and were less likely to have a history of violent behaviour than the men.

The findings highlight the lack of overall improvement experienced by both the men and the women in this study in terms of their social functioning and quality of life after being in contact with the RCCS for twelve months. The findings replicate those of Bond et al (1988) but contradict previous studies which have found that the provision of intensive community-based services for people with long-term mental health problems results in an improvement in quality of life and social functioning (Okin et al 1983, Muijen et al 1992, Repper and Perkins 1995, Barry and Crosby 1996). The social functioning scores achieved by the women as measured by the Life Skills Profile (Parker and Rosen 1989) suggest a group with relatively poor social functioning with probable difficulties in maintaining their physical health, carrying out the tasks of daily living, communicating with others, maintaining friendships and retaining contact with life outside the mental health services. The women however, did have significantly higher social contact scores than the men suggesting that they were more likely to show warmth towards others, engage in outside interests and maintain friendships.

The findings of the Quality of Life Interview (Lehman 1988) suggest that the lives of the women were very limited on entry into the service and after twelve months. Although slightly more of the women were going to places to meet people other than a mental health service or were attending social gatherings after twelve months in the service, generally their social contact with others remained very limited. Their activities generally revolved around those required for survival such as cooking and shopping, and those requiring little contact with others such as watching television or listening to the radio. The impoverished lives of these women is further emphasized by the findings which suggest that they were less satisfied with the neighbourhood they were living in, less satisfied with their social relationships with others and fewer women claimed to have close friends who were not family members after having been in contact with the service for twelve months.

There is not a simple explanation for the lack of improvement in both the social functioning and quality of life of these women. Nevertheless the information gathered about the experiences of the women during the twelve month period does suggest some possible explanations. Five of the ten women for example, experienced a relapse in their psychotic symptoms which necessitated either a readmission to one of the RCCS residential units or a transfer to the acute psychiatric unit. Relapse of psychotic symptoms and subsequent readmission is not an unusual event for either young women or young men with a long-term mental health problem (Lewis and Joyce 1990), and it is often impossible to prevent periodic deterioration in functioning and increased distress (Perkins and Dilks 1992). The effects of an admission however can be profound both in terms of the clients perception of themselves and the disruption to their programme of rehabilitation.

All of the women in this sample also experienced a number of life events during this period which may have contributed to their overall lack of improvement in social functioning and quality of life. People with long-term mental health problems are particularly vulnerable to the everyday stresses which most people take in their stride (Brown and Birley 1968, Day et al 1987, Ambelas 1987), and even minor or positive changes can have detrimental consequences for the individual by exacerbating their cognitive, emotional or behavioural problems, and affecting their ability to cope. These women however, experienced a range of life events which would tax the mental health of anyone.

Seven of the women had a sexual partner on entry into the service. All of these partners were men and six were known clients within the mental health services. Such relationships between clients in not uncommon as they often feel more comfortable with, more at ease with, and have more in common with, other similarly socially disabled people (Perkins and Dilks 1992). Additionally their mental health problems and associated disabilities mean that their experiences and reality differ from many of their mentally healthy contemporaries. This coupled with their difficulties in initiating and maintaining social relationships with others makes it more likely that they will forge relationships with those whom they share a common experience. The one woman who had a relationship with a man who was not a client of the mental health services appeared to minimize her particular problems in his company. This was evident from her refusal to take medication when she went to see him. The vulnerability of these women however, is emphasised by the abusive nature of four of these relationships. Each of the four women had been verbally and physically abused during the period of the study. Such abuse included stealing their money, hitting them, threatening them and burning them with lighted cigarettes. The high incidence of such abuse amongst these women has been highlighted (c.f. Carmen et al 1984, Jacobson 1989, Darves-Bornoz et al 1995), and it is argued that it is an indicator of their social vulnerability. Their flattened or inappropriate emotional expression creates risk situations, and a lack of coping and interpersonal skills often prevents them from protecting themselves (Darves-Bornoz 1995). The fragile nature of these women's relationships is further emphasized by the breakdown of four relationships, three in response to the abuse from their male partner.

A further woman had been sexually abused as a child by her father whom she had not seen since she was fourteen years old. Her feelings about these past experiences came to the fore during this study as her family were pressurizing her to reconcile with her abusive father who was dying. This woman had kept the abuse secret until the pressure from her family became so stressful that she was forced to reveal it to trusted members of staff on the residential unit. This pattern of childhood sexual abuse and subsequent secrecy is not unusual amongst these women. Muenzenmaier et al (1993) for example, suggest that the high incidence of childhood sexual abuse is often overlooked in the care of women with long-term mental health problems. This can be attributed to the reluctance of the women to report such abuse due to shame, guilt and fear of being blamed, or a reluctance by mental health professionals to enquire about abuse histories (Rose et al 1991).

The complex issues around the desire for motherhood and the often inevitable sequelae of loss of children was also evident. During this study one of the women had her pregnancy terminated, and a second gave birth to a child who was immediately fostered and later put forward for adoption. Both of these women were in a relationship with male clients during the period of their pregnancy, although studies have suggested that such relationships where the male partner is not functioning optimally may not be particularly supportive (Krener et al 1989, Mowbray et al 1995). Furthermore, pregnant women with long-term mental health problems have been found to have little contact with significant others, family members or appropriate community-based professionals (Rudolph et al 1990). Finally it has also been suggested that as a result of their psychiatric disabilities, the problems surrounding the pregnancy may be experienced as more stressful and are likely to be debilitating and related to increased dysfunction (Belle 1982). The long-term effects of the loss of a child was illustrated by the experiences of two of the other women. One was very distressed around the anniversary of her baby's death which had occurred several years previously. The second was having to cope with very mixed feelings about her now adult daughter who was adopted at birth, wanting to see her.

These examples graphically illustrate the tensions which young clients experience in attempting to strive for a similar lifestyle to that of their mentally healthy contemporaries. The difficulties the women experienced in maintaining their sexual relationships with their partners, the abuse they suffered and their inability to care for their children must inevitably reinforce their feelings of being different. The pain of failure and of being different however is not necessarily purely associated with the examples of major life events already identified. Such feelings may also be reinforced when attempts to be independent cause great stress. One of the women for example, was unable to cope alone for a short period of time when her parents went away on holiday, and found meeting up with old school friends extremely stressful.

There is an extensive body of research which has explored the links between life events and their influence on psychotic symptoms and the course of illness, much of which stems from the first major study in this area by Brown and Birley (1968). Although many of the research findings are inconclusive or conflicting there is considerable evidence to suggest a relationship between life events and changes in symptoms over time among people with a psychotic illness. For example, a number of studies have demonstrated that high levels of stress associated with life events are related to a worsening in psychotic symptoms and subsequent relapse (c.f. Ventura et al 1992, Ventura et al 1989, Malla et al 1990, Norman and Malla 1993a, Bebbington et al 1993, Hirsch et al 1996). In addition there is some evidence that clients with a psychotic illness experience more life events with more associated stress than people in the general population. From a study of life events and psychosis using a sample of 97 clients, Bebbington et al (1993) theorize that "it remains possible that the mere fact of having been ill once, or of having the sort of personality associated with an increased likelihood of psychotic breakdown, might lead to a lifestyle that renders the experience of independent life events more likely. So there may be something about the way that psychotic clients live that increases the chance of them having large numbers of life events". Bebbington et al (1993) also found that there were notably more life events identified for the women clients in their sample when compared to the men, although no explanation for this finding was given.

The results from this body of research on the relationship between the stress associated with life events and the relapse of psychotic symptoms, and the high incidence of life events experienced by people with psychotic illnesses when compared to the general population have to be treated with caution. Norman and Malla (1993b) for example, suggest that such research is fraught with conceptual and methodological problems such as issues related to the nature and measurement of stress, the definition and measurement of life events, the likelihood of reciprocal influences between stress and symptoms, the adequate assessment of symptoms and the varying definitions of relapse.

It is difficult to draw comparisons between this body of research and the findings of this study as the research designs are very different. The studies cited for example, have been designed specifically to investigate the relationship between life events and relapse and have measured the incidence of life events using assessment tools specifically designed for this purpose. These tools have recently been comprehensively reviewed by Paykel (1997). In comparison the large number of independent life events experienced by the women in this study over the twelve month study period only emerged after the data had been analysed. Such a finding was relatively unexpected as the primary focus of collecting the descriptive data was to identify changes in service use and the rationale given for services being changed or remaining the same. Nevertheless the results from the body of research on life events does illuminate the experiences of the women in this study. The large number of life events experienced by the women as compared to the men replicates the findings of Bebbington et al (1993). This finding suggests that the vulnerability of these young women coupled with their desire to achieve the goals of 'normal' adult womanhood leads them into situations where they are likely to experience multiple negative life events. Such an explanation is offered tentatively however, as it may also reflect biased reporting by the service providers. The design of this study also makes it difficult to explore the relationship between the high number of life events and subsequent relapse of psychotic symptoms. Nevertheless the stress associated with the life events may explain the overall lack of improvement in social functioning and quality of life over this period.

A close examination of the service providers' responses to the complex needs of these women revealed a number of interesting findings. There was evidence that the staff responded relatively swiftly to a deterioration in the mental health of five of the women and in-patient treatment and support was provided in each case. Similarly there was evidence that discharge to independent accommodation was a planned event and considerable support was provided from a range of services. There was however, little evidence that the staff responded to the very specific needs of the women which emerged during the twelve month study period such as the stress associated with unwanted pregnancy, the loss of children, childhood sexual abuse, bereavement, abusive relationships with partners, breakdown of relationships and the complex issues around the desire to be like their contemporaries but having to constantly confront being different. The importance of responding to such needs to minimize the associated stress which may in turn affect the clients' social functioning and symptoms has been strongly emphasized (Leff et al 1982, Falloon et al 1985, Hogarty et al 1986, Norman and Malla 1993b).

There was evidence that the service providers had endeavoured to engage the women in a range of day care activities both within and outside the mental health services. Despite these efforts six of the women were not involved in any identified activities or receiving any additional support at the end of the study. The reasons for this lack of involvement are inevitably complex and could be atributed to a number of factors. It is possible that the women may have been put off using the services, particularly those provided within the RCCS, because of their orientation towards men (Perkins and Repper 1996), especially as so many of the women appear to have had difficult and traumatic experiences with men. It is also possible that the women were reluctant to use the available services because they did not provide them with the appropriate support to help them cope with and manage their particular experiences and stressors. Their unwillingness to accept help may also reflect their relative youth and a general reluctance to perceive themselves as mentally ill and subsequently different from their contemporaries. Two of the women for example, were very conscious of their physical appearance and refused to participate in ordinary leisure activities in the community where their differences could possibly be identified and remarked upon. Finally it is possible that the predominance of men within the RCCS and their particular problems such as non compliance with medication, aggressive and threatening behaviour and their misuse of alcohol and drugs, may be forcing the services to focus on them, as compared to the women who are less overtly demanding.

7.4.2 Methodological issues

The difficulties encountered in both conducting this study and in interpreting the findings were expected. Many of the problems have been highlighted in previous studies and it would have been naive to assume they could have been avoided. Nevertheless it was hoped that the design of the study which included a descriptive account of the progress of clients during the twelve month study period would overcome some of the issues around identifying some of the extraneous variables which may have a bearing on outcome. This exploration of progress however, threw up a set of additional problems which were not anticipated. The four key areas of difficulty encountered in this study included the use of the Quality of Life Interview (Lehman 1988) as a measurement of outcome, the exploration of progress, the question of bias, and the practical issues of interviewing clients. These will be considered in turn.

The methodological difficulties that arise in measuring quality of life have been described (c.f. Barry et al 1993). Judgements of quality of life, as demonstrated in the Quality of Life Interview (Lehman 1988) rely on self report measures of both objective and subjective indicators of well-being. The objective indicators are generally viewed as being relatively unproblematic methodologically in that the validity of the data such as employment or living situation can usually be checked from other sources. The validity of the subjective indicators however has been questioned as studies using quality of life measures find that there is little or no relationship between the objective and subjective indices (c.f. Barry et al 1993, Oliver et al 1995, Barry and Zissi 1997). Clients with long-term mental health problems tend to report high levels of satisfaction in most life areas against a background of economic disadvantage and restricted social and unemployment opportunities (c.f. Baker and Intagliata 1982, Lehman 1982). This phenomenon was evident in the results of this study where clients were generally satisfied with aspects of their lives as measured by the subjective indices even though the objective indices showed that all the clients were unemployed, and few had social contacts or were involved in activities outside the mental health services. Lehman (1996) however, argues that whilst clients may perceive the quality of their lives differently than social norms would predict, this in itself is not enough to question the validity of the measure. He suggests that such results may reflect the idiosyncratic views and values of people with long-term mental health problems. Alternatively their satisfaction may reflect an accommodation to adversity. He illustrates this point by suggesting that clients who have lived with social isolation, unemployment, poverty or adverse circumstances for extended periods of time may report relatively positive life satisfaction. Lehman

(1996) concludes his arguement by suggesting that conversely interventions that promote positive change, such as active rehabilitation, may produce transient decreases in life satisfaction because of the clients' renewed awareness of how their lives could be better.

Questions have also been raised about the sensitivity of quality of life measures in identifying life domains affected by service interventions. The majority of quality of life studies are cross-sectional in design and do not inform about changes in life satisfaction over time. The small number of studies that have employed a longitudinal repeated-measures design (c.f. Okin et al 1983, Gibbons and Butler 1987, Okin and Pearsall 1993) use small samples of clients and the sensitivity of the quality of life tool in measuring outcome has not been discussed (Barry and Zissi 1997). In a recent longitudinal repeated-measures study, Barry and Crosby (1996) report that improvements in the quality of life of clients who had moved from hospital to community-based settings were evident in the objective quality of life indices, the qualitative data and other outcome measures used in the study, but were not reflected in the life satisfaction ratings which remained relatively stable. This finding reflects the view of Oliver et al (1997) who suggest that a fairly major social intervention may be needed to produce an improvement in a client's rating of life satisfaction. Interpreting the findings of this study was therefore problematic as it was difficult to tease out whether the lack of improvement in quality of life was due to the failure of the service to impact on the subjective well-being of the clients or was due to the insensitivity of the measure.

Finally it has been argued that one of the most interesting features of measuring quality of life has been the inclusion of the voice of the service user in evaluative studies (Oliver et al 1995). Anecdotal evidence suggests that clients enjoy talking about their experiences and being asked how they feel about things (Oliver et al 1997). This was reflected in this study as clients were extremely forthcoming in the interviews and additional time was frequently spent with clients discussing issues that had arisen. The difficulties encountered in administrating the Quality of Life Interview

(Lehman 1988) however, raise questions about the appropriateness of using fixed-response schedules with clients with long-term mental health problems. First, a relatively high number of the clients found it difficult to respond to the subjective quality of life questions asking them how they felt about different aspects of their lives. Either the clients found it difficult to understand the question or failed to see its relevance. At times it was sufficient to repeat the question allowing the client time to think but on several occasions it was necessary to paraphrase the question and explain it more simply. It was also difficult not to respond either verbally or non-verbally when clients gave a response which the researcher found hard to accept. Examples included clients who stated that they were delighted with their sex lives or very satisfied with their relationships with their families when it was known that these clients either did not have a sexual partner, or had no contact with their family. A slight hesitation to record responses such as these actually prompted a small number of clients to revise their response. These issues have been discussed by Antaki and Rapley (1996) and Rapley and Antaki (1996) who argue that fixed-reponse interview schedules often force interviewers to paraphrase complex questions which can in turn distort the actual nature of the question being asked. They also highlight the problems around interviewing disadvantaged groups of clients as researchers can be reluctant to accept their views and may unconsciously pursue legitimate, plausable and acceptable answers. In addition Barry et al (1993) argue that a positive response bias may be encountered in relation to clients' assessments of life satisfaction as they may feel a certain desire to please the interviewer or be unwilling to be seen to complain. This traditional notion of the submissiveness of vulnerable clients and a willingness to please acquiesence has, however, been recently criticized by Rapley and Antaki (1996) who found little evidence to support this view.

The second area of difficulty encountered in this study was the collection and analysis of the descriptive data on the progress of clients during their first twelve months in the RCCS. The quality and richness of the information gathered varied widely despite efforts to ask the same set of questions to each of the key workers on a monthly basis. Although each of the key workers only had to recall information about their clients during the previous month, such information was inevitably affected by memory, bias and personal interests. For example, it was easier to get the key workers to elaborate on the events leading up to a clients's admission to one of the acute mental health wards, than to explain why a particular client was reluctant to attend a day centre. The analysis of the descriptive data raised two further issues. First, the number of life events experienced by the clients was unexpected. Although care was taken only to highlight those events which could be considered as independent, for example outside the control of the client and not altered by controlling their illness, the number of events reported was entirely dependent on the information supplied by the key workers. With hindsight it would be interesting to see if the same life events and / or more of them would have been identified by using one of the assessment tools reviewed by Paykel (1997). Second, the information gathered about service use focused on identifying the range of services a client was using at any one time rather than a more detailed exploration of what the client actually did in any of the services. For example, although a client may attend a day centre regularly, they may not actively engage in any of the therapeutic activities but purely use the facilities as a source of warmth, a free meal and some human contact. Similarly the focus and content of individual sessions between the key workers and their clients were not explored. Such information could have been gathered from the clients' care plans and progress notes and might have produced some additional insights into the ways in which the key workers responded to the clients' individual needs.

The third area of difficulty which arose whilst conducting this study was the limitations of the sampling method and the approach taken to analyzing the quantitative data. The practical difficulties of recruiting a sufficient number of clients to take part in this study cannot be underestimated. As was explained in Section 7.2.1 it was planned that the sample would consist of consecutive admissions into the RCCS from 1/1/94, and that ideally the sample would consist of

30 men and 30 women. The actual sample of 10 women and 31 men were recruited from 19 women and 41 men admitted over this period. There is therefore no way of knowing whether the actual sample was representative of admissions into the RCCS, or whether it was representative only of those clients who were willing and well enough to take part. The problems of obtaining representative samples in health services research have been raised by Bland (1995) who acknowledges the practical difficulties. He does suggest however, that the limitations of the sample have to be considered when interpreting and generalizing the findings to wider populations.

The approach taken to analyzing the quantitative data was influenced not only by the characteristics and structure of the data itself but also by the methods used by other researchers working in the mental health research field. For example, Everitt (1998) notes that the most frequently used methods for analyzing longitudinal data in contemporary mental health research are ANOVA and MANOVA. Despite the sophistication of these statistical tests the analysis of longitudinal data is not straighforward particularly if clients drop out of studies which results in an incomplete data set. One of the current practices of dealing with missing values when using ANOVA and MANOVA in longitudinal studies is to use only subjects who have a complete set of data. In this study, for example, five men were excluded from the analysis as the social functioning and quality of life data were not obtained at the twelve month follow up. The exclusion of five men from the analysis however has a number of implications. For example, the exclusion of the missing values which may be very informative could mask the actual findings. On a pragmatic level considerable effort was made during the data collection period of this study to minimize the amount of missing data. In addition the approach to statistical analysis was very much influenced by current practice in the mental health field. Nevertheless the findings again have to be treated with caution as Everitt (1998) suggests that a wholly satisfactory analysis of longitudinal data with missing values is not feasible. Furthermore he argues that it is time that the limitations of MANOVA in the analysis of longitudinal data with missing values is acknowledged. This useful paper finally suggests a number of recently developed techniques for analyzing longitudinal data which can accommodate missing values as an alternative to MANOVA (Everitt 1998).

The final area of difficulty encountered in this study revolved around the practical issues of interviewing clients with long-term mental health problems. An unanticipated experience was that it frequently took up to three or four visits to meet with the clients on either the residential units or in their own homes to carry out the interviews even though care had been taken to inform them of the dates and times of the interviews by letter and through the key workers. Usually clients claimed that they had forgotten about the interview and had gone out, although the possibility of their wanting to avoid being interviewed cannot be ruled out. Consequently organizing and conducting these interviews was very time consuming and frequently frustrating.

Many of the clients also had relatively florid symptoms such as auditory hallucinations and delusional ideas and in some instances these were compounded by suspiciousness, irritability and poor concentration. It was therefore necessary to manage the interviews sensitively, striking a balance between completing each interview without putting undue pressure on the clients. The past clinical experience of the researcher in working with such clients was invaluable throughout this period. Although similar issues have been raised by other researchers working in this field (c.f. Lehman 1996), there has been little discussion of the risks associated with interviewing such clients. Many of the interviews took place on the residential units where such risks were minimized due to the nearby presence of staff and other clients. A number of the interviews however, were undertaken alone by the researcher in the clients' own homes. For practical reasons the researcher worked alone as it was difficult to elicit the support of another researcher or a member of the mental health staff as the interviews were time consuming and often did not occur if the client was out. A number of precautions were taken to minimize the risks such as checking with the key worker that it was safe to visit particular clients alone, leaving details of whereabouts and expected times of return with colleagues, and dressing appropriately and in an unprovocative manner. Despite these precautions however, two frightening and potentially dangerous situations did occur with male clients. The first involved being locked in a house with a client who kept the key on his person and having to ask to be let out. The second was with a client who became increasingly agitated and sexually aroused throughout the interview. As it became more obvious that he was going to act on his feelings, the researcher terminated the interview, quickly left the flat only to be caught and held at the entrance by the client. It was only by shouting loudly that the researcher was able to escape. At one level, such incidents further illustrate the very lonely and isolated lives of these young clients. At another, it reinforces the need for two people to be involved in interviewing clients in their own homes and to take all the necessary precautions to minimize the potential risks.

7.4.3 Effectiveness and responsiveness

This study highlights the difficulties of assessing whether the RCCS was effective and responsive in meeting the needs of women with long-term mental health problems. The evaluation criteria of effectiveness and responsiveness were drawn from the aims of the RCCS which reflect a commitment to improving the social functioning and quality of life of clients by providing a flexible, responsive service which meets their individual and changing needs. It is also committed to developing services to meet unmet needs. The results of this study highlight the lack of improvement in both the social functioning and quality of life of the women after twelve months in the service. The RCCS did appear to be flexible and responsive in managing the issues around relapse of illness and discharge to independent accommodation, although there was considerable evidence to suggest that the additional support offered did not appear to be acceptable to many of the women, nor appropriate to meet their particular difficulties. There was little evidence that services were being developed to meet the many unmet needs of these women, or that use was being made of the many appropriate facilities, groups and services outside the RCCS. Finally there was an overriding assumption that the women would be prepared to use the existing services with encouragement, and little consideration that it may be more appropriate for the staff and services to change what they currently provide to meet the women's needs. If equitable provision for women is to be achieved, a range of interventions and services must be available to meet their needs which includes the necessary support to help them cope with the particular stressors associated with loss, childhood sexual abuse, abusive relationships and the alienating feelings of failure and of being different.

Such conclusions on the effectiveness and responsiveness of the RCCS in meeting the needs of women with long-term mental health problems must be treated with caution. A poor overall outcome, for example, does not necessarily imply a poor quality of care (Brugha and Lindsay 1996, Ramon 1996). More importantly this study raises the question as to whether outcome should be measured in terms of improvement. As Repper and Brooker (1998a) point out, the emphasis on improvement as an indication of the success of a service may not be appropriate for this client group. They argue for example, that stable engagement with appropriate services is a measure of success for people who have previously tended to lose contact with the support they need, or the maintenance of levels of social functioning and quality of life is a positive achievement for many clients.

7.5 Conclusion

The aim of this study was to compare the effectiveness and responsiveness of services provided over time for men and women with long-term mental health problems. A longitudinal design was employed to assess the service input and outcome for a sample of 31 men and 10 women. The initial socio-demographic and psychiatric characteristics, level of social functioning, satisfaction with services and quality of life of this sample was assessed on admission into the RCCS and one year later, and their use of all services was monitored over this time.

A description of the clients on entry into the RCCS showed that they shared many of the characteristics of a group of clients commonly referred to as young adult chronic patients (c.f. Pepper et al 1981, Lamb 1982). The differences between the men and the women were most marked in the area of personal relationships. The women were more likely to be currently or previously married, more likely to have had children, and a higher proportion reported having close friends and someone they could confide in.

An examination of the progress of the clients over the twelve months from admission into the RCCS highlighted a number of key differences between the men and the women. The women experienced a greater number of life events than the men, changed their accommodation more frequently, and the services appeared to be less responsive to their particular needs.

The outcome after twelve months in the RCCS suggested that overall the social functioning and quality of life of the clients had not improved. There were some changes in service use, notably the greater number of clients living independently.

The discussion focused on three key areas. First, the findings which illuminated the experiences of women with long-term mental health problems were highlighted. Second, the methodological issues which arose from this study were explored. These included the problems of measuring process and outcome and the subsequent data analysis, a critique of the measurement of quality of life using a standardized assessment tool, and the risks involved in interviewing clients alone in their own homes. Finally, the difficulties of evaluating the effectiveness and responsiveness of the RCCS in meeting the needs of women with long-term mental health problems were highlighted.

Chapter Eight

The Perspective of the Service Providers

8.1 Introduction

The four studies already presented in chapters five to seven have highlighted the experiences of women with long-term mental health problems within the mental health services and identified a number of key concerns. There was a need however, to explore these issues in more depth to gain an understanding of the problems experienced by mental health providers in planning and delivering a service to women. The contact with service providers throughout the period of data collection for the first four studies had also proved very fruitful as they frequently commented on the development of the evaluation, and offered their opinions on the particular problems experienced by women with long-term mental health problems within mental health services. More importantly they suggested a number of service providers who either had a particular interest in these women, had been instrumental in developing services to meet their needs, or were known to have a particular expertise in aspects of their care and treatment. It was therefore decided to contact these key service providers in order to conduct in-depth interviews with them about their experiences of working with women with long-term mental health problems.

This study has three aims. First, to identify the particular problems and needs of women with long-term mental health problems from the perspective of the service providers. Second, to elicit their views on the appropriateness and adequacy of locally provided services and how these might be improved. Third, to gain an understanding of the problems experienced by service providers in planning and delivering a service to women with long-term mental health problems.

8.2 Method

The views and experiences of the service providers were explored by conducting five semi-structured individual interviews and one group interview. A non emergent research design was employed so that all the qualitative data were collected prior to analysis. This differs from the emergent design of qualitative research described by Lincoln and Guba (1985) where data is analyzed as it is collected and new avenues of enquiry are pursued in subsequent interviews. The decision to employ a non emergent design for this study was made for three reasons. First, the researcher had a clear idea of what questions needed to be asked to meet the aims of the study. Second, the sample of service providers were deliberately selected to ensure that a range of views would be represented. Third, the focus of this study was sufficiently broad to allow service providers to introduce and explore particular areas of interest. Although Maykut and Morehouse (1994) argue that a non emergent approach to qualitative research is less open and responsive than an emergent approach, they nevertheless maintain that the former approach can yield important findings.

8.2.1 Sample

Morse and Field (1996) suggest that two principles guide the selection of a sample for qualitative research. First is the identification and utilization of participants who can best inform the research, and second is that sufficient participants are included so that enough data are collected to develop a full and rich description of the phenomenon under investigation. The sample consisted of service providers from a range of professional backgrounds who were working in a variety of settings both within and outside the Rehabilitation and Community Care Service (RCCS). These service providers were selected as they were willing to talk, occupied key professional positions and had a special interest and / or expertise in working with women with long-term mental health problems. Efforts were also made to ensure that the sample consisted of people who would offer different perspectives and experiences. This was an attempt to increase the likelihood that the variability common in any social phenomenon would be represented in the data (Maykut and Morehouse 1994). The sample included a service manager with responsibility for the residential services in the RCCS, a consultant psychiatrist with an expertise in caring for pregnant women with long-term mental health problems, an Afro-Caribbean mental health worker, a social worker working with homeless women, a community occupational therapist, and a group of eight care managers who met regularly on a formal basis to discuss professional issues concerning their work with women with long-term mental health problems. The eight care managers were interviewed as a group and the other five service providers were interviewed individually.

The service providers selected for this study were all women. This was intentional for three reasons. First, it was hoped that women service providers might be able to draw on some of their own life experiences as women to illustrate their understanding of the disadvantaged position of women with long-term mental health problems. Second, regular contact with services both within and outside the RCCS throughout the evaluation suggested that it was female rather than male service providers who were predominately responsible for caring for or organizing the care for women with long-term mental health problems. Third, this was an attempt to overcome the one-sided relationship which so often exists in research. For example, Webb (1993) suggests that frequently researchers have a different status from those being researched. They are usually more highly educated and so are more assertive and articulate. They approach potential participants and ask them to be involved in a project, and thus are in a different and more powerful structural position. In this study the researcher shared a similar mental health background to the service providers and was similarly committed to improving services for women with long-term mental health problems. It was envisaged that these commonalities would encourage rapport and participation in the interviews and thus enhance the richness and quality of the data.

8.2.2 Data collection tool

A semi-structured interview schedule was developed to guide both the individual interviews and the group interview. A semi-structured format was selected as the researcher had a clear view on what questions needed to be asked but was unable to predict the answers. This format would therefore ensure that the information required would be obtained, while at the same time permitting the service providers freedom of responses to illustrate the issues raised.

The interview schedule was developed by first listing all the topics that needed to be covered. These topics were then converted into open-ended questions which were carefully worded to ensure that they only addressed one topic. Each question also included a number of suggested prompts which were designed to either encourage the service providers to elaborate on particular issues raised such as 'please explain....' or 'can you tell me about a time that happened ?', or to elicit their views on particular areas of interest such as sexuality or relationships with other people. Finally the questions were listed in a logical order. The final semi-structured interview schedule consisted of a series of open-ended questions designed to explore the service providers' views on the particular problems and needs of women with long-term mental health problems, the adequacy and appropriateness of service provision, and how services might be further developed. The schedule was pretested on colleagues and slight alterations were made to the wording of some of the questions. The number of prompts was also reduced as these inhibited the flow of the interview. A copy of the amended version of the interview schedule can be seen in appendix P.

8.2.3 Procedure

The five individual interviews were arranged by first contacting the service providers by letter. This letter provided background information and explained the purpose of the interview. All of the service providers agreed to take part in the study and arrangements were made to interview them in their work environment. All the interviews took place between March and July 1995. The group interview with the care managers was arranged by attending one of their regular meetings, explaining the purpose of the study and inviting them to participate. There was genuine interest amongst the care managers to take part and the group interview was conducted in July 1995.

The five interviews and the group interview were conducted in a similar manner. Efforts were made to ensure that the interviews were conducted in private with little opportunity for interruption. The researcher began each interview by briefly explaining its purpose and the form it would take. The open-ended questions were then used as a means of encouraging the participants to explore issues around the focus of enquiry. In order to enhance the quality and richness of the data obtained, a conversational tone was adopted throughout in an attempt to get the participants talking. The prompts were also a useful means of eliciting examples and stories to illustrate the issues raised.

The interviews lasted between forty five minutes and one hour, the group interview lasted for one hour. Each one was tape recorded with the participants' permission and later transcribed. The transcribed interviews were returned to the participants to read and make additional comments if they wished. None of the participants wanted to add anything to the data and there were no requests to veto particular comments or opinions.

This study raised particular problems with regards to the anonymity of the participants. Most were well known within the RCCS as they either had a clearly identified area of expertise or were known to have a particular interest in women with long-term mental health problems. Although the participants were aware that they could easily be identified as a participant, none were unwilling to take part. Assurances were given by the researcher however, that opinions, views and quotes would not be attributed to an identified individual in the study.

8.2.4 Analysis

Strauss and Corbin (1990) describe three approaches to analyzing qualitative data which vary along a continuum ranging from a low level of interpretation and abstraction, to a high level of interpretation and abstraction required for theory building. The first approach is that taken when the data are presented without any analysis as the goal is to let the research participants speak for themselves as much as possible, to tell their stories without interpretation. The second approach requires some selection and interpretation of the data as the goal is not only to accurately describe the phenomenon under investigation, but also to reconstruct the data into a recognizable reality for both the participants and the reader. The third approach focuses on the development of theory and requires the highest level of interpretation and abstraction from the data in order to arrive at the organizing concepts of a theory to explain the phenomenon being investigated. An example of the third approach is that of grounded theory (Glaser and Strauss 1967).

The second approach described by Strauss and Corbin (1990) was selected to analyze the qualitative data in this study for several reasons. First, the wealth of data generated in the interviews provided an opportunity to explore the issues beyond a pure description. It was therefore hoped that a description together with an interpretation of the data would add another dimension to the findings already presented in chapters five to seven. Second, the use of a semi-structured interview schedule which placed some boundaries around the focus of the study mitigated against the development of theory. For example, all of the participants were asked the same set of open questions and there was no attempt to focus on issues and themes which emerged from earlier interviews in the later ones.

Within this approach, the constant comparative method described by Maykut and Morehouse (1994) was used to analyze the data. This method, which was first described by Glaser and Strauss (1967) and Lincoln and Guba (1985), was selected as it provided clear, systematic steps for the analysis of substantial amounts of qualitative data. There are several computer programmes available which are designed to assist in the process of analyzing qualitative data, for example Ethnograph and NUDIST. It was decided however to adopt a more 'hands-on' approach as the researcher preferred to be able to visualize large amounts of data simultaneously and to manipulate the data manually.

First, each of the audio tapes were transcribed word for word and typed. Once typed the manuscripts were checked against the audio tape for accuracy and corrected. The accurate transcripts were then photocopied and the subsequent analysis was conducted using these photocopies. A code was attached to each paragraph so that individual participants could be identified. This was a useful means of checking the source of views in the later stages of the analysis and the context in which they occurred.

Second, each of the transcribed interviews were read carefully in order to identify units of meaning in the data. Units of meaning consisted of individual sentences, several sentences or paragraphs and were identified if the meaning was clear and understandable without additional information. In some instances the question or prompt was also included if it added to understanding. These units of meaning were then separated from each other by drawing lines across the page of text. All of the data were categorized into units of meaning in this way. The marked text was then reviewed and a word or phrase was printed on the text beneath the code identifying the source of the data. Finally the individual units of meaning were cut apart from the rest of the text.

The third stage of the analysis focused on the development of a coding framework which reflected the main issues raised in the interviews. Initially four broad categories were identified in the data which reflected the questions in the interview schedule, namely, problems and needs of women with long-term mental health problems, problems and needs of particular groups of women with long-term mental health problems, special service provision made for such women, and recommendations for the future development of services. The separate units of meaning were then sorted into one of the four categories. The constant comparative method was then used to identify sub-categories within the four broad categories. Each unit of meaning was compared with the other units of meaning and subsequently grouped with similar units of meaning. This process was one of continuous refinement as initial sub-categories were changed, merged or omitted and new sub-categories generated as the analysis progressed. The aim of this process was to develop a set of sub-categories within each of the four broad categories that provided a reasonable representation and reconstruction of the data collected. All the units of meaning were then taped onto large sheets of paper representing each sub-category. Further refinement of these sub-categories was carried out by writing a propositional statement for each. Maykut and Morehouse (1994) describe a propositional statement as one which conveys the overall meaning of the units of data gathered together under one sub-category heading, for example, older women with long-term mental health problems mourn the loss of a life that many mentally healthy women take for granted. Although devising the propositional statements was difficult, it was a valuable exercise as it did help to identify units of meaning that did not fit into the sub-categories identified and consequently were categorized elsewhere. The resulting coding framework can be seen in Figure 1.

This descriptive reduction of the interviews into categories and sub-categories allowed an overall picture of the problems experienced by women with long-term mental health problems from the perspective of the service providers, together with their recommendations of how services could be improved, to be built up. The validity of these preliminary findings were checked in two ways. First, the initial categorization was checked by a second researcher who had read the transcribed interviews. Second, the findings were fed back to a group of staff working in the RCCS at a research meeting who confirmed their accuracy, hence validating the analysis at this stage.

Figure 1: Initial coding framework reflecting the main categories and sub-categories arising from the interviews with service providers

Problems
motherhood and parenting
the loss of any kind of normal life
loneliness and social isolation
no meaningful role in life
low self esteem
sexual exploitation and vulnerability
sexual abuse
harassment and violence
physical health
little choice as regards where they live or who they live with

Groups of women with particular problems
younger women
older women
lesbian women
homeless women
women from ethnic minority groups

Issues raised by service providers

Services provided
women-only house
women's groups
cultural and gender awareness training
problems with existing services

Recommendations
befriending service
female key workers and medical staff
women's network
health education
safety
access to primary health care services

Although the initial findings were informative and interesting, a pure description of the data contained within each of the sub-categories produced little understanding of the nature of the service providers' work in providing a service to women with long-term mental health problems. In addition, re-reading the interviews, both as a whole and within sub-categories, led to a realization that the issues identified were interrelated to such an extent that they could not be presented as distinct areas. This realization prompted the final stage of the analysis which involved the search for and the identification of themes which not only extended throughout the set of interviews but also provided a means of understanding the relationships between the sub-categories identified in the data.

As Morse and Field (1996) explain, such themes are usually difficult to identify as they tend to lie beneath the surface of the interviews rather than being concrete entities directly described by interviewees. In this study the themes were identified by reading and re-reading the interviews and then reflecting on the interviews as a whole to generate ideas for summarizing and linking together the issues raised. This process was very time consuming as many of the initial ideas generated did not provide a satisfactory explanatory framework. Over time however, and with increased familiarity with the data, two overriding themes emerged. These two themes, once identified, appeared to be significant concepts that not only linked the issues raised in the interviews together, but also provided a means of understanding the difficulties which service providers face when seeking to provide a service for women with long-term mental health problems.

The first of the two themes identified was the service providers as empathic women. The disadvantaged and impoverished lives of women with long-term mental health problems were highlighted by service providers who emphasized their vulnerability, social isolation and lack of power. The range of needs identified were broad and included issues that had become standard good practice in some of the services, but were only beginning to be addressed by others, together with recommendations for good practice. Underpinning these issues was a recognition that the women had a number of individual rights which should be met within the existing services. These included the right to be safe, and for privacy, choice, support, independence and care services.

The second theme identified was the service providers as paid professionals. Within this role the service providers felt the need to protect women with long-term mental health problems from their perceived vulnerabilities. This duty to protect was reflected in their attitudes towards the behaviour of the women in particular. There was a sense of the service providers 'knowing what was best for the women' especially when they were required to make decisions concerning clients' care. This was particularly marked in discussions around the women's sexuality and fertility. The service providers however, appeared to experience a conflict between respecting the individual rights of the women and protecting them. Although role conflict was not an issue raised in any of the interviews, it emerged from examples of frustration and lack of power, a sense of hopelessness in trying to improve the quality of life of women with long-term mental health problems, and the varying coping strategies which the service providers adopted to manage their situation.

The importance of highlighting the provisions made for the trustworthiness of qualitative research is acknowledged. These provisions will be considered and explored in the discussion with reference to the issues which arose from conducting, analyzing and writing up this study.

8.3 Results

The aim of this section is to present the findings of the study by weaving together descriptions, interpretations and direct quotes into a narrative which illustrates the service providers' experiences of working with women with long-term mental health problems. The two themes introduced in the previous section will serve as a framework within which to present the findings.

8.3.1 Service providers as empathic women

The initial analysis allowed an overall picture of the problems experienced by women with long-term mental health problems from the perspective of the service providers to be built up. The problems identified are highlighted in Table 30.

Table 30: Problems experienced by women with long-term mental health problems

Nervousness or wariness of men : Many of the women are wary or even frightened of men, particularly if they have had restricted contact in the past, or a history of sexual or physical abuse.

Vulnerability to abuse and exploitation by male clients: Within the services there were examples of women being abused and exploited by male clients, such as demands for sex in return for cigarettes or friendship.

Vulnerability to physical and verbal abuse and general harassment by the public: In many cases this was exacerbated by the geographical locations of some of the services or their housing and women living or attending services in the inner city areas were perceived as being particularly at risk.

Lack of self confidence: Negative experiences of mental health services in the past and the daily struggle of living, frequently results in a lack of confidence to discuss their problems with staff and identify what they want and need from the services.

No meaningful role in life: Many of the women experience difficulties in finding an appropriate role in life. They have missed out on the traditional role of being a wife and mother, and have frequently not had a job.

Little choice as regards where they live or who they live with: Women who live in residential or group homes in particular, often have no choice about who they live with, and at times experience difficulties in their relationships with other clients.

Loneliness and social isolation: The women are often lonely and isolated and find initiating and maintaining relationships difficult.

The loss of any kind of normal life: The older women who have been in institutions for a long time in particular, mourn the loss of any kind of normal life. This loss is frequently exacerbated by the lack of choice they sometimes have about basic things such as where they live and who they live with.

The growing number of unplanned or unwanted pregnancies: There were examples of women being unable to cope with their children and the inevitability of the children being fostered or adopted

The discussions however, went further than these practical issues, and taken as a whole, illustrated the empathy shown by the service providers towards these women. This empathy was demonstrated by the extent to which the service providers appeared able to 'step into the shoes' of women with long-term mental health problems and imagine the trials of their daily lives and experiences. The service providers therefore not only identified a range of problems experienced by women with long-term mental health problems but more importantly highlighted a number of associated feelings. Such feelings included loss and grief, loneliness and isolation, vulnerability and lack of power, being labelled as mad or different, and lack of choice and control. Whilst the feelings attributed to women with long-term mental health problems will be presented in some detail, it is important to note that these findings are from the perspective of the service providers alone. These findings therefore, may not reflect the actual feelings experienced by women with long-term mental health problems.

Loss and grief

Accounts of loss and grief pervaded all the interviews but were primarily focused around issues associated with the loss of children, and the loss of any kind of normal life.

The growing number of unplanned pregnancies amongst younger women with long-term mental health problems was highlighted in all the interviews and many of the service providers gave examples of working with pregnant women or women who had children. Their accounts however, were dominated by examples of women being unable to cope with caring for their children and the inevitability of the children being fostered or adopted. The subsequent loss and despair felt by the women was recognized. One of the service providers for example, had worked with several women whose children had been taken away at birth and her comment graphically describes the impact of such a loss,

> *"...they really need a lot of counselling and help about that (having the baby taken away) as they suffer a lot of grief. They (the women) don't know where to go for help...the grief makes them more ill and as they see the likelihood of ever getting their children back drifting further and further away it just makes the problem worse".*

The detrimental effect of grief and loss on the women's mental health was further demonstrated by examples of women *"showing quite severe disturbance"* or of being *"unhappy and disturbed"* after their children had been removed from them. The service providers also recognized that such feelings were compounded by fear that further pregnancies would result in additional losses. As one service provider explained,

> *"...there is a fear (among the women) of getting pregnant again and having the same thing happen (child taken away)...you (service providers) know its going to happen if they get pregnant again"*

This fear was acknowledged by other service providers who recognized the powerlessness of pregnant women with long-term mental health problems. For example they described the women as being *"at the mercy of the Social Services who are quite convinced that adoption is the best option for absolutely everyone"*, and of some doctors who maintain that *"a person with schizophrenia is not the right person to look after a child because the essence of schizophrenia is that they cannot meet a child's basic needs"*.

Feelings of loss were also attributed to older women with long-term mental health problems, particularly those who had been cared for in institutions for many years. The group of care managers for example, felt that many older women with long-term mental health problems mourned the loss of not having been a mother, aunt or grandmother. It was also suggested that some older women still desire a sexual relationship but are resigned to the fact that they are unlikely to get the opportunity. The service providers suggested that some of the older women coped with these feelings by taking pleasure in talking to staff about their families or looking at photographs of the staff's children. In essence the service providers felt that many of the older women mourned the loss of a life that many mentally healthy women take for granted. One service provider succinctly summarized these issues by commenting that,

> *"I suppose the loss for my older women clients is the loss of any kind of normal life...just being a human being in society"*

Loneliness and isolation

Feelings of loneliness and isolation were terms frequently used by the service providers to describe the daily lives of women with long-term mental health problems. Many of the women for example, had few or no friends and rarely anyone to talk to that they trusted other than a mental health professional. The service providers suggested that this loneliness and isolation stemmed from the women's difficulties in making and maintaining positive relationships with others, their reluctance to discuss problems with other people, and their low confidence and self esteem. It appeared that for many women with long-term mental health problems their only social contact was with service providers. One of the service providers described this situation by saying,

> *"I think that a lot of the women would just like some friends really....sad as it is to say, often their worker is seen as their friend, they (the women) will say 'you're the only friend I've got', and that's pretty sad"*

It was also suggested that the younger women with long-term mental health problems had particular difficulties in this area. One of the care managers for example, explained that many of the younger women do not see themselves as part of a psychiatric service and yet found developing social relationships or going to ordinary outside activities difficult. Consequently they tend to fall between the two and become increasingly isolated and friendless.

Vulnerability

The vulnerability of women with long-term mental health problems both within and outside the mental health services was emphasized in all of the interviews. The service providers gave examples of the women not feeling safe, being harassed and abused by the general public, of being pestered for sex by male clients, of being physically attacked, sexually exploited and abused. One of the service providers suggested that the strong desire of many women with long-term mental health problems for companionship, friendships and sexual relationships coupled with their low confidence and lack of assertiveness skills created situations in which physical and sexual exploitation frequently occurred.

The service providers also suggested that the women were often exploited in other ways particularly within the mental health services. For example, it was suggested that staff often expect women with long-term mental health problems living in residential homes or attending day centres to take on domestic roles such as keeping the homes clean and producing meals. It was also observed that whilst the male clients sit around, the women are expected to clear tables and make tea. This sense of the women's vulnerability was summed up in a comment by one of the service providers,

> *"I don't know of any female client who hasn't experienced abuse or exploitation of one kind or another. I think they are often quite vulnerable within the psychiatric services".*

Being labelled as mad or different

The issues around women with long-term mental health problems being labelled as mad or different prompted much discussion in the interviews. The fact that many of the women's problems were not taken seriously was often attributed to the RCCS being dominated by male clients and staffed by male doctors. It was suggested that strong feelings of anger amongst some women with long-term mental health problems was the result of not being taken seriously by male doctors. As one service provider said,

> *"If they do see a male doctor they often come out feeling more angry because their feelings have not been acknowledged. That's a really sad state of affairs....one or two of my female clients absolutely refuse to see a doctor"*

This situation was further illustrated in the attempts made by several of the service providers to encourage women with long-term mental health problems to visit their general practitioners to sort out a variety of physical problems. One of the service providers appeared to have great insight into the possible difficulties such women may have in discussing their problems,

> *"I think that the fact of some women having a psychiatric diagnosis prevents them from being able to voice other concerns they may have because they have been labelled. I think that there is a fear that whatever they might voice to the doctor its always going to be 'Oh its because she's schizophrenic'.....they keep a lot in because they have got a label".*

This insight was reinforced by many examples given by service providers of general practitioners either overtly or covertly attributing the women's physical problems to their mental illness. One service provider for example, described a situation in which she had accompanied one of her female clients to see the general practitioner to discuss a number of physical problems associated with the menopause. After the consultation the general practitioner sent the female client out of the room and said to the service provider *"you do realize that this is all part of her mental health problem"*.

Lack of choice and control

Some of the issues already raised suggest the lack of choice and control women with long-term mental health problems experience in their daily lives. For example their ability to be adequate mothers is questioned and their children often taken away and placed in care, their seeming inability to maintain personal safety and avoid exploitation, and the hurdles they face to ensure that their mental health and physical needs are met. The lack of choice and control experienced by the women however, was particularly emphasized in the comments made by service providers concerning the problems associated with living communally in the range of residential facilities both within and outside the RCCS. It was noted for example, that women with long-term mental health problems generally have little choice or control as regards where they live or who they live with, and at times experience difficulties in their relationships with other clients.

Several of the service providers suggested that the choice of where women with long-term mental health problems could live within the residential services was primarily dictated by availability of places rather than personal preference. Consequently there were examples of women being placed inappropriately with little consideration of their individual needs. This is illustrated by the following quote,

> *"I think the trouble is that the places are so full that as soon as a vacancy comes up they (the women) are put into that place whatever. One old lady was put into a bungalow with three men. She was a really genteel lady and these men, a couple of them, were quite horrendous really. We couldn't believe it could we? It was awful we thought. Her needs weren't looked at".*

The lack of choice experienced by the women as to where they live automatically results in a lack of choice as to whom they live with. The women consequently find themselves sleeping next door to and sharing facilities with relative strangers. One of the service providers was very concerned about this lack of choice and quite clearly empathized with the women's experiences,

> *"You are asking women to do something (share a house with strangers) that you would never consider doing yourself. Its not just that they're men but they're strangers. Would you move into a house with three strangers ? And they are expected to live a normal life".*

Finally the service providers noted that few of the residential facilities had been designed to accommodate friends who wanted to live together or clients with a partner,

> *"Women who have a friend or partner don't have the choice to live with them. There isn't the facilities for them because all the rooms are single. There is no thought that some women might like to share and live together".*

Individual rights

Underpinning the empathy shown by the service providers towards women with long-term mental health problems was a recognition that the women had a number of individual rights which should be met within the existing services. These included the right to be safe, and for privacy, choice, support, independence and care services. See Table 31 for a summary of the individual rights identified by the service providers.

Table 31: The individual rights of women with long-term mental health problems

Safety: practical help to ensure safety within and outside the services.

Attention to physical health: such as breast screening, cervical smears, help through the menopause, education and support in managing menstruation and sex education and contraceptive advice; using mainstream health facilities. Ideally the clients should have a choice over the gender of the health care worker as many of the women find discussing personal issues with men embarrassing.

Companionship: They need someone to talk to that they can trust as they are often lonely and isolated

Privacy when living communally with men: suggestions included separate washing, bathing and toilet facilities, and ideally access to a quiet room in which to entertain visitors.

A choice as regards the sex of their key worker: particularly if they had experienced difficult relationships with men in the past.

Support with daily living: practical help and support with childcare, housework, managing leisure time, gaining independence, and exploring an appropriate role.

To be listened to and have their problems taken seriously: particularly by their key workers, psychiatrists and general practitioners.

8.3.2 Service providers as professionals

The second theme identified in the interviews was the role played by service providers as paid mental health professionals working with women with long-term mental health problems. There was considerable evidence to suggest that the service providers felt a duty to protect the women from their perceived vulnerabilities. This duty to protect was reflected in examples of service providers appearing to know what was best for the women and of taking control and making decisions for them. These issues were most clearly highlighted in discussions around the sexuality of women with long-term mental health problems.

Duty to protect

The vulnerability of women with long-term mental health problems as perceived by the service providers has already been identified in the previous section. There was further evidence however, which suggested that at times the service providers felt that women with long-term mental health problems were unable to make rational decisions for themselves or to judge whether their behaviour was appropriate. Consequently judgements were sometimes made concerning the behaviour of women with long-term mental health problems, particularly if this behaviour did not conform to 'normal' socially acceptable standards. The following two examples illustrate this point with reference to the women's sexual behaviour,

> *"Sex for example, is literally on the minute, there's no safe sex and they (the women) are fairly promiscuous because it (sex) is the only form of warmth and affection they can get".*

> *"A lot of the women dress very loudly I suppose, some of them wear very short skirts, possibly with wellington boots mind you. They dress very flamboyantly and tend to have a series of very casual relationships".*

The inability of the women to make realistic decisions for themselves was particularly emphasized with reference to pregnancy and child rearing. One service provider expressed the view that some women with long-term mental health problems feel that somehow having a baby will make them whole and well. The service provider felt very strongly that perpetuating this myth was wrong particularly when she felt that the chances of such women successfully looking after a child was limited,

> *"How on earth can you expect a woman to take on the responsibility of a baby when she can't even look after herself".*

The women's desires to become mothers, live independently, access services alone and not always accompanied by a staff member, or have sexual relationships were often discouraged by the service providers who felt a duty to protect them; primarily because of their perceived vulnerability and inability to cope with new and stressful situations but also because of the potential risk of exacerbating illness. This role of protector came across strongly in the interviews as illustrated in the following example.

> *"You need to protect the women from the possibility of sexual exploitation. They have a right to companionship, sexuality and living ordinary lives but they should be protected".*

Knowing best

The role of protector was further illustrated in the decisions which the service providers made concerning the care given to pregnant women with long-term mental health problems. Such decisions highlighted the women's lack of power to make choices as the service providers took control, made decisions for the women, and finally justified their actions with reference to professional knowledge and experience. Underpinning all these actions was a sense that the service providers felt that they knew what was best for the women,

> *"We try and take over the management of the pregnancy because their ante-natal care is quite complex. If necessary we admit them during pregnancy to make them safe incubators because there can be problems with peripatetic life-styles and sleeping rough.....and when these women are pregnant they deserve a bit of molly-coddling".*

Ultimately the service providers have the power to influence the decisions made by the women as regards proceeding with or terminating a pregnancy. They are also involved in the decisions concerning whether or not a child remains with its mother. Many of the service providers expressed the view that judgements are made very early on in pregnancy about how a mother with long-term mental health problems will cope with being a mother. These judgements were not only based on an assessment of the women's ability to mother, their emotional stability, their existing coping strategies and support networks, but were influenced by an overriding observation that the chances of a severely disabled, single, unsupported mother being able to care for a child was low. Finally the service providers' duty to protect was again demonstrated, this time not in favour of the women but in giving priority to the child. Several of the service providers felt for example, that the child's needs had to be the priority and not the mothers,

> *"...if someone with a long-term mental health problems chooses to become pregnant then they deserve every bit of support that is reasonably possible, but the child's needs have to be the priority not the mother's"*

Role conflict

Throughout the interviews the service providers appeared to experience a conflict between respecting the individual rights of women with long-term mental health problems and protecting them from their perceived vulnerabilities. This conflict emerged from the frustration and lack of power expressed by the service providers in attempting to provide a service to meet the women's needs, their sense of hopelessness in trying to improve the women's quality of life, and the coping strategies they adopted to manage the conflicts and tensions experienced in their work.

Frustration and lack of power

The frustration and lack of power experienced by the service providers in attempting to provide a service to meet the needs of women with long-term mental health problems was evident in the large number of problems with the existing services that they identified. These problems are identified in Table 32.

Table 32: Problems with existing services provided for women with long-term mental health problems

Women's needs not given a high priority, the range of services provided tend to be male dominated: *"The women have been a very low profile group for a very long time and patient care is very male dominated...they don't have the same level of provision as the men. A service which is dominated by one sex tends not to meet the needs of the other very well".*
No female consultants or senior medical staff within the Rehabilitation and Community Care Service.
Inadequate and/or restricted access to counselling services for the women to discuss issues around sexual abuse, domestic violence, grief and loss: *"There is one clinical nurse specialist but she has a full case load and so she can't always take the women on"*
Inadequate and/or inconsistent advice on contraception, safe sex, pre-natal and ante-natal health, the effects of psychotropic medication on the foetus, and childcare:
No provision for women to live in a supported environment with their children: *"There are no places where young women can go with their children, sadly, other than the refuges"*
Lack of facilities and opportunities for younger women within the Rehabilitation and Community Care Service: *"There doesn't seem to be anything on offer for younger clients, we've got women's groups running but they don't seem to attract the younger women".*
General Practitioners are frequently unsympathetic and attribute physical health problems to underlying mental health problems: *"I have a female client who is going to see her GP for physical problems. He's not really interested....puts it down to mental health"*
Few opportunities for women to spend time alone together in the residential and day care services: *"The services don't offer the emotional-type of support where women can just get together, share common feelings and just talk to other women".*
Limited clinical supervision for service providers working with women who have been the victims of sexual abuse or domestic violence: *" We need supervision ourselves to deal with sensitive issues and apart from A (female team leader) we have three male team leaders...there are certain things I don't feel able to discuss with my male team leader".*
Few facilities to meet the special needs of women from ethnic minority groups.
Low expectations for women: *"There are low expectations for women, there are higher expectations for young men who could have achieved something in their lives but didn't because of their illness".*

Several of the service providers felt that many of the problems with the services stemmed from the fact that women with long-term mental health problems were seen as a low priority group when compared with male clients, clients from ethnic minority groups or clients who also misused alcohol or drugs. One of the service providers felt strongly that one of the fundamental problems is that few of the services had actually been set up with the women's specific needs in mind. She continued by suggesting that a lot of the services had been designed around completely different needs or not even needs at all.

This situation appeared to create a great deal of frustration and the service providers felt powerless to improve the services in any meaningful way. Although they did give examples of innovative practice it did appear that they were having to work on small projects rather than tackle the issues head on. For example several of the service providers felt that women's issues were not generally taken seriously by the senior service managers, who appeared more concerned with efficiency and cost-effectiveness. The following comment encapsulates these views,

> *"The really frustrating thing is that I actually feel quite powerless to change anything"*

These feelings of frustration and lack of power were further complicated in some situations because of the staff's fear of repercussion. They expressed concern for example, that it would be seen as their fault should a women get pregnant and that they should have done something to prevent it,

> *"Staff always worry that it will be seen as their fault if a client gets pregnant, that in some way they should have stopped this women having sex and that they will get into trouble for it"*.

A sense of hopelessness

The service providers appeared to feel a sense of hopelessness in trying to improve the quality of life of women with long-term mental health problems whilst simultaneously trying to protect and keep them safe. This sense of hopelessness was fuelled by frustrating encounters with other service providers, the seeming inability of some women with long-term mental health problems to take on any responsibility for their own lives, and the well intentioned interventions made by service providers which resulted in the women with long-term mental health problems feeling worse about themselves.

Several of the service providers felt that often other staff within the RCCS did not take the problems experienced by women with long-term mental health problems seriously. This included the lack of attention paid to issues around contraception and safe sex, the needs of particular groups of women such as those from ethnic minorities, and the problems associated with communal living. This issue was most clearly demonstrated in the examples of the lack concern shown by some staff about the management of harassment and sexual exploitation within the residential and day care units. One service provider clearly demonstrates this sense of hopelessness in the following example,

> *"I can think of several incidents where some of the older women have complained to their workers about being harassed by male clients in the units. When you actually bring this up with the staff concerned it has been rather pooh-poohed, as though 'well she makes her own choices and if she wants to do that then that's OK'. If you try and say, 'well she doesn't want to do that, she's complaining but she feels pressurized to do that', it's not dealt with. There have been a couple of occasions when I have really tried to deal with it but they (the staff) have been quite aggressive and have done nothing".*

There was also a feeling of hopelessness around the inability or reluctance of women with long-term mental health problems to accept the help they were offered or to ask for what they wanted. For example, several of the service providers commented that the women very much accept things as they are, accept things being done to them, do not question things, and do not put forward suggestions of their own. Consequently the service providers found organizing and running specific services such as women's groups rather disheartening as the women needed a lot of encouragement to attend, only attended sporadically and were very reluctant to take on any responsibility for organizing events. Even when the women felt able to ask for help they would at times reject any help offered. The following comment made by one of the service providers who was working with a young woman with long-term mental health problems illustrates this point,

> *"She (the woman) would come up and say 'I want to talk to you, I need some help', but when you made an appointment she wouldn't keep it, totally unable to ever engage with me"*

Finally there were some interesting examples of the service providers intervening to protect women with long-term mental health problems. Some of these actions resulted in the women possibly feeling worse about themselves which in turn increased the service providers' sense of hopelessness in trying to change anything. For example,

> *"In one of the residential units there was a young woman who would go with anyone (have sexual intercourse) for two cigarettes. We did try and work with her about trying to value herself and seeing herself as important and that she was actually worth a bit more than two cigarettes. But she ended up in this catch-22 of*

> *'I shouldn't be doing it, I'm worth more than that but actually I want some affection and some closeness and some physical contact as well'. This was her only way of getting it, so it's really hard to try and deal with that and to help her in any way at all. We ended up making her feel worse because at least before she just did it without thinking that she was worth more and it didn't worry her".*

Coping strategies

The findings presented so far illustrate that the service providers were able to describe the impoverished lives of women with long-term mental health problems and appeared to express genuine concern for their well-being and acknowledged their difficulties and needs. This concern or empathy however, created certain conflicts with the role service providers were expected to play in protecting the women and ensuring their safety. In order to manage this conflict and the resulting feelings of frustration, lack of power and hopelessness, the service providers appeared to adopt a number of coping strategies. These coping strategies included justifying their actions, setting low horizons for the women, criticizing other staff, and coping alone.

There were numerous examples of the service providers attempting to justify their actions. These examples primarily focused around the decisions made by service providers concerning the care of pregnant women with long-term mental health problems. Decisions made about the type of ante-natal care a woman received, whether or not a pregnancy should be terminated, and the recommendations for whether a woman was capable of bringing up a child alone were not seen as *"really interfering"*. Conversely such decisions were justified with reference to professional experience, research knowledge, and of being in the best interests of the woman. One of the service providers also suggested that decisions made on behalf of the women often reflect what women with long-term mental health problems themselves actually want,

> *"They (the women) want to be good mothers and if they can't, if they know they are not capable, they know it....in the main our chronic schizophrenic mothers are very child orientated and want to do their best for the baby and some of them actually prefer the baby to be fostered for that reason".*

The service providers also appeared to set low horizons for the women and there was an assumption that they have few hopes or expectations for the future, and absolutely nothing to look forward to,

> *"The only choice they have is to have relationships with other clients because there is no chance of them (the women) having a relationship with anyone else".*

Many of the service providers appeared to cope with their difficult situation by criticizing the work of other staff. Staff were criticized for providing inadequate advice about contraception, for failing to detect pregnancies, for not considering the needs of mothers and their children, and for their lack of concern about the women's safety. One of the service providers in particular, was very critical of the inconsistencies shown by staff when working with women with long-term mental health problems. In the following example she questions the rationale given by care managers for not wanting to give sexually active women Depo-Provera injections,

> *"The care managers would not have any compunction about putting Depixol into someone's bottom when they don't particularly see the point of it, but oh no to give Depo-Provera on that basis is totally unwarranted. I can't get my head around that....its quite acceptable to do all kinds of other things to people against their will, but not that (give Depo-Provera)".*

Finally 'coping alone' was a strategy adopted by several of the service providers. They gave examples of deciding to cope alone when doctors did not take the problems experienced by women with long-term mental health problems seriously, in circumstances when the necessary support and help requested was unforthcoming, or when there were no other facilities available. In some instances however, this coping alone could also be interpreted as a mechanism that the service providers employed to feel needed by the clients and also as a means of professional control and dominance. For example,

> *"I tend to try and cope on my own because I know that the doctors won't listen to what they've got to say so I don't even bother taking the women to see them (the doctors). I know that I'm receptive to listening to what my clients say and will be there for them whenever".*

8.4 Discussion

The results of this study highlight the very real difficulties experienced by service providers working with women with long-term mental health problems. Throughout the interviews the service providers demonstrated an understanding of the women's problems and needs. There were many examples of the service providers trying to imagine what the women's lives must be like and what they must be feeling. The service providers however, also recognized that as a group, women with long-term mental health problems are frequently vulnerable and require protection not only from the public, other clients and male staff but also at times from themselves. The practice of respecting the women's rights whilst simultaneously protecting them inevitably created a degree of role conflict and tension amongst the service providers. In order to illuminate these findings the following issues will be explored. First, the concept of empathy will be considered. Second, the conflicts and tensions experienced by the service providers in their work with women with long-term mental health problems will be discussed with reference to the wider social context in which such work occurs. The final part of the discussion will reflect upon the methodological issues which arose during this study. These include the role of the researcher and the trustworthiness of the qualitative approach used.

At one level the ability of the service providers to empathize with women with long-term mental health problems was evident from the findings of this study. Such a finding was not completely unexpected. For example, a recent qualitative study by Repper et al (1994) suggested that a trusting relationship between care managers and their clients with long-term mental health problems was based on empathic understanding as well as having realistic expectations about progress, adopting a long-term rather than a short-term perspective, and being flexible. Repper et al (1994) suggest that such empathy develops through working with clients over time and provides a means by which care managers can better understand the clients' wishes and needs. The importance of service providers being able to empathize with clients is also highlighted in much of the literature on client-centred counselling. Burnard (1988) for example, suggests that the ability to empathize with clients alongside being trustworthy, respectful, non-judgmental and genuine is the hallmark of an effective, meaningful therapeutic relationship. This point is illustrated by Rogers (1967, p57) when he remarks that "I am often impressed with the fact that even a minimum amount of empathic understanding is helpful, although there is no doubt that it is most helpful when I can see and formulate clearly the meanings in the client's experience".

At another level the concept of empathy is very difficult to define and it is often used synonymously with sympathy, altruism and compassion. Nadelson (1993), in a very thoughtful critique of the relationship between ethics, empathy and gender in health care, questions whether individual service providers can truly empathize with people who have different values, experiences, beliefs and ideals. She continues by arguing that service providers must appreciate their individual capacities for empathy by developing an understanding of their personal limitations and bias. A similar view is put forward by Perkins and Repper (1996) when they suggest that unless a service provider has actually had long-term mental health problems it is not possible to know what life with these difficulties is like. The lives and experiences of people with long-term mental health problems are often profoundly different from those working with them. For example, mental health service providers have rarely experienced the serious cognitive and emotional difficulties of the people they work with; have not experienced the bereavements and losses that these often entail; and have not experienced the social disadvantages, discrimination and stigma of being a 'mental patient'. Perkins and Repper (1996) therefore argue that an ability to truly empathize with a person with long-term mental health problems is questionable. Instead they suggest that at best service providers should work towards trying to understand and accept clients' accounts of their lives, accept that emotional responses to situations are real for clients and not necessarily a manifestation of illness, and sympathize with feelings of loss and loneliness.

It is possible that in an effort to understand the experiences of women with long-term mental health problems, the service providers in this study failed to recognize that which it is not possible to understand. This is not a criticism of their practice but merely an acknowledgement of the huge gulf between women with long-term mental health problems and service providers who have jobs, status, homes, friends, family and a social life of which their clients can only dream. The inevitable inability of service providers to bridge this gulf and truly empathize with women with long-term mental health problems might explain some of the frustrations they encountered in their work. For example, the service providers were frequently frustrated and found it difficult to understand women who had problems in asking for what they wanted and needed, speaking up for themselves, or refusing the help and support offered. .

Such feelings of frustration were compounded not only by the felt lack of empathy shown towards women with long-term mental health problems by other staff within the mental health services, but also by the responsibilities bestowed upon service providers as professionals. Throughout mental health services there is an assumption that it is the duty of service providers to provide vulnerable individuals with the help and support that they need. A service provider's duty of care rests upon an understanding of a client's needs. Needs however are difficult to define and what a service provider identifies as a need may not necessarily reflect what the clients consider to be their needs. Because of this frequent lack of agreement about what is defined as a need, choices have to be made about whose definition to adopt. Perkins and Fisher (1996) found that the needs identified in care plans were those identified by the service providers rather than needs identified by the client. Consequently some of the needs being addressed would not be considered needs by the individual concerned.

This situation therefore may account for some of the conflict experienced by service providers in their work. If the service providers make decisions about what a person needs then they are assuming that they know better than the client, that they have a right to make decisions for people because they are not capable of making decisions for themselves. This duty of care was illustrated in this study quite clearly in the examples of service providers attempting to control the fertility of women with long-term mental health problems, managing their pregnancies, and making judgements about their parenting capabilities. This duty of looking after and protecting those who cannot look after themselves however invariably infringes upon the rights of women with long-term mental health problems to make decisions for themselves and make choices about their lives.

In an exploration of these issues Perkins and Repper (1996) argue that although any society imposes limits on the behaviour of its citizens, people with long-term mental health problems are doubly disadvantaged as they are not only limited by the laws that apply to everyone else but also by additional laws enshrined in mental health legislation. They further argue that whilst there may be some justification for this unequal position, it does mean that people with long-term mental health problems do not have the rights of other citizens. Consequently service providers working with the most honourable and caring motives find a conflict between care and protection and respecting the individual rights of clients with long-term mental health problems. For female service providers working with women with long-term mental health problems this situation may be further accentuated by the paternalism of the health care system and the invisibility of women both in decisions about their own care, and in positions where decisions about the delivery of health care are made (Nadelson 1993).

The conflicts experienced by the service providers in this study are not easy to resolve. On the one hand they are attempting to meet the individual needs of women with long-term mental health problems and to respect their individual rights whilst not truly understanding and empathizing with their experiences and lives. On the other hand the service providers are working within a society which expects mental health professionals to care for and protect vulnerable individuals, and to control their behaviour both within the health care environment and in the wider community.

Many of the issues raised in this discussion have been further explored by Barham (1997) in his analysis of the historical changes of care delivery for clients with long-term mental health problems both in hospital and more recently in the community. He suggests that the current preoccupation with cure, improving clients' quality of life and ensuring access into mainstream community activities can foster unrealistic hopes amongst service providers, clients and the wider society that the segregation of the 'mad' will become a thing of the past. Furthermore he argues that the 'mad' will remain a feature of contemporary society, that they are still a very vulnerable group, and their lives will probably remain ordinary, humdrum and unexceptional. This realism is grounded in the view that people with long-term mental health problems are unlikely to lead exciting and dynamic lives in the foreseeable future and will possibly need continuous protection and support from mental health service providers. His argument provides a base from which service providers can begin to accept that feelings of tension and conflict are the inevitable consequences of trying to meet unrealistic expectations and of carrying out their professional and social obligations. Rather than attempting to resolve this conflict it may be more appropriate for service providers to accept it and acknowledge that their work with women with long-term mental health problems necessarily involves an element of control and protection, public education, and a respect of individual rights and choice. Such an approach would also acknowledge the difficulties of truly empathizing with such women. Instead professional relationships with the women should be based on realism and acceptance with an emphasis on working towards the long-term rather than the short-term good.

The final part of this discussion will focus on the methodological issues which arose whilst conducting this study. These are the provisions that were made to ensure the trustworthiness of the study and the role of the researcher.

The importance of establishing the trustworthiness of qualitative research has been much emphasized in the literature. This issue is particularly important in the health field, with its strong tradition of biomedical research using quantitative methods, where qualitative research is often criticized for lacking scientific rigour (Mays and Pope 1995). It has been argued that the trustworthiness and rigour of any study using qualitative methods is enhanced by a purposive process of clearly explaining and describing each stage of the research activity (Fitzpatrick and Boulton 1994, Andrews et al 1996). To help the researcher in this task a number of checklists have been published (c.f. Maykut and Morehouse 1994, Mays and Pope 1995, Morse and Field 1996, Ziebland and Wright 1997). These checklists cover broadly similar issues and suggest that the researcher reflects back upon the whole research activity to ensure that sufficient transparency has been achieved so that informed judgements can be made about the plausibility and credibility of the findings.

Using these checklists as a guide the following provisions were made in this study to enhance the trustworthiness of the findings. First, particular care was taken in writing up the methods section of this study to ensure that each stage of the research process was documented in detail. For example, the sampling strategy was clearly described and justified and a diverse range of service providers were included in the sample; the development of the semi-structured interview schedule was described in detail; and the procedures for conducting the fieldwork were outlined. Particular emphasis was placed on clearly justifying the procedures adopted for analyzing the data and each stage of the analysis was documented. The initial categorization of the data was checked by another researcher. The identification of the themes in the data however, involved a degree of creativity and imagination. It was at this stage in the analysis that steps were taken to ensure that the interpretations fairly and accurately reflected the experiences of the service providers, and did not simply verify the preconceptions of the researcher.

The accuracy of the interpretations were checked in the first instance by a process called respondent validation (c.f. Lincoln and Guba 1985, Mays and Pope 1995, Ziebland and Wright 1997). This is a process of asking the initial respondents or a similar group of service providers whether the interpretations make sense within their context of practice, whether the interpretations accurately describe their experience and whether a recognizable reality has been produced. This was achieved by presenting the findings to a group of about twenty service providers, some of whom had been interviewed for this study, at a research forum held in the RCCS. The presentation generated a great deal of discussion and the overwhelming view expressed was that the interpretation accurately described their experiences of working with women with long-term mental health problems. One of the service providers in particular agreed wholeheartedly with the interpretation and described their position as a *"no-win"* and a *"catch -22 situation"*.

The interpretations were further checked by a process of theoretical verification (c.f. Morse and

Field 1996, Ziebland and Wright 1997). This was achieved in the discussion by drawing comparisons between the findings of this study and the work of researchers working in similar fields. This process allows the researcher to clarify where the work lies in relation to the existing body of knowledge on the subject and is a further means of demonstrating the validity and trustworthiness of the findings.

The importance of reflecting on the researcher's role in a qualitative study is frequently emphasized (c.f. Maykut and Morehouse 1994, Schutz 1994, Britten 1995, Ely et al 1997). This emphasis reflects the view in qualitative research that the researcher's role is a paradoxical one. For example, the researcher needs to be tuned into the experiences and meanings of the respondents whilst at the same time being aware of personal bias and preconceptions which may influence every stage of the research process. Whilst it is impossible to identify all bias, Ely et al (1997) suggest that it is important to acknowledge relevant past experiences which may colour what is seen, and to consider which biases hindered or helped in the research.

The researcher has had considerable experience of working clinically with clients with long-term mental health problems and has an understanding of the difficulties inherent in such a role. More recently this understanding has been enhanced through supervising the clinical practice of student mental health nurses who are trying to gain an understanding of the lives of people with mental health problems whilst exploring the obligations and boundaries of their professional role. The interpersonal skills acquired over this period were invaluable both in establishing rapport and gaining the trust of the service providers, and in conducting the individual and group interviews. For example, the researcher was very aware of what constituted good interview technique and care was taken not to ask leading questions, to actively listen rather than talk, to pick up verbal and non verbal cues, to avoid jumping from topic to topic, and to give the service providers enough time to explain and explore the issues raised. In addition the researcher was familiar with the language and terminology used by the service providers. These past experiences possibly provided an entry into the world of the service providers which might otherwise have been denied.

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Conversely these past experiences may have sensitized the researcher to the conflicts experienced by the service providers in their work with women with long-term mental health problems. As Schutz (1994) points out, each researcher sees research findings through their own personal theoretical 'lens' and that reporting and interpreting findings may be the result of a self reflective personal journey or as an empathic experience. Throughout each stage of this study, efforts were made to set aside preconceived ideas and to guard against the inclusion of personal experiences. It is however, impossible to judge how much the researcher's acknowledged bias influenced both the interpretation and reporting of these findings.

8.5 Conclusion

The aim of this study was to gain an understanding of the problems experienced by service providers in planning and delivering a service to women with long-term mental health problems. Qualitative data were collected by conducting five semi-structured interviews with individual service providers and one group interview with eight service providers.

Two overriding themes emerged from the analysis of the data, namely service providers as empathic women, and service providers as professionals. These two themes served as a framework within which the findings were presented.

As empathic women, the service providers highlighted many problems experienced by women with long-term mental health problems such as their vulnerability to abuse and exploitation, their lack of a meaningful role in life, and the growing number of unplanned or unwanted pregnancies. More importantly, the service providers were able to imagine some of the feelings experienced by women with long-term mental health problems in the course of their daily lives such as loss and grief, loneliness and lack of power. Underpinning the empathy shown by the service providers was a recognition that women with long-term mental health problems have individual rights which should be met within the existing services.

As professionals, the service providers felt a duty to protect women with long-term mental health problems from their perceived vulnerabilities. This duty to protect was reflected in examples of service providers appearing to know what was best for the women and of taking control and making decisions for them. The service providers however, appeared to experience a conflict between respecting the rights of women with long-term mental health problems and protecting them.

The discussion focused on illuminating the findings by drawing on the work of researchers in related fields. First, the concept of empathy was explored and the ability of service providers to truly empathize with women with long-term mental health problems was questioned. Second, explanations for the role conflict experienced by the service providers were considered. Finally the provisions made to ensure the transparency and trustworthiness of this study were highlighted together with a reflection on the role played by the researcher.

Chapter Nine

The Perspective of Women with Long-Term Mental Health Problems

9.1 Introduction

The final study in this evaluation explores issues from the perspective of women with long-term mental health problems currently receiving care and support within the Rehabilitation and Community Care Service (RCCS). With the exception of studies by Estroff (1985), McCourt Perring (1993), Barham and Hayward (1995), Perkins (1996) and Ritsher et al (1997), there is a dearth of literature which has explored the experiences, views and opinions of such women using methods other than a standardized structured questionnaire or interview schedule. This study builds on these studies and the approach taken was also influenced by the work of Rogers et al (1993). For example, the approach started from the premise that the views expressed by the women with long-term mental health problems in this study were valid in their own right. There was no assumption made that the views expressed were a definitive version of reality, rather the views expressed were the women's version of reality. Such views may therefore be very different from those expressed by the service providers in chapters six and eight.

Methodologically, a study which seeks to give women with long-term mental health problems a voice, presents the researcher with a number of challenges. From a practical point of view, many of these women, because of the nature of their social disabilities, may have a poor concentration span, may be experiencing hallucinations, they may be poorly motivated or have a low self confidence and self esteem; all factors which might make eliciting their views difficult. There is also a widely held belief that people with long-term mental health problems are incapable of providing a rational and valid opinion about the services they are receiving (Rogers et al 1993). This study therefore seeks not only to give women with long-term mental health problems a voice, but also critically evaluates the methods used so that recommendations can be made for further research in this area.

The study has four aims: to gain an understanding of the impact of long-term mental health problems on the lives of women; to explore the wishes and aspirations of these women; to discuss their views of the services they currently receive; and to generate suggestions of ways in which services might better meet their needs.

9.2 Method

The views, opinions and experiences of women with long-term mental health problems were explored by conducting five focus groups within the RCCS. As in the previous study presented in chapter eight, a non emergent research design was employed so that all the qualitative data were collected prior to analysis. The decision to employ a non emergent design for this study was made for two reasons. First, efforts were made to include women with long-term mental health problems of different ages and who were in contact with the range of services provided within the RCCS. This was to ensure that a range of views would be represented. Second, the intention was to facilitate the focus groups in such a way that the women would feel able to introduce topics and issues of particular concern to them.

9.2.1 Focus groups

Krueger (1994, p6) defines a focus group as a "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive and non threatening environment". The group is focused in the sense that it involves some kind of collective activity such as exploring a particular set of questions. The group is led by a facilitator who keeps the participants focused on the topic being explored. Focus groups are distinguished from group interviews by the explicit use of the group interaction as research data (Morgan 1988, Kitzinger 1994, 1995).

The historical development and use of focus groups has been described in key texts (c.f. Morgan 1988, 1993, Krueger 1994). These texts suggest that there is nothing new about the focus group method as it was first mentioned as a market research technique in the 1920's and in social sciences research from the 1950's. It remains a popular method in both market research and in the social sciences. More recently focus groups have been increasingly advocated as a useful method to obtain the views of clients, carers and service providers about health and health care (NHS Management Executive 1992, Fitzpatrick and Boulton 1994, Murray et al 1994). For example, focus groups are a popular method for assessing health education messages (c.f. Nyamathi and Schuler 1990, Weiss et al 1993, Anderson 1994). They are widely used to examine clients and carers experience of illness and health services (c.f. Duncan and Morgan 1994, Coyne and Calarco 1995, Glass 1995, Pulice et al 1995). Focus groups have also been used to assess how health care teams perceive the needs of clients (c.f. Rantz and McShane 1994, Thornton 1996), and in evaluating the education of health care staff (c.f. Lankshear 1993, Macintosh 1993).

The focus group method was selected for this study for the following reasons. First, focus groups do not discriminate against people who cannot read or write (Gray-Vickrey 1993, Kitzinger 1995). This reliance on verbal rather than written communication is very important for clients with long-term mental health problems as there is some evidence which suggests that up to 30% of such clients receiving care within the long-term mental health services have problems with reading and/or writing (Nottingham Needs Assessment Planning Project Survey 1990). Second, focus groups can encourage participation from people who are reluctant to be interviewed on their own or who feel that they have nothing to say (Kitzinger 1995). Again this may be advantageous for women with long-term mental health problems whose views are seldom sought and whose self confidence and self esteem is often reported to be low. A focus group can often provide a safe environment for clients to share their thoughts and feelings without fear of criticism (Gray-Vickrey 1993).

Third, the facilitator is less in control of a focus group than is the interviewer in a one to one interview, so it is a method which maximizes the expression of perspectives not imposed by the researcher (Morgan 1988, Fitzpatrick and Boulton 1994, Krueger 1994). For example, the participants' interaction among themselves replaces their interaction with the facilitator, leading to a greater emphasis on the clients' point of view. This potential shift in the balance of power between the researcher and the women with long-term mental health problems was considered crucial in this study as a means of exploring and understanding issues from the women's perspective. Fourth, Morgan and Krueger (1993) suggest that focus groups are a method that is respectful and non condescending. For example, by creating and sustaining an atmosphere that promotes meaningful interaction, focus groups convey a human sensitivity, a willingness to listen, and a respect for opposing views. Fifth, the friendliness of focus groups can also be a major advantage, and researchers familiar with the method note that participants typically enjoy their discussions together (Morgan and Krueger 1993, Krueger 1994). Finally, as Kitzinger (1994) argues, women, unlike most men, have a well established tradition of sharing personal information with other women and it is no coincidence that many self help and therapeutic techniques for women are based on group work.

Whilst there is no right way to plan and conduct focus groups (Morgan and Krueger 1993), the literature does suggest a number of key principles which should be considered. These principles underpin the selection of the sample, the number of participants in each focus group, the number of focus groups conducted, the methods of recording and analyzing the data, the role of the facilitator, and the procedures involved in running the groups. These principles will be considered in sections 9.2.2 to 9.2.5 together with the rationale for modifying the method for use with women with long-term mental health problems.

9.2.2 Sample

Selecting women with long-term mental health problems to take part in the study was a complex undertaking; primarily because of the difficulties in accessing such women, and ensuring that the women selected would be willing and able to participate. These problems were discussed with a range of service providers within the RCCS who suggested that it would be easier to access existing groups of women within the service rather than attempting to set up groups solely for the purpose of this study. The service providers felt for example, that the women were unlikely to attend a specifically organized group in a neutral setting because of problems with transport and general worries about what might be expected of them. To illustrate the difficulties of getting women with long-term mental health problems together, many of the service providers gave examples of women's groups and women-only events and outings that had been disbanded through lack of interest and poor attendance.

Whilst many texts advocate the use of random sampling for focus groups, it is acknowledged that such an approach can often be problematic particularly with groups of people known to be difficult to access. In addition Morgan (1988) argues that the small number of participants ultimately selected are unlikely to be truly representative of a large population. Many studies using focus groups have therefore selected participants according the particular needs of the study. For example, Weiss et al (1993) used a convenience sample of men and women attending a methadone clinic, Coyne and Calarco (1995) used men and women who were currently in treatment for depression and on antidepressant medication who volunteered to participate, and Kitzinger (1994) used pre-existing groups of people who knew each other through work or socializing to explore the effect of media messages about AIDS.

For this study it was therefore decided to organize the focus groups with the pre-existing groups of women within the RCCS. These pre-existing groups included the numerous organized women's groups that were run within the service, and the informal groups of women who spent time together in the day centres and the residential units. This decision however, did limit the women who took part in the study to those who participated in organized activities within the RCCS, and effectively excluded those who were reluctant to engage in the services. Nevertheless it did represent the best means of accessing groups of women with long-term mental health problems.

It is acknowledged therefore, that this approach to selecting a sample of women was not perfect. Nevertheless an attempt was made to select groups of women who represented the wide age range of women receiving care within the RCCS, the varying lengths of time in contact with the mental health services, and finally women who were living independently and those who were currently in-patients or living in supported accommodation in the community. A list of pre-existing groups was compiled from the information obtained in the survey of services for women with long-term mental health problems within the RCCS (see Section 6.2), and from discussions with a number of service providers. Some of the identified groups had distinct aims and a set programme of activities. Others were informal groups of women which had developed through a mutual desire for support and companionship or through physical proximity on the in-patient units. A short profile was written on each of the groups which highlighted the nature and purpose of the group, frequency of meetings if applicable, and the characteristics of the women who participated. From these profiles five groups were selected for inclusion in the study. These groups were selected as they represented, as near as possible, the diversity of women with long-term mental health problems receiving care within the RCCS.

A brief description of each of the pre-existing groups selected has been included in this section to illustrate the varying backgrounds of the women who took part in the study.

Pre-existing group 1:

A women's group at one of the RCCS day centres. The overall aims of the group were to encourage women with long-term mental health problems to discuss issues that affect them, to provide an opportunity to talk about specific female worries, and to learn about health and social issues concerning women. The objectives were to develop the women's communication skills, to increase their awareness of women's issues, to receive and give support by talking and listening, and to increase self esteem, personal identity and a sense of being valued. The aims and objectives were formulated by the women who originally attended the group and the two facilitators. The group met once a week for two hours at the day centre. It was a closed group of eight women who attended the day centre regularly. All of the women had been in contact with the mental health services for at least ten years. Two of the day centre staff facilitated the group and attended regularly to encourage a group cohesiveness and identity. The group was viewed positively by both the women and the facilitators.

Pre-existing group 2:

A women's group run by women care managers. The aims of the group were enjoyment, socializing, support and friendship. An emphasis was placed on using facilities other than those provided by the mental health services. The women, together with the care managers, organized a programme of activities which included shopping trips, visits to the cinema, meals out, bowling, and outings to places of interest. The group met once a week in a local community centre or elsewhere if a specific activity had been organized. It was an open group with a membership of about fifteen women. There was however a core group of women who attended regularly and others whose attendance was more sporadic. The women were encouraged to attend and the care managers often provided transport for those who found using public transport difficult or frightening. Their ages ranged from 25 years to women in their late 50's, they lived in a variety of supported and independent accommodation, and they had very different experiences of the mental health services.

Pre-existing group 3:

A women's group at one of the RCCS day centres. The group did not have any specific aims but the emphasis was very much on diversional activities rather than sitting and discussing particular issues. A monthly programme of activities was drawn up by the facilitator with the women. Past activities included bingo, cinema trips, baking, watching a video, beetle drives and making Christmas cards. The group met once a week at the day centre unless outside activities were planned. It was an open group of about six women who attended regularly. All the women who attended lived independently in the community and came to the day centre regularly. The women's ages ranged from 30 to 60 years.

Pre-existing group 4:

A women's group run by the RCCS community occupational therapists. The aims of the group were to increase social interaction, to widen the women's interests, to enable friends to keep in contact with one another, and to have fun. A three monthly programme was planned in collaboration with the women and past activities included talks on healthy eating, making collages, painting, and beauty sessions. The group met once a week at a community centre. It was primarily aimed at those women who had been in contact with the mental health services for many years and who now received limited input. Many of the women knew each other from prolonged periods of hospitalization in the past. All of the women who attended lived in supported accommodation in the community. Many were quite elderly and transport was provided to and from the group by staff.

Pre-existing group 5:

An informal group of women who were in-patients on one of the RCCS residential units. These women were under 40 years of age and had limited past contact with the mental health services. The emphasis in the unit was on individual work with clients and there were few organized activities. The women rarely knew one another prior to admission.

There were two main reasons for conducting five focus groups. First, gaining access to the pre-existing groups of women with long-term mental health problems was immensely time consuming. This process of gaining access is explored further in Section 9.2.4, however the time constraints of the evaluation as a whole mitigated against running more that this number. Second, the literature suggests that research that aims at exploring personal perspectives will probably take only a few groups, particularly if there is some structure imposed by the facilitator (Morgan 1988). More specifically Kitzinger (1994) argues that many focus group studies rely on no more that four to five groups, and that this may be a perfectly adequate number when working with particular groups of people.

It is usually recommended that the participants of focus groups should be reasonably homogeneous. This is because too much heterogeneity can result in the participants feeling inhibited from revealing personal experiences (Fitzpatrick and Boulton 1994, Krueger 1994). In this study all the women who took part had long-term mental health problems, all were receiving care within the RCCS, and they were either in-patients or attending some form of organized activity within the service.

It is often recommended that ideally focus groups should be composed of individuals who are strangers to each other to avoid biases and to avoid the formation of sub-groups conducting conversations between themselves (Ziebland and Wright 1997). However, as Morgan and Krueger (1993) point out, the rigid application of this rule would make it very difficult to conduct focus groups in a number of situations. In this study, many of the women knew each other, some very well, particularly if they had been in contact with the mental health services for many years. It would therefore be very difficult to organize a group of women who did not know one another. Due to the nature of their disabilities however, it was decided that it would be advantageous to run these groups with women who were familiar with one another as they would possibly feel more comfortable talking to people they knew as many find social interaction with new people difficult. This decision was strengthened by the comments made by Kitzinger (1994) who conducted a series of focus groups using existing friendship groups. She found that participants who knew each other well could relate each others comments to actual incidents in their daily lives. Whilst the women knowing one another may have certain advantages, it was acknowledged that shared past experiences and events could become more of a focus than the new issues raised in the groups, and that there was a possibility that familiarity might inhibit disclosure.

Finally, the decision as to how many women to include in each of the focus groups was considered. Again many of the texts recommend that focus groups should consist of between four and ten participants (Morgan 1988, 1993, Krueger 1994). Such texts suggest that when a group exceeds twelve participants there is a tendency for the group to fragment. Conversely whilst smaller groups afford more opportunities to share ideas and can encourage a greater individual contribution, they can result in a smaller pool of total ideas. In order to maximize the opportunities for running the focus groups in this study it was decided that a minimum of two and a maximum of eight women in each group would increase the likelihood of five focus groups being run. It was hoped that more than two participants would take part in any one group but that a planned group would go ahead even if the numbers of women who attended were low.

In the study fourteen women with long-term mental health problems participated in five focus groups. Four women participated in the first group, two women in the second, three women in the third and fourth groups, and two women in the fifth. Although the number of women who participated in each of the groups was relatively low, this was unavoidable due to the factors which are discussed in Section 9.2.4. The characteristics of the women who participated in the focus groups are summarized in Table 33.

Table 33: Characteristics of the women who participated in the focus groups (N=14)

characteristics		number
Age range:	20-29 years 30-39 years 40-49 years 50-59 years 60 + years	1 3 1 6 3
Marital status:	single divorced married	9 3 2
Women with children		4
Women in contact with children		1
Living arrangements:	independent inpatient group home private registered home professionally supported housing	4 3 1 5 1
Attending day centre at least once a week		9
Allocated care manager		14
Unemployed		14
Time in contact with mental health services		range: 10-40 years

9.2.3 Data collection tools

9.2.3.1 Discussion guidelines

In order to guide and give some structure to the focus groups, a set of discussion guidelines were developed using a framework suggested by Knodel (1993). The discussion guidelines were developed by first identifying the broad areas that needed to be covered in the focus groups. Once identified these broad areas were converted into open-ended questions and listed in logical order. The questions were designed to explore three areas of particular interest. First, to explore how the lives of the women had been affected by their long-term mental health problems. Second, to find out what the women currently wanted out of life and whether or not they were getting the help they needed. Finally, to elicit what they thought about the current services they were receiving, and whether there was any other help or services they would like.

The guidelines were kept deliberately simple and brief for two reasons. First, such a format would enable the researcher to introduce additional comments and questions if required. Second, it would encourage the women to discuss the questions posed in some detail and would enable them to introduce their own particular issues. A number of key prompts were also included in the guidelines to encourage discussion around known areas of difficulties for women with long-term mental health problems such as personal relationships, motherhood, physical and sexual harassment, physical problems, and medication. These prompts were simply noted in the guidelines without formulating a separate question so that the researcher could introduce them in a more natural manner. A copy of the discussion guidelines can be see in appendix Q.

9.2.3.2 Fieldwork diary

Comprehensive fieldnotes were made throughout the duration of the study and recorded in a diary. This included information on how access was gained to the pre-existing groups of women with long-term mental health problems, how each of the focus groups was planned and organized, the characteristics of the women who participated, seating arrangements, attempts made to put the women at their ease, gaining consent, and the length of each group. The diary also included the researcher's reflections on the content of the discussions, the group dynamics, personal feelings about facilitating the groups, and any problems encountered.

9.2.4 Procedure

The five focus groups were organized and conducted over a period of nine months from October 1995 to June 1996. Access to each of the pre-existing groups of women was gained initially by approaching the service providers who either organized the groups or who managed the day centres or in-patient services. This initial contact was followed by a more formal meeting in which the aims of the focus groups were discussed and the approach explained. All the service providers approached were enthusiastic about the study and were willing to discuss it with the women. The researcher attended at least one meeting of each of the organized women's groups prior to conducting the focus groups to meet the women and explain the purpose of the study. A visit was also made to the women who were in-patients on the residential unit. This personal contact was very useful as not only was verbal consent from the women obtained, but it was an invaluable opportunity to meet the women, answer any questions and allay their anxieties.

For practical reasons it was decided not to run the focus groups on neutral ground but to organize them in the venues where the women normally met for their meetings or on the in-patient unit. It was assumed that the women would probably feel more at ease in familiar surroundings, and would be more likely to attend. Despite this preparation three of the focus groups were cancelled due to poor weather or poor attendance and had to be rearranged. One of the focus groups was rearranged four times. In each of the focus groups less women eventually attended than was planned. This was possibly due to their anxieties about participating although such feelings were not expressed at earlier meetings.

The running of each of the focus groups followed a similar pattern. The researcher arrived early to ensure that the identified room was adequately prepared. The chairs were arranged in a circle around a table on which refreshments were provided. As the women arrived they were offered refreshments as a means of encouraging conversation and dispelling anxieties. In four of the focus groups one of the service providers who knew the women requested to attend and remained throughout. The service providers did not contribute verbally in the focus groups. Before starting the focus groups the researcher explained the purpose of the study again and gained the women's verbal consent to tape record the discussion. In all the focus groups the women consented for the tape recorder to be used. Each focus group was structured using the discussion guidelines described in Section 9.2.3.1. The groups ranged in length from 35 to 60 minutes. At the end of each group there was a short period of time allocated for further refreshments and social conversation which was not tape recorded.

As soon as possible after each focus group a summary of key issues raised and personal impressions and reflections were recorded in the fieldwork diary. The tape recordings of the focus groups were then transcribed and typed. These were sent to all the women and the service providers for comments. None of the women or service providers wished to change the transcriptions in any way.

The role of the researcher as facilitator of these focus groups raised many personal and methodological issues. These will be considered in the discussion.

9.2.5 Analysis

The approach taken to analyzing the qualitative data in this study was the same as that used in chapter eight with some modifications to take into account the interactive nature of some of the data. The aim was not only to describe and interpret the women's accounts, but also to reconstruct the data into a recognizable reality. The constant comparative method described by Maykut and Morehouse (1994) was used to analyze the data.

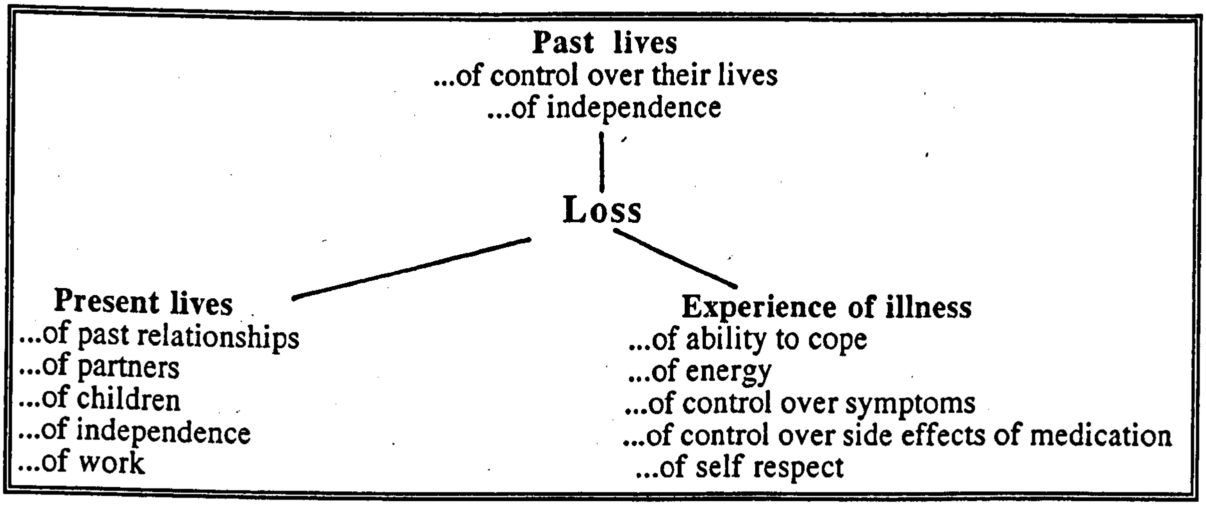
First, each of the transcribed tapes were checked for accuracy and corrected. The corrected manuscripts were then photocopied and the subsequent analysis was done using the photocopied transcripts. The transcripts were then read through carefully and each contribution was coded so that individual women could be identified. This was an important means of not only identifying the context in which comments were made in the later stages of the analysis, but also as a means of identifying whether the contributions made by the younger women for example, were different to those made by the older women.

Second, the transcripts were read again in order to identify units of meaning in the data. Units of meaning consisted of contributions made by individual women and short interactions between two or more women. The criteria for identifying a unit of meaning was that it had to be clear and understandable without additional information. All of the data were categorized into units of meaning in this way and each unit of meaning was separated from the others by drawing lines across the page of text. Each unit of meaning was summarized by a word or phrase which was printed on the text. Finally the individual units of meaning were cut apart from the rest of the text.

Third, as the analysis progressed and as the researcher's familiarity with the data increased, it became apparent that it was inappropriate to develop a coding framework which reflected the main issues raised in the focus groups prior to the identification of themes which extended throughout the data. This was because the data suggested three strong themes into which all of the data could be categorized. The separate units of meaning were then sorted into one of the three broad themes. The constant comparative method was used to identify categories and sub-categories within the three themes. The validity of the categorization and the themes identified were checked by two researchers who had read the transcribed focus groups.

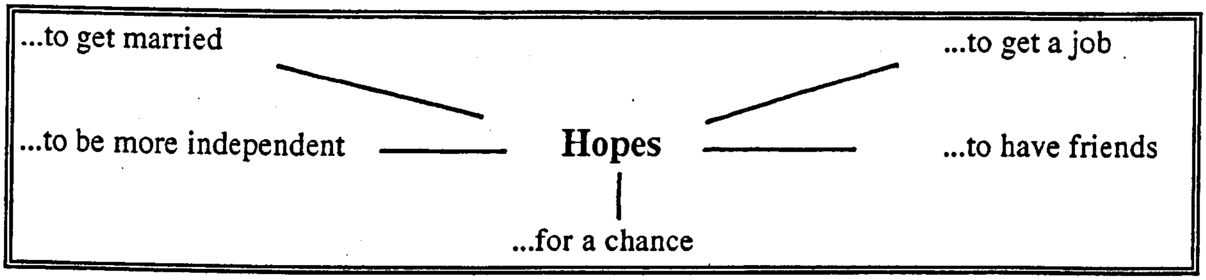
The first theme identified was the sense of losses which the women had suffered, in many cases throughout their lives, but particularly since the onset of their mental health problems. The women conveyed a picture of their lives over which they had very limited control. Even before the onset of their mental health problems, they had frequently experienced little independence and many hardships. As a result of the disabilities associated with their mental health problems they had lost most of the material comforts and emotional supports that many people take for granted, and there was little in their lives over which they had a sense of control or choice. The resulting coding framework within this theme can be seen in Figure 2.

Figure 2: Loss in the lives of women with long-term mental health problems



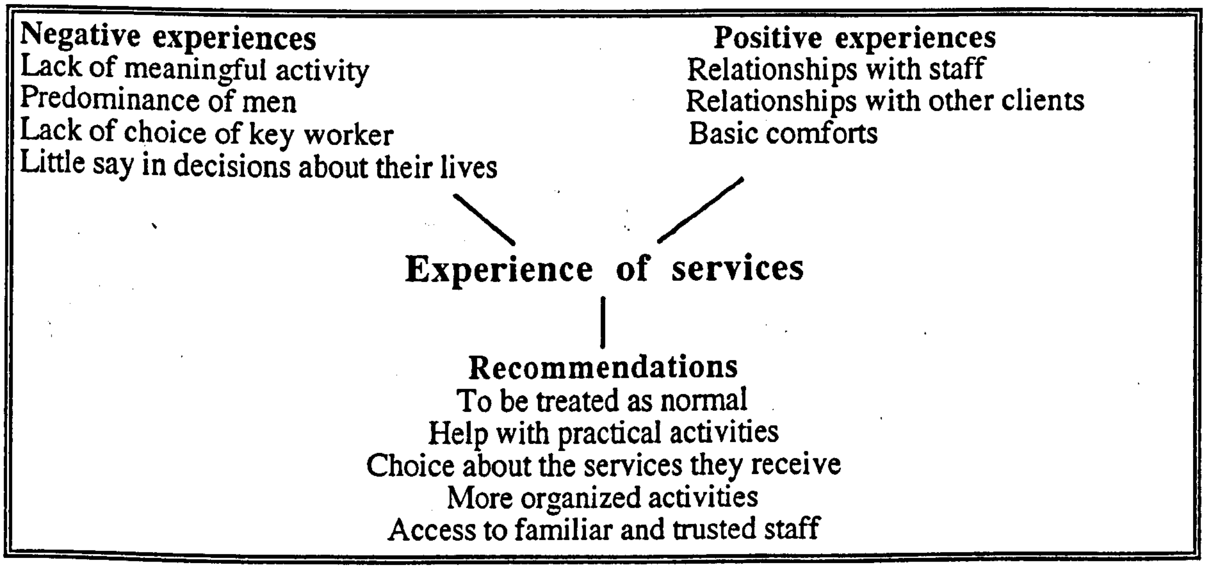
The second theme identified was hope. In spite of the losses suffered by these women, they conveyed a sense of resignation to their situation and many continued to have hopes for the future. These were not unrealistic dreams but very ordinary aspirations such as getting married, having friends, a job, a home and something to do with their time. The coding framework within this theme can be seen in Figure 3:

Figure 3: The hopes of women with long-term mental health problems



Third, the women were able to identify those aspects of the services which they valued and ways in which mental health services might help them achieve their wishes. The women were also able to identify aspects of the service which limited their opportunities. Many of the women had very low expectations of the service and the suggestions for change and improvement often reflected the standards which most services were working towards. The coding framework within this theme can be seen in Figure 4.

Figure 4: The women's view of service provision



9.3 Results

The three themes introduced in the previous section will serve as a framework to present the findings. The illustrative quotes from the focus groups which are used throughout are not attributed to individual women to ensure their anonymity.

9.3.1 Loss

The sense of loss experienced by women with long-term mental health problems was very apparent in all five focus groups. This sense of loss was conveyed in the women's descriptions of their lives before they developed their mental health problems, in their present lives, and in their explorations of what it was like to have long-term mental health problems.

Past lives

All of the women had experienced their first episode of mental illness in their twenties or early thirties. Prior to the onset of their illness most of the women appear to have led relatively ordinary lives. Five of the women had been married and four had children. Most of the women had worked, often in a series of unskilled jobs rather than developing a career. Even before their first contact with mental health services however, several of the women described chaotic events which marked a loss of control over their lives and a loss of independence. Two of the single women for example, described the pressure placed upon them by their families to care for ageing relatives. A further two women described chaotic upbringings and disruptive childhoods which were characterized by a lack of stability and continuity. One women openly talked about being sexually abused by her father. This disruption in the past lives of some of these women is illustrated in the following quote,

> *"My step mother used to shove me about, so I went to live in London with my aunt, then she died and they brought me back home again to my dad"*.

Present lives

The women talked about their present lives with frequent reference to the ways in which having mental health problems had affected their lives and the many losses that had ensued. The experience of developing mental health problems appears to have been a milestone for many of the women and it was often used as a marker to distinguish between their past 'normal' selves and their current experiences. The loss of their past selves was compounded when people behaved differently towards them because of their mental health problems. For example, two of the younger women explored this issue in one of the focus groups,

> *"People treat you differently, like they're treading on shells, and they think that if they say the wrong thing you're going to flare up...so people are careful about what they say and do."*

> *"Yes, my family and friends act differently towards me too. They are afraid to say the wrong things, afraid that you're going to jump down their throats...quite different to how they treated me before".*

Five of the women were currently or had been married, three were divorced at the time of the study. A further two of the women had long-term relationships but did not live with their partners. All of the women who had been married had experienced their first episode of illness after their marriage. Although one of the women described a warm and supportive relationship with her husband, the experiences of the divorced women in particular were very different. They each described lonely and unsupportive marriages, having very little money, and having to raise children alone with very little help from their husbands. Despite these hardships the women described the experience of marriage breakdown and managing alone as painful and difficult. One of the women vividly described the impact of this loss,

> *"He left when the children were all at school, he's married now to someone else. As time went on I felt happier in myself, not worrying about whether he was going to come home or not...it hurts to remember".*

Although four of the women had children, only one saw her children regularly. The six children of one of the women had moved away from the area, did not keep contact with her and she only had a vague idea of where they lived. The single child of another woman lived locally but did not want to have anything to do with his mother. Both these women expressed a strong desire to see their children again. As one of the women said, *"...the only thing I would like is to see my children again"*. The sadness, loss and resignation expressed by the women who had lost contact with their children is perhaps best illustrated by the woman whose child was taken away from her in infancy,

> *"I got married when I was twenty two and had a daughter. But I couldn't look after her because I became ill. The foster lady used to bring her to see me every so often when she had the time".*
>
> How old was she when you last saw her ? (researcher)
>
> *"Eleven, and then they stopped coming and I lost contact with her".*
>
> How old would she be now ? (researcher)
>
> *"About thirty three".*

Throughout the discussions many of the women drew comparisons between their current and past lives. Despite the hardships which many of the women had experienced in the past they spoke nostalgically and at length about their old homes, their jobs, their independence, privacy and freedom of choice over how to spend their time. One of the women for example, described in detail the decor of the flat she had lived in when she was first married, whilst another talked about her job in a launderette in which she took great pride. The loss of such independence and choice was keenly felt and was often associated with a loss of self-worth, a sense of being needed, enjoyment, personal satisfaction and financial security. One of the women who now lives in a private registered home said,

> *"I used to have a flat on my own, I live in a house now with four men. It was lovely (the flat), you could do what you liked. You could go out when you liked...I didn't get lonely...I enjoyed it better...I'm happiest when I'm on my own".*

Experience of illness

Finally the women spoke about the impact of their mental health problems on their daily lives. Again this often amounted to a loss of control over their situation. Many of the women for example, explained the onset and subsequent experience of mental illness as an inability to cope. This included not coping with work, with looking after their children, and domestic responsibilities such as housework, shopping and cooking. As one woman said,

> *"Everything seemed to go wrong, nothing seemed to go right. I had quite a lot of breakdowns. I did a lot of drinking and just really couldn't cope. I couldn't cope with anything".*

Several of the women also commented on their loss of energy. This loss of energy affected their ability to carry out daily activities and effectively prevented them from doing some of the things that they would like to do. It is noteworthy that a few of the women appeared listless and tired during the focus groups, and one actually said that she was going to have a sleep in the day centre after the group was finished. This loss of energy is illustrated in the following two comments,

> *"I was living on the third floor and by the time I got to the top with my shopping I just used to sit on the settee and go to sleep...and that was the afternoon gone".*

> *"I was so tired, I ended up spending most of the time in bed".*

Some of the women talked about the acute phases of their illness and their subsequent admission to psychiatric hospital. These episodes were characterized by a fear of the unknown, and *"being frightened"* was a phrase that was used on several occasions to explain their reactions to both the symptoms of their illness and of being admitted to hospital. This loss of control over symptoms was graphically described by one woman,

> *"I started hallucinating and I worried about it. I thought my husband was trapped in a black bag. I saw it in my hallucinations...it frightened me to death".*

The younger women also expressed frustration over their loss of control over the side effects of their medication, which were perceived as unpleasant and anti-social. The women for example, experienced tremors, blurred vision, dribbling, restlessness, and a desire to pace about. These younger women described how they would try and hide the most obvious side effects when they were in the company of others such as consciously striving to keep their limbs still and eating sweets to counteract dry mouths.

Finally some of the women expressed a loss of self-respect and self-worth as a consequence of having mental health problems. For example they felt personally responsible and blamed themselves for becoming ill and subsequently not being able to manage and cope with life better. Two of the comments made by the women illustrate this point,

> *"I should be able to help myself more and not feel sorry for myself"*

> *"I blame myself for being ill. I think it's my fault for getting ill"*

9.3.2 Hope

Whilst loss was a pervading theme throughout all the focus groups, there was also a large measure of hope. Most of the women continued to aspire to a more ordinary future that included relationships, work, friends, and doing the things that people without mental health problems do. The younger women in particular, retained high hopes of having jobs in the future, getting married, becoming independent, and of just being normal. As one women said *"I just want to be normal again, you know, the way I was before I was ill"*. These quite ordinary aspirations were seen as a means of improving their self confidence, providing opportunities to meet people and make friends, and becoming financially independent. The following quotes illustrate the aspirations of the younger women who took part in the focus groups,

> *"I would like to live on my own again"*.

> *"Just to meet someone nice and get married...well it seems like everyone does it, gets married and has kids don't they ?"*.

> *"Just to get a job, have a good job and lots of friends...earning your own money, being your own person"*

The women however, did acknowledge that some of their hopes would not be realized without help and their ability to cope with stressful situations made certain hopes unrealistic. One woman for example, who was very keen to get a job, was planning to work as a part-time voluntary worker for a while to see if she could cope with the demands of such work. Two of the women also suggested that it was easier and less stressful to have relationships with other mental health service users as they could more easily understand the women's experiences. For example,

> *"I'm going out with a man who's got a mental illness as well.....it works quite well, he understands me and I understand him, so it works both ways".*

Finally several of the younger women expressed their hopes and aspirations for the future in terms of dreams. There were examples of dreams coming true, and of women hanging on to dreams as a means of coping with the reality of their lives. The following quotes illustrate the importance of having a dream to these women,

> *"One of my dreams might be coming true, I've been offered a flat so if I like it I'm going to take it. It's a big step for me as it is the first time I've lived on my own. I think if I'm given the chance I'll make a go of it".*

> *"I had dreams of getting on, but I ignore them now, they were rubbish...you have to have a dream sometimes though".*

The older women in the focus groups had less clear aspirations and hopes for the future. Whilst the majority of older women appeared fairly positive about their future, there were inevitable regrets concerning their multiple losses and a certain resignation as regards the quality of their current lives. Several of the women felt that they had missed out on normal life and on reflection wished their lives had been different. As one of the older women said,

> *"Well I'd like it changed, that's all (her life)...they're all doing well (her children) apart from me".*

9.3.3 Views about services

Negative experiences

The negative issues raised about the mental health services centred around the lack of personal choice that the women experienced. Many of the women recognized that there were fewer women than men in the RCCS. Although they mentioned the specific provision made for women in the service such as the women's groups and the women-only rooms in the day centres, the overwhelming view was that the service focused more on the needs of the men. As one of the women who attended the day centre regularly said,

> *"I've noticed that there are a lot more men than women. I think they ought to have more for the women, there's too much for the men I think...there is more for the men I've noticed than the women".*

Feeling lonely and isolated in a service dominated by male clients was also an issue, as was the fact that the women were frequently not actively involved in any activities but tended to sit around doing very little. These comments were generally made by the women who had fairly regular contact with the service as in-patients or through attending the day centres. This is illustrated by a comment made by a woman concerning her recent in-patient stay on one of the short-term residential units,

> *"You spend a lot of time sitting around doing nothing and thinking... just sitting around smoking, drinking tea, chatting and watching television".*

Although an effort is made within the RCCS to ensure that the women have the choice of a female key worker, there are times when this is difficult to achieve particularly in the in-patient areas. Some of the women experienced difficulties in relating to male members of staff, particularly those women who have had traumatic relationships with men in the past. One of the younger women said,

> *"I've had a lot of bad experiences in the past. I can't talk to a man, you think they are the same as the man you had the bad experiences with. I've lost my confidence, you have to build that up again".*

A number of the women lived communally in registered homes or as in-patients, and the lack of choice and control as regards where they lived, who they lived with, and how they lived was marked. Two of the older women had been moved around the residential services a great deal but were unable to provide an explanation for this beyond the fact that they had been given little choice. The difficulties of communal living included loneliness, lack of peace and privacy, a lack of control over their living environment, and the expectation that they would do the domestic tasks. Two of the women who were living in the same registered home described some of the problems they experienced,

> *"Sometimes I wish I hadn't come to the RW (registered home). I don't know why, it just seems a bit of a mess in there. I don't like the dining room as there are things cluttered around and they (the other residents) leave pots on the table".*

> *"Also some of the residents need to pull their weight a bit, if you let them they'll end up getting you to do all the work, like cleaning. Sometimes the men are lazy and leave all the work to us".*

Finally two of the younger women felt that at times they had little control or say in decisions which affected their lives. One of the women for example, complained about the side effects of her medication and felt she should have been given more information by the staff about the reasons for taking it, how long she was going to have to take it for, and how the medication was going to affect her. She maintained that the staff seldom provided such information unless she specifically asked. The second woman didn't know the reasons for the staff preventing her return to work,

> *"I'd love to go back to work, but they won't let me go back. I ask them why (the medical staff) and they don't tell you really. They just start talking in this hospital language, all these big words I don't understand".*

Positive experiences

The women's positive experiences of the mental health services revolved around good relationships with staff and other clients, companionship, and basic comforts. The women generally had very positive feelings towards the staff, particularly those who were perceived as caring, helpful and committed. Most of the women had been given a choice about having a female key worker. The women were particularly positive about staff who were encouraging, good listeners, and who were available when needed. As one of the women who lived independently said,

> *"She's (key worker) there if I need her at the end of the telephone. If I want to talk she's always there. She helps me with everything in any way she can".*

The company of other service users and the opportunity to talk and socialize was important to the women. The women related to each other well in the focus groups and there was considerable warmth and support in addition to much laughter, and shared sadness. The women frequently referred to other service users in their discussions and appeared to value their support and company. The women who were currently in-patients valued the support and company of other users who shared their accommodation. They also found that living with men can often be a positive experience. These comments about communal living contradict those of the women living in the registered homes but may be due to the temporary status of in-patient care versus the more permanent arrangements in the registered homes. The importance of companionship was described by two of the younger women on the in-patient unit,

> *"We have a group on a Saturday where we all get together in one of the houses and have a natter, a cup of tea, a fag and whatever. On Sundays we have a communal meal and everyone joins in".*

> *"I'd rather share a house with men than all women. I'm quite happy about it, there is a nice atmosphere and I have a good laugh here...I don't really have any problems with men, no problems at all. No hassle".*

Finally some of the women, particularly the older women living in registered homes, valued *"being looked after"* by the staff. They appreciated the staff *"doing little things"* with them such as going shopping together or helping them with the domestic chores. They also enjoyed the secondary benefits of physical warmth, nice meals, and a cheerful homely atmosphere. As one of the older women explained,

> *"I like it there (registered home) because its nice and warm. I'm getting well looked after. We've got a new cook and she's very good, and they (the staff) do the cleaning...it's just nice".*

Recommendations

Many of the women found it difficult to make concrete suggestions for how the services could be improved or changed to better meet their needs. A number of women however did make the following suggestions which again reflect their very ordinary aspirations and demands.

First, there was an emphasis on wanting to be treated as normal by people within and outside the mental health services, *"...that's all we want, to be treated as normal"*. This links with the desire to get more involved in ordinary everyday activities that most people take for granted, such as going shopping or going to college. As one of the women who attended the day centre said, *"I'd just like someone to take three or four of us shopping, now and again"*.

Second, the women would appreciate a choice concerning the services they receive. It should not be assumed however, that all the women want women key workers or to live in single sex accommodation. Some of the women preferred living in mixed accommodation and would choose this option over living in a women-only house, and felt comfortable talking to both male and female staff.

Third, some suggestions were made concerning the types of activities they would like to participate in. Examples included woodwork, crafts, embroidery and patchwork. The women viewed these activities as creative, relaxing and productive in that *"you've got something at the end of it as well"*. One of the younger women was also keen to get involved in a sport such as football. Finally, a good support network and staff backup was seen as essential for women making the transition from hospital to independent living. The two women on the in-patient unit for example, were very keen to establish their support mechanisms prior to discharge and placed an emphasis on developing good relationships with the staff responsible for them,

> *"Just knowing that someone is there if you need them...you know, to fall back on".*

> *"I'd like it to be people I know (staff), I don't want complete strangers coming in. I want to get to know the staff before I move out so I can feel confident letting them into my flat".*

9.4 Discussion

This study makes two unique contributions to the overall evaluation. First, the findings provide an insight into the experience of living with long-term mental health problems from the women's perspective which has been little explored in the research literature to date. Second, the practical, methodological and ethical difficulties which arose from this work with such a vulnerable and disabled group of women raised a number of issues which have again been little addressed in the literature. The discussion has been divided into two parts, namely, a consideration of the key findings followed by an exploration of the practical, methodological and ethical issues.

9.4.1 Key findings

The experiences which the women with long-term mental health problems describe are characterized by material, social and personal loss, and disadvantage. Many of the women described impoverished lives which predated their mental health problems. Whilst poverty, disruptive childhoods and working in menial jobs might be shared by their male counterparts, other issues were more specifically associated with their role as women. For example, raising children alone on a low income, sexual abuse, and looking after ageing parents. After developing their mental health problems, the women's lives were marked by events and relationships which appear to have systematically reduced their independence, choices, dignity, self respect and ultimately their power. What emerges from the findings as a whole is the profound sense of loss which the women have to cope with alongside the struggle of managing their daily lives. Once again, there were the losses of job, home and relationships that these women undoubtedly shared with men in similar situations, but there were others, especially loss of children, that the women felt particularly acutely.

Smith (1987) suggests that the experience of loss is an integral part of the human condition and that for many women loss can be viewed as a recurrent theme throughout their lives. Such inevitable losses for women include the loss of childhood as the passage from girl to woman is rarely celebrated in our society; the losses associated with motherhood such as miscarriage, inability to conceive and children leaving home; the loss of functioning associated with the menopause; and the loss of sexual attractiveness associated with ageing in a society which frequently views older men as greying and distinguished and older women as simply old. Women with long-term mental health problems however experience such inevitable losses within the context of mourning for the loss of any kind of normal life. The extraordinary experiences associated with their mental health problems means that not only do they experience the normal losses associated with being a woman but suffer additional losses as a consequence of their illness.

One theoretical framework which analyses the disadvantages and losses experienced by people with long-term mental health problems is that of social disablement described by Wing and Morris

(1981). Social disability is seen as a direct consequence of primary impairments which arise from the illness itself, and pre existing and/or subsequent social disadvantages such as the lack of occupational or social skills, the absence of social supports, the lack of enabling services, and stigmatizing social attributes. Wing (1993) argues that primary impairments and social disadvantage in turn have an adverse affect on clients' self confidence and self esteem, their coping strategies, and their ability to function and manage their daily lives.

Several researchers working within the framework of social disability have begun to explore the impact and meaning of loss for people with long-term mental health problems particularly in relation to the high incidence of depression amongst those with schizophrenia. Birchwood and Shepherd (1992) for example, suggest that such depression may be a psychological response to a chronic and apparently uncontrollable illness. Alternatively Appelo et al (1994) argue that the loss of hope and self esteem which many people with long-term mental health problems experience can be understood as a grief reaction to the very many losses they have suffered. It is being increasingly advocated therefore that supportive psychotherapy has a significant role to play in the care of people with long-term mental health problems. Such supportive psychotherapy should place an emphasis on helping clients adjust to the losses that have occurred in their lives, to work towards an acceptance and resolution of these losses, and as a means of helping clients cope with the human issues of having a long-term illness and dealing with everyday life difficulties (c.f. Appelo et al 1994, Carson and Holloway 1996). Finally Birchwood and Shepherd (1992) argue that mental health staff should foster a blame-free acceptance of the illness and work with clients to develop a sense of mastery over it. This issue is particularly relevant for the women in this study who felt personally responsible for becoming ill and that in some ways they could have done something to prevent it.

Although the women clearly blame themselves for their predicaments, their diminished lives cannot be attributed solely to limitations in their own power, resources and coping strategies. The sense of personal failure felt by the women can only be exacerbated by explanations and interventions which purely concentrate on individual dysfunction and responsibilities. There are other, much wider, social and structural factors which impact on their lives. Lamb (1982) for example, argues that whilst community care provides an opportunity for clients with long-term mental health problems to live relatively normal lives, it also effectively exposes such clients to the same stresses and concerns as everyone else in addition to those associated with their illness. In the past hospitalization meant that such clients were given asylum from the demands of the world and they were not forced into an existence in which they constantly compare their situation with others living seemingly more normal lives. This situation is exacerbated as people with mental health problems are often not considered to belong to the community as of right, but only if their behaviour is acceptable and does not contravene the boundaries of normality (Perkins 1991). There is now considerable evidence that the societal images and stigma of mental illness works against people with long-term mental health problems and effectively interferes with their attempts to create a more positive self image (Strauss 1989, Taylor and Perkins 1991, Bhugra and Buchanan 1993). Notions of violence, the need for segregation, and clients being a danger to children for example, all help convey a negative view of mental illness which hinders self acceptance.

Despite the very many losses experienced by the women, a sense of hope ran through all of the focus groups. The younger women in particular retained aspirations for the future which included employment, relationships, independence and financial security. Underpinning all these aspirations was a desire to be, and to be treated by others as normal. In a qualitative study of the experiences of young men with schizophrenia leaving psychiatric hospital, Lorencz (1991) describes a similar phenomenon. The men in her study had similar aspirations to the women and overwhelmingly wanted to be, in their words, ordinary. When discussing this phenomenon

Lorencz (1991) suggests that the aspirations to become ordinary is in some senses paradoxical as adults are not generally viewed as striving for ordinariness. Rather adults more often strive towards outstanding life careers. When viewed from the clients frame of reference however, the aspirations of ordinariness loses some of its paradoxical impact. For example, the young women in this study had led such extraordinary lives that to be normal or ordinary meant becoming relatively invisible, productive community members, rather than visible, unproductive and stigmatized members.

The gradual loss of hope and aspirations for the future as clients with long-term mental health problems got older was evident in this study and has been reported in the literature. Barry et al (1993) for example, suggest that coping with a major mental illness over an extended period, together with the process of adapting to a dependent lifestyle may lower levels of expectations and aspirations to the extent that the gap between what a client has and expects may be very narrow. Such a limited existence amongst older people with long-term mental health problems may also be the result of their weighing up the costs of striving for independence and achievement against giving in to dependency, which poses less risk of failure and stress (Lamb 1982).

Finally, the women in this study were able to identify negative and positive aspects of the services they were receiving together with some recommendations for changes or developments. The key issues which emerged included the lack of choice and control the women had concerning decisions in their lives, the importance of good relationships with staff, and the desire to be more involved in ordinary, everyday activities. These ideas are not new however, and suggestions for how staff can address these issues and develop better working relationships with clients have been the focus of several texts and papers (c.f. Perkins and Dilks 1992, Perkins and Repper 1996). What is interesting about these findings is that the women's opinions of the services very much focused on what they were currently receiving and few attempts were made to suggest radical departures from that which was already being provided or being worked towards by service providers. This is not surprising in the light of the observations made by several researchers that people with long-term mental health problems, as a result of their restricted life experiences, low aspirations and depressed expectations, tend to report satisfaction with life conditions and services that fall below generally accepted norms (Lamb 1982, Barry et al 1993, Barry and Zissi 1997).

The focus groups however, did highlight two key areas which are only beginning to be addressed within the long-term mental health services. The issue of loss for example, pervades the lives of women with long-term mental health problems. There is considerable scope therefore for services to consider the most appropriate means of enabling the women to come to terms with such loss, and of ways of minimizing the losses they experience in the future. It is important however to acknowledge that these women have to contend with their social disabilities on a daily basis and are unlikely to ever feel completely 'normal' because of their past experiences or to truly come to terms with the loss of their 'normal' past selves. The second important issue to emerge is what can be done during the lifespan of these women to ensure that they retain some continued hopes and aspirations. This is a complex issue as staff need to avoid fostering hopes and aspirations that might be unrealistic whilst working with the women towards achieving some of the realistic ones. It will be interesting to observe whether the next few decades of community care will result in people with long-term mental health problems who have continued hopes for the future, however modest, and whose horizons have not narrowed as a consequence of institutionalization.

9.4.2 Practical, methodological and ethical issues

The qualitative approach taken in this study was deliberately selected as the most appropriate means of exploring the views and experiences of women with long-term mental health problems. Within this approach the researcher was able to focus on the women's experiences of having long-term mental health problems, how that affected their lives, and the strategies they adopted to cope with their situation. Whilst such an approach is strongly recommended as the best way of exploring the subtleties and personal meanings of living with a long-term illness (c.f. Conrad 1990, Barham and Hayward 1991), it nevertheless raised a number of practical, methodological and ethical issues for the researcher. In addition it could be argued that some of the difficulties which arose were exacerbated by the vulnerable and disabled group of women that the researcher was working with. The four key issues which will be considered in this section include the role of the researcher as facilitator, communication and interaction in the focus groups, accepting the women's reality, and the thin divide between research and therapy. Much of the material for this section came from the comprehensive fieldnotes made by the researcher throughout the period of this study.

The role of the researcher as facilitator

The importance of the role of the researcher as facilitator cannot be over emphasized in this study as it impacted on the stance taken towards the women who participated, the process of facilitating the focus groups, and the methods used to ensure that the data were gathered ethically without exploiting the women. It is generally agreed that whilst the facilitators of focus groups do not necessarily require formal training, they do require substantial interpersonal skills such as the ability to listen and avoid becoming personally involved in the discussions (Morgan 1993, Krueger 1994, Ziebland and Wright 1997). The researcher had considerable experience of running groups prior to conducting this study. This experience included a mental health nurse training with a strong emphasis on group dynamics and interpersonal skills, and several years experience of facilitating client support and therapy groups under the direct supervision of a trained psychotherapist. Such experience was invaluable and arguably vital for running the focus groups with women with long-term mental health problems as the researcher was able to reflect on the dynamics which occurred in each of the groups, understood the importance of keeping the group members safe, and was able to maintain attention outward towards the events occurring within each of the groups rather than inward towards thinking about the next question to be asked.

The question of whether to adopt an 'insider' or an 'outsider' stance to the women in this study was a difficult one. At one level the researcher was keen to adopt a stance which empowered the women and avoided the hierarchical power relationships which frequently exist between researcher and researched. Feminist researchers for example, have rejected the inevitability of such a power hierarchy. Instead, they have argued for research in which there is reciprocity between the researcher and the researched. Such reciprocity, it has been claimed, encourages a non-exploitative relationship where the women being studied are not treated simply as a source of data. Research then becomes a means of sharing information and, rather than being seen as a source of bias, the personal involvement of the researcher is an important element in establishing trust and thus obtaining good quality data (Maynard 1995). Feminist studies which have discussed the advantages of a reciprocal relationship between the researcher and the researched include Webb's (1984) study in which she described how she shared her experiences as a gynaecology patient with hysterectomy patients, and how this seemed to have a positive effect and encourage rapport, and Oakley's (1990) paper in which she reflects on the approach she adopted when interviewing women for her research on motherhood.

This notion of reciprocity has however been questioned. Ribbens (1989), in a critique of feminist studies claiming a reciprocal relationship between the researcher and researched, argues that the relationships described cannot be seen as truly reciprocal in that much of the researchers' contributions were of a factual nature in contrast to the personal experiences which the women contributed. This leads Ribbens (1989) to conclude that a one sided relationship, even between women researchers and participants, is inevitable, primarily because the researchers are usually more highly educated and articulate, but also because they approach the potential participants and are consequently in a different and more powerful position than the women.

The gap between the life experiences, current life style and status of the researcher compared with the women participating in the focus groups cannot be denied. It would have been naive therefore, to attempt to develop a truly reciprocal relationship. Apart from being the same sex, the researcher had little in common with the women, and an exchange of life experiences may have inhibited the women and possibly made them feel inadequate. Instead the researcher adopted a friendly, warm stance towards the women whilst at the same time remaining slightly detached. In some senses the researcher behaved like an 'ideal guest' which involved being interested in and positive towards the women and willingly becoming involved in a range of activities beyond the focus groups themselves. For example, the researcher was invited to a women's day event, a social afternoon and a women's poetry reading. Although the researcher did not discuss any of her own personal experiences with the women in the focus groups, questions asked about the researcher's children, family life and home were willingly answered.

Within this warm, friendly but slightly detached stance towards the women, the researcher nevertheless made an effort to reduce the power imbalance in the focus groups. This was achieved by minimizing direct questioning so that the women could raise and discuss issues of relevance to them, and allowing them to talk in as much depth as they felt comfortable without interrupting and moving them on. Requests by individual women to leave the focus groups for short periods of time, either for a cigarette or to get more tea, were also respected.

Communication and interaction

As has been previously discussed, focus groups explicitly exploit group interaction as part of the method. This means that instead of the researcher asking each person to respond to a question in turn, people are encouraged to talk to one another, exchange anecdotes and comment on each others experiences and points of view (Morgan 1988, Krueger 1994, Kitzinger 1994, 1995). There was little evidence of this type of interaction in the five focus groups, although this did vary between the groups. The focus group of younger women living in the short term residential unit for example, contained several instances of women developing and exploring ideas raised by others, whereas the focus group of older women was far less interactive.

In all the focus groups the women mainly directed their comments to the researcher and were often reluctant to discuss issues amongst themselves. This was possibly a reflection of the women's poor communication and social skills, and their lack of experience of sharing ideas in a group. Many of the women also appeared quite reticent and their reluctance to talk may have reflected their low self confidence, low self esteem, and a general feeling that they had nothing of importance to contribute. In addition the women were used to having their lives 'managed' by care staff within the mental health services and possibly viewed the researcher as a similar person of power who had to be pleased and obeyed. Whilst the researcher became increasingly aware of these dynamics as the study progressed, it was difficult to see how they could be resolved. Instead the researcher spent considerable effort trying to put the women at their ease, and often resorted to fairly direct facilitation if it appeared that the women were finding it difficult to contribute. In most instances asking each woman in turn what they felt about particular issues proved advantageous. For example, it was a tactful means of encouraging the quieter women to contribute whilst restraining the dominant ones, and the women appeared to feel more comfortable with this approach and often talked at length in response to a direct question.

Whilst the level of verbal interaction in the focus groups was low, there was evidence of other types of interaction amongst the women. In particular there appeared to be considerable empathy between the women, non-verbal acknowledgement of shared experiences, and they were frequently very supportive towards one another. One of the focus groups in particular was very jolly and there was a lot of shared laughter. Much of this laughter was generated by one of the women imitating a male client whom they all knew. This is illustrated by the following quote taken from that focus group,

> *"I can go to sleep in the day centre if I want to, in the quiet room.....Dennis is usually there. He goes 'woo, woo'* (lots of laughter from the women)...*I feel comfortable with Dennis* (more laughter)".

In another of the focus groups there was much shared sadness as the women talked about their experiences of losing partners and children since becoming ill. This feeling of sadness pervaded the whole group as the women listened attentively to each story. Finally there was a woman in one of the focus groups who was extremely difficult to understand as her speech was very slurred. The other women in the group were very supportive and protective towards her. For example, they tried to encourage her to join in and frequently repeated what she had said. This support enabled the woman to feel part of the group and protected her from the embarrassment of having to repeat things that the researcher had not understood.

Accepting the women's reality

Underpinning this study was a desire to report the women's own version of reality and to accept their contributions as valid in their own right. Whilst the researcher accepts the notion of multiple realities, it was nevertheless difficult at times not to question whether the women were telling 'the truth' particularly when their perceptions differed so radically from those of the researcher. One of the women for example, described a past life of multiple admissions to psychiatric hospital, loss of friends, loneliness and poverty. Later on in the group she said very firmly that she was very happy with her life and her current home, enjoyed coming to the day centre, and did not want anything more or for anything to be different. As the woman said,

> *"...well I'm enjoying life as it is. I find more enjoyment now that I come to the day centre. I'm on top of the world since I've been at the day centre, and I thank God for the staff, they've been great. If it wasn't for them I wouldn't have got better....no, I wouldn't change it (my life), no I'm happy".*

Such a difference in this woman's recollections of her past experiences and her current satisfaction with life can be accounted for in a number of ways. It may be that in contrast to her past, her current life was infinitely preferable. Alternatively it may be that as a consequence of the long-term nature of her illness, her aspirations for a different life were so diminished that she was genuinely satisfied with her current situation. The companionship available within the day centre and the support provided by the staff may also have contributed to her happiness and feelings of self worth. Nevertheless this example, amongst others, prompted the researcher to question the validity of the women's contributions.

Dean and Whyte (1990) suggest that researchers should not ask themselves whether respondents are telling the truth, but instead should concentrate on identifying what the informants' contributions reveal about their feelings and perceptions and what inferences can be made from them about their life experiences. The authors also suggest that informants often express conflicting views and that such views can vary according to the situations in which they find themselves. This latter point has also been raised by Fitzpatrick and Boulton (1994) who highlight that little is currently known about how the effects of social desirability and conformity influence the expression of views in focus groups. Efforts have been made throughout this study to report the views and opinions of women with long-term mental health problems as accurately as possible using minimal interpretation. It has to be acknowledged however that the researcher's role in this study inevitably influenced both the nature of the data collected and the interpretation and presentation of the results.

Research versus therapy

This study falls very clearly into a field of research which is frequently referred to as sensitive. Research is considered to be sensitive when the people being studied are powerless or disadvantaged, where there is an opportunity for people to feel exploited or degraded, or where the subject matter relates to personal experiences (Lee 1993, Gibson 1996, Ziebland and Wright 1997). All of these issues were pertinent in this study and steps were taken throughout to ensure that the women did not feel exploited, and that they did not feel pressurized to discuss personal experiences against their will.

Groups however, are a complex phenomenon and there is a tendency for group members to reveal more in discussion with others than they would in a one-to-one situation. Whilst this phenomenon is advantageous for focus groups exploring non-personal issues, it can pose problems for researchers wanting to explore issues of a more personal nature. In this study, two focus groups in particular, raised questions about the ability of the researcher to avoid exploiting the women, and highlighted the importance of being a trained facilitator. The first example was in a group where a young woman talked about a long-term relationship with her male partner who had a depressive illness like herself. Without any prompting she described how he had committed suicide and her subsequent feelings of loss and betrayal,

> *"I was in one relationship for about sixteen years, he suffered depression like me. About three years ago he killed himself. We had this pact where if he was down he would come to me and if I was feeling down I would go to him...I felt let down because he was feeling down and didn't come to me and then killed himself".*

The second example was a focus group in which all of the women talked in some detail about the loss of their children. This group generated powerful feelings of sadness in the researcher, amongst the women with long-term mental health problems and in the occupational therapist who had requested to sit in. One of the women and the occupational therapist became quite tearful at one stage. Such self disclosure raised a number of issues. First, the need to keep the group safe became as important as gathering the data. Whilst the women were permitted to discuss their painful and emotional experiences, the researcher moved the discussion on if it was evident that the women were becoming distressed. As far as possible this was done sensitively by waiting for a suitable break in the self disclosure, openly acknowledging the woman's contribution, and posing another question to the group. Superficial issues were usually introduced at the end of each group in an attempt to lighten the atmosphere. There was a tension however between the need to finish the groups on a positive note whilst at the same time respecting the amount of self disclosure.

Second, the distinction between a focus group and a therapy group became quite blurred at times. The discussions contained a great deal of self disclosure and went far beyond an exploration of the women's experiences within the mental health services. As a researcher, the desire to collect the best quality data possible was very important and much of the richest data arose from the women revealing often very painful personal experiences. As a facilitator however, there was a need to consider the personal cost of such disclosure to the women. This placed the researcher in a considerable ethical dilemma particularly when there was little opportunity to follow the women up after the group. This situation was addressed by eliciting the support of the staff who sat in on four of the focus groups. All of these staff were willing to discuss the issues raised with individual women in the weeks following the focus groups. None of these staff identified that any of the women had appeared distressed as a result of participating in the focus groups when the researcher contacted them by telephone a few weeks later.

9.5 Conclusion

The aims of this study were to gain an understanding of the impact of long-term mental health problems on the lives of women with long-term mental health problems, to explore their wishes and aspirations, to discuss their views of the services they currently receive, and to generate suggestions of ways in which services might better meet their needs. Qualitative data were collected by conducting five focus groups with women with long-term mental health problems of varying ages and who were receiving a range of services within the RCCS.

Three themes emerged from the analysis of the data, namely loss, hope, and views about services. The sense of loss pervaded all the focus groups. Some of the losses predated the onset of the women's mental health problems, but many were the result of the long-term and disabling nature of their illnesses. These included loss of independence, homes, partners, children, and of being perceived as normal by others. Despite these overwhelming losses many of the women retained hopes and aspirations for the future. These hopes and aspirations were very ordinary and were usually for things which most mentally well people take for granted such as relationships, employment and a role in life. The women identified negative and positive aspects of the services they were receiving together with some recommendations for change. The key issues which emerged included the lack of choice and control the women had in decisions concerning their lives, the importance of good relationships with staff, and the desire to be involved in ordinary, everyday activities.

The discussion was divided into two parts. First, the key findings were explored with reference to related research. Second, the practical, methodological and ethical issues which arose from the study were considered. These issues included the role of the researcher as facilitator, communication and interaction in the focus groups, accepting the women's reality, and the thin divide between research and therapy.

Chapter Ten

Discussion

10.1 Introduction

The 1990's mark a period of unprecedented attention on people with long-term mental health problems for a number of reasons. First, the accelerating shift from institutional to community-based care has raised concerns about the ability of the newly established services to meet the needs of these vulnerable people and of preventing them losing contact with services altogether (Mental Health Foundation 1994). Second, this shift has been accompanied by a growing concern that levels of risk will inevitably increase within the public domain (Morgan 1998). These concerns have been fuelled by the actions of a small group of people with long-term mental health problems (c.f. Spokes et al 1988, Ritchie et al 1994) and the accompanying media attention which has only served to intensify public concern and fear (Sayce 1995). Third, the growing voice of service users and their families has drawn attention to the rights of people with long-term mental health problems and their potential role in planning, providing and evaluating services (Pilgrim and Rogers 1997).

The broad policy context of health care has provided a backdrop to these issues, but it has also been influenced by it (Repper and Brooker 1998b). For example, as the importance of collaboration between different agencies providing care has become apparent, so specific policies for people with long-term mental health problems have been introduced to ensure that mechanisms for monitoring and review are in place (c.f. Department of Health 1990b; 1994a,b & c; 1995a & b). Such an emphasis on people with long-term mental health problems has not occurred without reason however. Although the large scale movement away from institutional to community-based care for people with long-term mental health problems began almost fifty years ago (see chapter one), the full implications of this shift are only now becoming clear. Numerous reports (c.f.

Mental Health Foundation 1994, Audit Commission 1994) and inquiries (c.f. Spokes et al 1988, Ritchie et al 1994) have drawn attention to the broad impact of de-institutionalization, and there is a growing body of research focusing on the lives of people who had previously spent long periods of time in psychiatric hospital (see chapter three). Overall, it is evident that community living is often difficult for people who have long-term mental health problems, many of whom experience frequent re-admissions in times of crisis and survive inadequately; in poverty and isolation, without work, with poor social supports and networks, and at risk of victimization, exploitation and homelessness (Barham and Hayward 1995, Barham 1997, Repper and Brooker 1998b).

Despite the intense policy and research focus on people with long-term mental health problems, the provision of services to meet their complex needs remains problematic. The diverse needs of these people means that mental health care is only partly about statutory services. Many of the factors which contribute to an individual's well-being - good housing, a meaningful role in life, friendship, employment, and leisure activities - cannot be provided by mental health services alone. Services need to create the conditions which enable people to have access to such opportunities in the wider community. Furthermore, the long-term nature of these people's problems means that services have to be flexible enough to respond to an individual's changing needs over many years (Onyett and Smith 1998).

As was argued in chapter two, mental health policy and services have tended to regard people with long-term mental health problems as an homogenous group. There has consequently been little emphasis on the differing needs of particular groups of clients such as women or people from black and ethnic minority backgrounds, although this situation is changing. This thesis arose out of a concern that although the growing research literature on women with long-term mental health problems has highlighted their particular difficulties (see chapter two), little was known about their experiences in mental health and other services and how such services could be organized to better meet their needs (Perkins and Rowland 1991). The overall aims of this thesis were therefore as follows:

- To explore the experiences of women with long-term mental health problems who are receiving care and support within the Rehabilitation and Community Care Service (RCCS) in Nottingham. This included an exploration of their difficulties both within and outside the service, and the identification of good and poor examples of service delivery.

- To contribute to existing knowledge by seeking to understand the way in which the organization and delivery of mental health services impact on the lives of women with long-term mental health problems.

- To produce findings which can be used to inform both mental health policy and practice.

The purpose of this final chapter is to consider how this thesis has addressed these overall aims, and to discuss why and in what way current knowledge about the experiences of women with long-term mental health problems is now different as a result of this research. The chapter is structured as follows. First, the findings of the six studies presented in chapters five to nine will be drawn upon as evidence for judging the success or otherwise of the RCCS in meeting the needs of women with long-term mental health problems. This judgement will be set against the evaluation criteria which were identified in chapter four. Although the findings of each of the studies have already been discussed with reference to the mental health literature, the findings as a whole will now be considered in order to demonstrate how this comprehensive evaluation has contributed to existing knowledge about the services provided for women with mental health problems. The second section attempts a conceptualization of the way in which the organization and delivery of mental health services impact on the lives of women with long-term mental health problems. This conceptualization was influenced by the range of theoretical perspectives and issues discussed in chapter one and they will be drawn upon as appropriate. The final section considers the implications of the findings upon policy and practice and a number of recommendations are made. The final section reflects on the strengths and limitations of this evaluation and directions are given for further research.

10.2 Does the Rehabilitation and Community Care Service meet the needs of women with long-term mental health problems ?

The evaluation criteria which informed the series of six studies which make up this evaluation were presented in chapter four. These criteria will be used as a framework within which to judge the success or otherwise of the RCCS in meeting the needs of women with long-term mental health problems. This will be achieved by drawing on the evidence generated in the six studies. As was discussed in chapter four, the selected criteria were drawn from the broad literature on community care, evaluation reviews of mental health care, the views of users generally, the views of women in the specific literature on women and mental health, and the stated aims of the RCCS. An attempt was made to ensure that the criteria ultimately selected reflected the views of the identified stakeholders in the service: namely, women with long-term mental health problems, service providers working both within and outside the RCCS, and managers and decision makers. As the current research evidence about the experiences of these women in long-term community-based services is relatively limited (see chapter two, section 2.6), the criteria were not intended as a rigid framework but more of a guide which allowed for the possibility of other issues to emerge. The criteria were therefore presented as questions rather than standards. These will now be considered in turn after briefly summarizing the key differences between the men and women with long-term mental health problems that were identified.

The differences between the current and past life experiences of women and men with long-term mental health problems were highlighted in a number of the studies. The two studies presented in chapters five and seven identified that compared to men, women with long-term mental health problems were more likely to be currently or previously married, and to have children. Whilst being married and having children is often considered to be the norm for mentally healthy women, this evaluation highlighted the very real difficulties experienced by some women with long-term mental health problems in their efforts to combine domestic roles with the added burden of significant social disabilities. Nine of the ten women with long-term mental health problems who were followed through over a period of twelve months from their acceptance into the RCCS, for example (see chapter 7), had problems relating to their domestic situation. Such problems included domestic violence, breakdown of relationships with partners, and two unplanned pregnancies which resulted in one termination and one child being put forward for adoption.

The impact of such difficulties on the past and current lives of women with long-term mental health problems were explored in the study presented in chapter nine. This study highlighted the sense of loss experienced by women with long-term mental health problems. This sense of loss was conveyed in their descriptions of their lives before they developed their mental health problems, in their present lives, and in their explorations of what it was like to have long-term mental health problems. Whilst previous studies have acknowledged the losses which many people with long-term mental health problems experience (c.f. Birchwood and Shepherd 1992, Appelo et al 1994), this detailed exploration of the impact and meaning of these losses for women is unique. Such losses included the loss of the personal and material aspects of their lives through which their role as women were defined. These included the loss of past relationships, partners, children, independence and work. The women also mourned the loss of a lack of control over their lives which included an inability to cope, the few choices they had in decisions about where and how they lived their lives, and their diminished self respect and self esteem.

Knowledge:

- *Are service providers aware of the particular problems and difficulties experienced by women with long-term mental health problems ?*

The service providers in chapters six and eight identified a number of problems and difficulties experienced by women with long-term mental health problems, most of which had been identified in previous research (c.f. Test and Berlin 1981; Bachrach 1984, 1985, 1988; Perkins 1991, 1996; Ritsher et al 1997). These problems included their vulnerability to abuse and exploitation both within the mental health services and in the wider community; a nervousness or wariness of men; low confidence and self esteem; difficulties in finding an appropriate role in life; isolation, loneliness and lack of family support; difficulties in interpersonal relationships; the growing number of unplanned or unwanted pregnancies; difficulties in looking after children and fears of them being taken into care; and the lack of choice and control over the nature of the services they receive.

Despite the wide range of problems identified by the service providers, there were varying levels of understanding and knowledge between the different groups of staff working within the RCCS and in the range of other facilities surveyed outside the RCCS. Not surprisingly the women service providers interviewed in chapter eight appeared to have a greater understanding. This possibly reflected their acknowledged interest in the welfare of women with long-term mental health problems and the subsequent decision to include their views in the evaluation. This group of service providers did more than simply highlight the above issues however. In most instances, they were able to illustrate the women's difficulties with pertinent examples from their own practice. More importantly, they demonstrated an ability to empathize to some degree with the daily challenges and pressures experienced by women with long-term mental health problems. This was evident from their ability to imagine the women's feelings of loss and grief, loneliness and isolation, vulnerability and lack of power, and being labelled as 'mad' or 'different'.

In contrast the other groups of male and female service providers working both within and outside the RCCS surveyed in chapter six, indicated varying levels of understanding of the problems experienced by women with long-term mental health problems. Some of the service providers were able to clearly identify a wide range of problems experienced by these women, whereas others were unable to identify any particular difficulties other than those associated with their mental health problems and/or social disabilities.

Two key issues emerge from this evidence. First, the empathic understanding between service providers and clients has been highlighted in previous studies of this client group (c.f. Repper et al 1994). Nevertheless, as was highlighted in chapter eight, it is debatable whether service providers can truly empathize with a group of women whose life experiences are so extraordinary and different from their own (c.f. Nadelson 1993). Instead it is arguably more realistic for service providers to work towards trying to understand the complexity of these women's lives, accept that their experiences are unique, and sympathize with feelings of loss and loneliness. Second, the lack of knowledge about these women's particular problems and difficulties amongst some groups of service providers raises concerns about their ability to provide the women with the help and support that they need.

Equity:

- *Do women with long-term mental health problems have equal access to a range of services according to their needs compared to men ?*

The range of services provided by the RCCS for both men and women with long-term mental health problems was described in chapter four. These included in-patient provision, outreach services, day care and clinical specialist services (see Table 3, Chapter 4). The overall findings suggest that the provision of these general services was inequitably distributed amongst the male and female clients within the RCCS. The findings of the study presented in chapter five highlighted that, whilst the social functioning of the 316 men and 164 women in the sample did not differ (see Table 12, chapter five), women were under-represented amongst those receiving a high level of input from the services. The women for example, were less likely to be attending one of the RCCS day centres or be in-patients than were the men. These findings were reinforced by the findings of the qualitative studies presented in chapters eight and nine. Several of the service providers interviewed in chapter eight felt that women with long-term mental health problems were seen as a low priority group when compared with male clients, clients from ethnic minority groups, or clients who also misused alcohol and/or drugs. The service providers also felt that the care within the RCCS was very orientated towards the male clients and that the women did not have the same level of provision as the men. Similar views were expressed by the women with long-term mental health problems in chapter nine. Although the women mentioned the specific provision made for them within the RCCS, such as the women's groups and the women-only rooms in the day centres, the overwhelming view was that the service focused more on the needs of the men.

A number of attempts have been made to explain these inequities which have also been found in previous studies of services for clients with long-term mental health problems (c.f. Perkins and Rowland 1991). For example, women may be reluctant to engage in the services on offer because they focus mainly on men (Perkins and Repper 1996), or because services dominated by male clients are perceived as threatening and unsafe (Perkins and Rowland 1991, MIND 1993a). Conversely it may be that service providers tend to focus more on the needs of men because of their increased propensity to aggressive behaviour and the problems associated with drug and alcohol misuse (Nadelson 1993). Whatever the reasons for such inequalities, services need to consider ways to emphasize the particular needs of women with long-term mental health problems so that both they and the service providers feel that their needs are considered on a par with those of men. This may involve making specific efforts to ensure that the services provided are 'women-friendly' and appropriate to help them cope with their particular difficulties.

Comprehensiveness:

- *What specific services are provided for and used by women with long-term mental health problems ?*
- *What links and networks exist between the RCCS and alternative provision for women in the wider community ?*

The opportunities for women with long-term mental health problems to access 'women-friendly' or 'women-specific' services were frequently compromised by lack of available information about the range of services available, the problems of accessing such services, and the ethos and structure of some services. These issues were most clearly explored in the two studies presented in chapter six. The first study identified that the current provision for women with long-term mental health problems within the RCCS was very patchy. Although there were some examples of good practice such as the women-only residential unit, sexual harassment policies and women's groups (see Table 16, chapter six), there was no evidence of an overall plan or policy to ensure a universally high level of attention to women's needs. There was some recognition of the potential role of local community services for women, but little evidence of knowledge concerning what services exist and how to access and support them. The second study in chapter six identified a wide range of organizations outside the RCCS which could be accessed by women with long-term mental health problems themselves or through their care managers to address specific areas of need. These organizations were generally committed to providing a service for these women as part of an overall support system, but recognized that few such women make use of their services. The organizations had little knowledge about the specific difficulties experienced by women with long-term mental health problems and therefore how access to their services could be ensured.

The findings of the two studies presented in chapter six also highlighted that collaboration between service providers was scarce even though many of the staff from the range of facilities outside the RCCS expressed an interest in working more closely with mental health services as part of an overall package of care for these women. There was some evidence that a few women were referred to agencies outside the RCCS, although the agencies identified were known to be accommodating to the needs of women with long-term mental health problems. Where the RCCS staff had actively worked together with non mental health women's organizations, such as the local Women's Centre, the results had been particularly favourable in enabling women with long-term mental health problems to access ordinary facilities. There were few such examples of collaboration however, and these were generally the result of initiatives undertaken by small groups of enthusiastic staff. There appeared to be no overall strategy to enable women to access a broad range of facilities to meet their complex needs.

Previous efforts have been made to identify and describe examples of good service provision and facilities for women with mental health problems in the United Kingdom (c.f. MIND 1993a, Good Practices for Mental Health 1994, Abel et al 1996, Payne 1998). Whilst these efforts are commendable, the majority of women's services identified are isolated initiatives which have been set up by small groups of enthusiastic service providers and/or users. What makes the two studies presented in chapter six unique is that the range of women orientated facilities within one service and its associated community were identified. The findings highlight that individual initiatives by service providers working in relative isolation from one another do little to ensure that all women with long-term mental health problems have access to a range of 'women-friendly' services to meet their particular needs.

Effectiveness:

- *What impact does the RCCS have on optimizing the quality of life of women with long-term mental health problems and reducing their social disabilities ?*

The issue as to whether the RCCS had a positive impact on the quality of life and social functioning of women with long-term mental health problems was most systematically explored in the longitudinal study presented in chapter seven. The findings of this study highlighted the lack of overall improvement experienced by both the sample of women and men in terms of their social functioning and quality of life after being in contact with the RCCS for twelve months (see section 7.3.3, chapter seven). The possible explanations for this lack of improvement in quality of life and social functioning have been comprehensively discussed in chapter seven. It is important to reiterate however, that this study possibly highlights that an emphasis on improvement as an indication of the success of a service may not be appropriate for this client group. As Repper and Brooker (1998a) argue, stable engagement with appropriate services for people who have previously tended to lose contact with the support they need, or the maintenance of levels of social functioning and quality of life is a positive achievement for many clients. None of the women followed through for a period of twelve months for this study lost contact with the service, and as a group they did not deteriorate in terms of their social functioning and quality of life as measured by the Life Skills Profile (Parker and Rosen 1989) and the Quality of Life Interview (Lehman 1988).

- *Are services flexible and responsive to changes in the needs of women with long-term mental health problems ?*

Although the longitudinal study presented in chapter seven demonstrated that the RCCS was responsive in managing the high incidence of relapse of psychotic symptoms experienced by both the men and the women, and in adequately preparing them for discharge from the residential units into independent accommodation, there was little evidence that the specific problems experienced by the women over the twelve month period in particular, were addressed. Such problems included abusive relationships with partners, physical illness, bereavement, re-establishing relationships with old friends, one termination of pregnancy and one child being fostered and then being put forward for adoption (see Table 25, chapter seven). Although four of the ten women were engaged in a variety of leisure and voluntary activities during this period, there was no evidence to suggest that any of the women were in receipt of specific interventions and support to help them cope, and come to terms with, the major life events which they had all experienced. Even though the women's overall quality of life and social functioning did not deteriorate over the twelve month period of this study, the question remains as to whether specific and appropriate support would have led to an overall improvement.

Although previous research has found that long-term care services are not particularly responsive to the changing needs of women (c.f. Perkins and Rowland 1991), the study presented in chapter seven extends current knowledge. Perkins and Rowland (1991) for example, focused only on whether or not services responded to an improvement or deterioration in the social functioning of women with long-term mental health problems. This study suggests that additionally services are not responsive or have limited resources to respond to the types of life events experienced by women with long-term mental health problems. This issue is reinforced by the views expressed by the service providers in chapter eight when they suggest that the RCCS has inadequate and/or restricted access to counselling services for the women to discuss issues around sexual abuse, domestic violence, grief and loss; and that there is limited clinical supervision for staff working with women who have been victims of sexual abuse and domestic violence (see chapter eight, Table 32).

Acceptability:

- *Are the existing services acceptable to women with long-term mental health problems ?*

The issue of the acceptability of the services provided for women with long-term mental health problems emerged in several of the studies. It was suggested in chapter five for example, that the under-representation of women in the RCCS day centres in particular, may reflect the fact that many women may have been put off using these services because of their orientation towards men (Perkins and Repper 1996), or because they find male dominated environments threatening and unsafe (Perkins and Rowland 1991). This suggestion was reinforced by the findings of the study presented in chapter seven where it was also suggested that women with long-term mental health problems may be reluctant to use the available services because they do not provide them with the appropriate support to help them cope with, and manage their particular experiences and stressors. In addition two of the women in chapter seven were very conscious of their physical appearance and refused to participate in ordinary leisure activities in the community where their differences could possibly be identified and remarked upon.

The acceptability of services in meeting the specific needs of women with long-term mental health problems was further explored in chapter eight. The service providers highlighted a number of examples of poor practice. These included general practitioners either overtly or covertly attributing the women's physical problems to their mental illness, and the lack of choice the women often had regarding where they lived or who they lived with. The women with long-term mental health problems in chapter nine also raised a number of pertinent issues. These women commented that they were frequently not actively involved in any activities but tended to sit around doing very little; they highlighted the difficulties of communal living which included a lack of choice about where they could live, loneliness, lack of peace and privacy, a lack of control over their living environment, and the expectation that they would do the domestic tasks; finally the younger women complained about the lack of control or say they had in decisions which affected their lives. This felt lack of control was reinforced by the paucity of information they received from service providers about their treatment and care.

The importance of services being acceptable to women with mental health problems has been emphasized (c.f. MIND 1992, 1993a, Gadd 1996), and indeed Perkins and Repper (1996) argue that there is little value in services being effective if they are unacceptable to users and subsequently not used. This evaluation has clearly highlighted how and in what ways certain aspects of service provision are unacceptable to women with long-term mental health problems.

Choice

- *How much choice do women have regarding the services they receive and the life decisions they have to make ?*
- *How much information are women given regarding the care options available to them*

The findings of the studies presented in chapter eight and nine suggest that many women with long-term mental health problems experience a lack of choice and control regarding both the services they receive and the life decisions they have to make. As has already been identified, the women generally have little choice regarding where they live or who they live with. The choice of where women could live was primarily dictated by availability of places rather than personal preference. Although the RCCS does provide a women-only house, it is an in-patient facility catering for women with relatively short-term rehabilitation needs. There were no similar facilities for women who needed ongoing support for much longer periods. Such women often found themselves in residential homes and hostels dominated by men. Despite the emphasis placed within the RCCS on giving women a choice about the sex of their key worker, this was often difficult to achieve on the in-patient units because of the numbers of male staff working there. In addition the women were obliged to have their mental health needs assessed by a male doctor as there were no female doctors at either consultant or registrar level working within the RCCS during the period of this evaluation.

The women's ability to be adequate mothers was also questioned by the service providers. The overriding view was that it was often necessary to intervene to ensure not only the well being of the mother but also that of the unborn child. There were examples of women being admitted during pregnancy for monitoring, and several women had had their children taken away and placed in care. Although the service providers were aware that there were a growing number of pregnancies amongst women with long-term mental health problems, there was no specific help provided within the RCCS such as parenting classes or a residential unit where women and their children could be supported. Consequently women with long-term mental health problems were faced with the stark choice of terminating the pregnancy, managing alone with limited support, or giving the child up.

The limited choice and control many of the women with long-term mental health problems felt that they had in their lives was reinforced by the lack of information many of them received about key areas of concern. Two of the women in chapter nine highlighted this issue when discussing their medication and their desire to return to work. They felt that information was seldom provided unless requested, and furthermore that it was often given in a way that they found difficult to understand.

The importance of enabling women to make choices about the services and treatment they receive, and being able to make decisions about important aspects of their lives has been highlighted in the literature (c.f. MIND 1992, 1993a, Gadd 1996, Perkins 1996, Payne 1998). This evaluation has shown however that women with long-term mental health problems appear to have very limited choice and control regarding certain aspects of their lives, and that their ability to make informed choices and decisions are limited by lack of opportunity and information.

Alleviation of distress:

- *What attempts are made to alleviate distress experienced by women ?*
- *How much emphasis is placed on developing caring therapeutic relationships ?*

The distress experienced by many women with long-term mental health problems was highlighted by the service providers in chapters six and eight, and by the women themselves in chapter nine. Much of this distress was not linked to symptoms of their illness but had either preceded their first breakdown, or was a consequence of the ongoing nature of their illness and the resulting social disabilities. Some of the women for example described chaotic and neglected childhoods and/or sexual abuse, and many had experienced profound losses such as the loss of children, relationships, homes, jobs and independence. There were also examples of abusive relationships, domestic violence and physical ill health.

Although the many distresses experienced by women with long-term mental health problems have been reported in the literature (c.f. Test and Berlin 1981, Bachrach 1984, 1985, Appelo et al 1994, Perkins 1996), efforts to help the women cope appeared to rest with individual service providers. The service providers themselves in chapter eight identified the inadequate and/or restricted access to counselling services within the RCCS for the women to discuss issues around sexual abuse, domestic violence, grief and loss. The service providers also identified that there were few opportunities for these women to spend time alone together in the residential and day care services to share common experiences and support one another.

Despite the lack of formal support such as counselling to help women with long-term mental health problems to cope with and manage their distress, there was considerable evidence that many of these women had meaningful therapeutic relationships with their key workers or other care staff. Several of the women in chapter nine for example described very positive supportive relationships with their key workers. The women were particularly positive about staff who were encouraging, good listeners and who were available when needed. Several of the older women valued being 'looked after' by the staff and doing activities with them such as shopping. The commitment of many of the service providers towards these women was also evident from the range of women-only activities organized in various parts of the RCCS (see chapter six), and in the awareness of their particular difficulties (see chapter eight). Whilst these individual endeavours are positive, the service providers in chapter eight felt nevertheless that limited clinical supervision made it difficult for them to work with women who had been the victims of sexual abuse and violence.

Safety:

- *Are efforts made to protect women from abuse and harm ?*

There was no overall policy on sexual harassment within the RCCS and no guidance for staff in managing issues such as safety, exploitation and domestic violence. The service providers in both chapters six and eight however, were aware of the vulnerability of women with long-term mental health problems and felt that such women had a right to practical help to ensure their safety within and outside the service. Complaints were made by some of the service providers in chapter eight about the lack of concern shown in some parts of the service about the management of harassment and sexual exploitation.

Whilst there has been increasing concern about the vulnerability and safety of women with mental health problems both within and outside the mental health services (c.f. Tonks 1993, Patel et al 1994, Crimlisk and Welch 1996, Henderson and Reveley 1996, Barlow and Wolfson 1997), the evidence from this evaluation suggests that these issues are not seen as a priority within the RCCS. Given the identified extent of abuse, exploitation and domestic violence experienced by women with long-term mental health problems (see chapter seven), the need to develop some guidance for how staff should manage and prevent these situations seems imperative. Interestingly there are equal opportunity and harassment policies for staff working in the Trust.

Respect:

- *Are the women supported in achieving valued social roles ?*

The women in chapter nine identified a range of valued social roles which they aspired to. These included mother, wife/partner, friend, and employee, amongst others. They also placed an emphasis on being treated as 'normal' by people both within and outside the services. Whilst there was some evidence of positive initiatives such as women working as volunteers (see chapter seven) and being supported in moving to independent accommodation (see chapters seven and nine), it became increasingly clear as the evaluation progressed that the service providers within the RCCS experienced a degree of role conflict which may have prevented them from encouraging women with long-term mental health problems to lead more independent lives. In chapter eight for example, there was considerable evidence to suggest that, whilst the service providers respected the rights of women with long-term mental health problems and acknowledged their aspirations for a more normal life, they felt constrained by their professional obligations to protect them from their perceived vulnerabilities. Consequently many of the service providers saw themselves as ultimately responsible for the women's care and were possibly not prepared to take the risks of encouraging such women towards a greater independence. These issues have been raised by Perkins and Repper (1998) and Morrall (1998) and will be discussed in more depth in section 10.3.

Summary

This evaluation has highlighted that whilst individual service providers were working towards providing a service which met the needs of women with long-term mental health problems, their work was carried out in relative isolation from one another. This lack of cohesiveness, visibility and impact may also reflect the way in which women's issues were viewed within the RCCS as a whole. As one senior service provider interviewed in chapter eight said,

> *"You don't want to be identified as the person on women's issues because it's a bit tacky basically. It doesn't get you promoted, it gets you the reputation of being soft, or not being able to deal with hard issues, or getting on your band-wagon again, in a way that campaigning for ethnic minority groups doesn't".*

If such a view pervades the RCCS it is hardly surprising that a cohesive policy for women had not been developed and that the examples of good practice rest on the initiatives of enthusiastic service providers working in relative isolation. This situation may also reflect the high levels of senior male staff within the RCCS. During this evaluation all of the consultants and three out of the four senior managers were men. Within such a male dominated hierarchy it is possible that the women's specific needs were not necessarily ignored, but simply not seen as a priority.

10.3 The predicament of women with long-term mental health problems

The strength of this thesis lies not only in the way that the success of the RCCS in meeting the needs of women with long-term mental health problems was judged from the range of identified stakeholder perspectives; but that taken together, the findings illuminate the way in which mental health policy and the current organization of services impact on the lives of these women and contribute to their current predicament. This thesis did not deliberately set out to explore issues such as the contradictory nature of mental health policy, power, social control or the oppression of women. Indeed, it is important to acknowledge that if the researcher had intended in the first instance to explore such issues, the design of the research would have been different. In this thesis these issues, amongst others, have emerged from the findings rather than being deliberately explored from the outset. Rather than being unusual, it appears that other researchers have had similar experiences.

The most clearly explicated example of this is that described by Bloor and McIntosh (1990) in their two studies of health visiting and therapeutic communities. The data for the former study were gathered from semi-structured interviews with eighty working class Glasgow mothers. The data for the latter were gathered from participant observation of four therapeutic communities: namely, a communally organized house for disturbed and mentally handicapped adolescents, a psychiatric day hospital for personality-disordered and neurotic patients, and two half-way houses for disturbed adolescents (Bloor and McIntosh 1990, p161). The following quote illustrates how Bloor and McIntosh (1990) applied a Foucauldian perspective after the data had been gathered to uncover both the surveillance activities of health professionals and care workers, and the strategies of resistance to that surveillance adopted by their clients,

> "Of course, the health visiting and therapeutic communities studies were not undertaken in order to compare professional-client relationships in different types of service provision, nor were they undertaken to elaborate a Foucauldian approach to client resistance. The possibility of writing this chapter only occurred to us *post hoc*, when we realized that we both had data bearing upon issues of power and contest which showed both similarities and dissimilarities in techniques of client resistance. Had we intended from the outset to produce a typology of client resistance we would have designed different studies, employing more readily comparable methods of data collection and possibly focusing on different research settings. Nevertheless, we feel that the analysis of client resistance produced here, albeit a mere by-product of *post hoc* comparisons of different studies, may have some value, both in terms of its applicability to some other forms of professional-

> client relationship, and in terms of its uniqueness as a typology of client resistance" (Bloor and McIntosh 1990, p161-162).

The experiences of Bloor and McIntosh (1990) provide an exemplar for how the findings of applied research can subsequently be conceptualized by drawing on theoretical frameworks not originally considered at the outset of the work. In an attempt to understand the predicament of women with long-term mental health problems, the researcher was influenced by a variety of theorists and researchers, including those whose ideas were discussed in chapters one and two. Their ideas will be drawn upon as appropriate in the following discussion. However, it is important to note that in the research and writing of this thesis, it has been found that the predicament of women with long-term mental health problems resists tidy theoretical analysis. A range of theoretical explanations will be therefore be drawn upon heuristically. The analysis is not an attempt to explain the women's predicament as it is, but to suggest another way of looking at it. The argument that runs throughout this section is that the conflicting nature of mental health policy and the organization and delivery of services continue to contribute to women with long-term mental health problems feeling different and being perceived as different by others. Whilst these women are now primarily cared for in community settings, they are not yet an integral part of the communities in which they find themselves.

Prior to deinstitutionalisation women with long-term mental health problems would have been excluded from society and cared for in isolated psychiatric hospitals. The problems associated with such exclusion have been comprehensively documented by Barton (1959) and Goffman (1961), amongst others. Goffman (1961) described psychiatric hospitals as a form of 'total institution', a segregated community, isolated from general life which developed practices common to other institutions, such as prisons. All these institutions are 'total' in that inmates work, sleep and play in the same place. They are segregated from general social life, and have restricted contact with life outside. There are rigid routines guiding every detail of inmates' lives, designed to ensure the smooth running of the institution rather than for the benefit of the inmates. They are regimented and employ block treatment, the same rules and practices apply to everyone irrespective of their individual needs. They are depersonalizing in that inmates are not accorded their individual rights and status as people. There is a large social distance between staff and residents. Residents have little control over what happens, decisions are made by staff. Inmates are deprived of normal social roles. In short, psychiatric hospitals like other institutions were considered to be authoritarian, custodial and deadening.

The experiences of women in psychiatric hospitals were, however, very different from those of men. Showalter (1987) comprehensively discusses these differences and in doing so highlights the many ways in which women were controlled and managed. The regimes within these hospitals generally reflected and reinforced conventional and accepted sex-role behaviour. While male clients worked in a variety of jobs in the workshops and hospital farms, the women patients tended to be involved in cleaning, laundry and sewing. The women had fewer opportunities than the men for outdoor activity, physical recreation, or even movement within the hospital. While physical exercise and manual labour seemed more necessary therapies for male patients, social activities and decorum were regarded as more important for women. The women were expected to care more about their appearance than men, and progress was often judged by an increasing concern about dress, hair and makeup. Finally, Showalter (1987, p79) argues that although all the patients were subject to surveillance, women were more closely and carefully watched than the men primarily to protect them from rape and seduction.

The current policy of community-based care offers the possibility of inclusion into social life rather than exclusion for women with long-term mental health problems. For example, the normalization philosophy which is reflected in the White Paper 'Caring for People' (Department of Health 1989a) emphasized the rights of people with health and social care needs to live a life as close to normal as possible; that is to participate in socially valued lifestyles which maximize opportunities for choice, self-realization and independence. More recently the Mental Health Foundation (1994) emphasized the rights of people with long-term mental health problems to have an appropriate place to live, an adequate income, a varied social life, employment and other day activities, help and support, respect and trust, and choice and consultation. Such a philosophy promises a more fulfilling life for women with long-term mental health problems. However, their predicament is arguably not so very different from that prior to deinstitutionalisation, albeit in very different settings. At least in the old psychiatric hospitals the denial of liberty, choice and control was explicit and expected, whereas now the possibility of an 'ordinary' or 'normal' life is denied at every turn. Rather than the promise of freedom, community care has brought with it a new set of problems for these women. These problems include their profound social disabilities and their need for long-term support, that the women feel different and are perceived by others as different, the double disadvantages of gender and disability, the continuing surveillance of every aspect of their lives, and finally the conflicting demands of current mental health policy which impacts on the way in which service providers work with these women. These problems will be considered in turn.

Despite the widespread use of neuroleptic medication and the advent of therapeutic approaches such as intensive rehabilitation, family interventions, psycho-social interventions and early interventions in psychotic relapse; many women with long-term mental health problems remain profoundly socially disabled and require ongoing support from a range of services to enable them to carry out their lives on a daily basis. The findings presented in chapter five clearly illustrate the extraordinary nature of the past and present lives of the 164 women with long-term mental health problems receiving care within the RCCS. The majority of women for example, had a serious mental illness such as schizophrenia, and many had experienced multiple psychiatric admissions. A high proportion were prescribed major tranquilizers and had additional problems associated with chronic physical health problems. In addition a number of the women had histories of substance misuse, violence towards people or property, or of being detained in prison or a special hospital (see Table 11, chapter five). The consequences of the long-term nature of their mental health problems was evident from the social functioning scores achieved by these women (see Table 12, chapter five). The low social functioning scores highlight their multiple social disabilities in a range of areas. Many of the women for example, have a tendency to neglect their physical health, have limited cooking and budgeting skills, neglect their personal hygiene, have problems living with others, have poor communication skills, and experience difficulties in making or maintaining friendships. All of these factors contribute to the stark reality that the majority of women with long-term mental health problems within the RCCS are single, live alone, and are unemployed (see Table 10, chapter five). Finally it should be emphasized that all the women (and men) receiving care within the RCCS are by definition multiply socially disabled and require a multiplicity of services (see section 4.2.2, chapter four).

Although long-term services such as the RCCS endeavour to support these women in community-based settings, they are often powerless to influence public intolerance towards them particularly when media attention has only served to intensify public concern and fear. Repper and Brooker (1996) for example, highlighted that 'Not In My Backyard' (NIMBY) campaigns are cruelly misinformed and vitriolic in some areas. Such local opposition to mental health facilities in the community leads to difficulties in siting new facilities, and even the closure of existing hospital based resources. The importance of public attitudes and behaviour to people with long-term mental health problems has been recognized by MIND who have run a major campaign to challenge stigmatization and NIMBYism (c.f. Repper et al 1997). However, this must compete with the distorted images of madness presented in the media in a society dominated by a need for normality. Such intolerance and opposition does little to make women with long-term mental health problems feel as if they are valued and belong to the communities in which they find themselves placed.

Despite the fact that the majority of women with long-term mental health problems in the RCCS live in community-based settings, they still viewed themselves as 'different' from their mentally-healthy peers and relatives. For example, they were made to feel different by the actions of friends, relatives and others. This was most clearly articulated in chapter nine where two of the younger women described how people behaved differently towards them because of their mental health problems. They described people acting as if they were treading on shells, being careful of what they said and did, and of being afraid of saying the wrong things. Another older woman in the same study articulated her feelings of being marginalised by saying that all her children were doing well, whilst she was not. Feeling different was also a barrier to accessing mainstream community activities. Two of the women in chapter seven for example, were very conscious of their physical appearance and were reluctant to participate in ordinary leisure activities in the community where their differences could possible be identified and remarked upon. These perceived differences were also illustrated by the women's hopes and aspirations for things that the majority of mentally healthy women take for granted such as independence, privacy, meaningful relationships, work and children. Overwhelmingly the younger women aspired to being normal and ordinary, to lead productive but unremarkable lives like the majority of their mentally healthy contemporaries. These hopes and aspirations bore little resemblance to the reality of their lives and served to emphasize their difference and marginalisation.

In some respects the feelings of 'difference' amongst women with long-term mental health problems were similar to those described by Barham and Hayward (1995) in their study of the lives of ex-psychiatric hospital patients. Barham and Hayward (1995) argue that such clients, whilst struggling to establish their 'personhood' in the community, struggle to resist becoming entrapped in the condition of 'mental patienthood'. This struggle, they argue has to do with how people with mental health problems are commonly perceived by society at large, the tendency for them to be identified largely in the vocabulary of difference rather than membership; and with material constraints on participation in social life, the tendency for clients to be marginalised or even pauperized (Barham and Hayward 1995, p137). Barham (1997) develops this argument further by drawing on the work of Mangen (1988) who writes,

> "Directly at issue is the marginalized position of the long-term mentally ill in society..... Their common social handicap stems from their denial of access to the full rights of citizenship, which extend beyond conventional civil and political rights to economic and social welfare. Viewed from this perspective, many long-term users of psychiatric services are profoundly disadvantaged: their relative poverty imposes massive restrictions on choices available to them in daily life and thus can be the major determinant of the level of autonomy they attain " (Mangen 1988, p73).

Whilst the predicament of women (and men) with long-term mental health problems can be viewed as an experience of difference and marginalisation (Estroff 1985, Barham and Hayward 1995, Barham 1997), the experiences of women are arguably very different from those of men. As Rogers and Pilgrim (1996, p16) argue, people with long-term mental health problems not only have to contend with the burden of their social disabilities and their perceived differences, but they also bring with them all the vulnerabilities of their race, class and gender background. Women with long-term mental health problems therefore have to contend with the additional and specific sources of disadvantage associated with their gender. This situation arguably doubly disadvantages these women in their quest to be ordinary and normal (Begum 1992, Orme 1998).

The last few years have seen extensive changes in women's lives. Pascall (1997) for example, argues that the old assumptions that women's place and security lay in the family is ever more challenged by the increase in women's labour market participation and educational achievements.

These changes have consequently loosened the knot of dependency on the family, and increased the possibilities for women to break away from abusive relationships and perhaps resist the overwhelming demands of unpaid work such as child care and looking after aged and sick relatives. Despite such progress, when class divisions are considered alongside gender, women remain disadvantaged when compared to men. Poverty has spread among women, as lone mothers and elderly people. The loss of safety nets and high-quality public services has particularly affected women, because women have depended heavily on welfare services (Pascall 1977, p244). Such women have not succeeded in shifting the balance of unpaid care to men, and issues around motherhood and care are essential to autonomy; to their ability to set up an independent household, to escape violence, to choose their own pattern of paid and unpaid work, and to make appropriate choices for their children and elderly or disabled dependents (Pascall 1997, p239).

The disadvantages experienced by many women are compounded by a pervading patriarchal oppression which includes patterns of subordination, stereotyping, and expectations and practices (Hutter and Williams 1981, Russell 1995). The stereotypes of women are inextricably tied up with sexual value; ability to care for others; the performance of domestic labour; and relationships to men, particularly husbands / partners. Moreover the 'normal' woman is constantly portrayed as a person with a childish incapacity to govern herself and in need of some protection (Hutter and Williams 1981, p17-19). Underlying these stereotypical assumptions is a double standard of behaviour, which designates certain forms of behaviour as appropriate for men and inappropriate for women. For example, societal tolerance of alcohol and drug misuse, career ambitions, neglect of families, and sexual promiscuity is higher for men than for women (Burr 1998, Saraga 1998). Women's perceived inability to make rational decisions for themselves also renders them liable to the control of medical experts. This has been explored extensively in the feminist literature and key examples include the increasing medical control of reproduction (c.f. Oakley 1984, Stanworth

1987), the management of older women in hospital (Evers 1985), and the medicalisation of premenstrual syndrome and the menopause (Ussher 1992, Harding 1997).

Miles (1993) has explored the multiple disadvantages experienced by women who also have a disability. These include the difficulties of obtaining employment and of accessing both practical and emotional support. In particular she highlights the very different impact that the stigma associated with mental health problems has on women,

> "There are aspects of stigma and rejection that bear more heavily on women than they do on men. Patterns of social support make the experience of rejection by the social network a more serious problem for women than for men. Women rely a great deal on their friends and wider kin group for support and less so on their husbands and partners. If rejection by network members is experienced, there is nowhere to turn. Men, relying mostly on their wives or partners for support, are less hard hit when friends, relatives and colleagues turn aside" (Miles 1993, p110).

Miles (1993) also argues that younger women with long-term mental health problems have to face the additional social disadvantage of being regarded as less valuable and desirable as a sexual partner, and of the largely feminine stigma accorded to those whose body shape fails to come up to the standards touted in the media. Women with long-term mental health problems often gain weight as a result of their sedentary life style and as a side effect of neuroleptic medication (Pratt 1998). Such disadvantages serve to enhance these women's experience of difference and marginalisation, and makes their ambitions to be perceived as normal and ordinary even more insurmountable.

It has been argued that all people in modern society are subject to surveillance (Porter 1998, p218).

For example, children at school are monitored to see whether they are polite and diligent; the work force are monitored regarding time keeping and productivity; and people seeking health care are expected to behave in certain, well defined ways. Earlier in this section it was highlighted that women with long-term mental health problems in psychiatric hospitals were subject to more rigorous surveillance than men in order to protect them from rape and seduction (Showalter 1987, p79). The extent of such surveillance is arguably much greater now they are living in community-based settings and more pervasive than that experienced by mentally healthy people. Reflecting both on the findings of this thesis and the thrust of contemporary mental health policy, the surveillance of women with long-term mental health problems appears to take on a number of forms. First, the vast majority of these women are, most of the time, not subject to powers of coercion under mental health legislation. Nevertheless these powers can act as an important (explicit or implicit) back-up threat to deprive them of choice and force them to do what service providers think best (Repper and Brooker 1998b). Second, all of the women in this investigation were cared for within the framework of the Care Programme Approach (Department of Health 1990b) and many would be included in the new supervision registers introduced in 1994 (Department of Health 1994b). Such approaches require service providers to regularly monitor and record these women's activities through ongoing assessment and multidisciplinary review. This surveillance not only monitors mental state and compliance with medication; but would also include discussions around their social circumstances, relationships with others, integration into the community, levels of domesticity, leisure activities, and personal appearance and hygiene. Third, it is evident from the findings of this investigation that the surveillance of these women went beyond the requirements of that dictated by current mental health policy and guidance. For example, service providers appeared to monitor almost every aspect of their public and private lives. This included judgements about the suitability of sexual partners, their contraceptive needs, their vulnerability to exploitation, their ability to be mothers, to hold down a job, and to be independent. There is consequently little, if anything, about these women's lives that is private and theirs alone.

The pervasive nature of such surveillance can be further understood by drawing on the work of Foucault. Foucault (1977) argued that the modern period saw the birth of new forms of power that were far more invasive than anything seen before. In his own terms, power relations now take the form of 'panoptic surveillance'. Panopticism literally means 'seeing everything'. Foucault took the term 'panopticon' from the nineteenth century English philosopher and social reformer Jeremy Bentham, who used it to describe a model prison that he had designed. The novelty of this prison was that, instead of throwing prisoners into a dungeon where they would be out of sight and out of mind, prison cells were arranged in such a fashion that their occupants could all be seen from a central guard post. The prisoners in the panopticon could never tell whether or not they were being watched, so they tended to behave at all times as if they were. As a result, Bentham argued, they would reform their behaviour (Porter 1998).

In the 'Birth of the Clinic' (Foucault 1976), Foucault focused specifically on the manner in which medical surveillance was carried out. He argued that the reality of the patient is constructed by what he terms the 'clinical gaze' of the physician. Under the clinical gaze, the patient becomes a body to be manipulated and is seen as nothing more than an object or a biological machine. Later in his career, Foucault (1982) developed the notion of pastoral power, which, in contrast to the clinical gaze, is a form of surveillance that directs itself towards people as individual subjects rather than objects. Whilst the clinical gaze reduced people to their bodies, at least its surveillance was limited to those bodies. In contrast by adding the psyche and social circumstances of patients to the gaze of health care workers, pastoral power widens the trawl of surveillance to the most intimate parts of patients' lives (Porter 1998). Finally, Foucault (1977), drawing on the work of Jeremy Bentham, argues that people become so accustomed to constant surveillance that they apply it to themselves by constantly monitoring their own behaviour and judging it against standards created by 'normalizing judgement' (Merquior 1991, p94). 'Normalizing judgements' are produced by experts using their knowledge to define what is 'normal', and thus the mentally ill, amongst others, are drawn more tightly into the net of experts and more evident forms of surveillance. The women with long-term mental health problems in this study were therefore not only subject to extensive surveillance by service providers, but they also judged themselves against what they perceived as 'normal' for mentally healthy women. Their desire for sexual partners, friends, employment and independence in the absence of such things could be seen as one way in which they judged themselves as different from others.

Foucault's work has been drawn on by a number of researchers seeking to understand the work of health professionals and/or the experience of patients (c.f. Bloor and McIntosh 1990, Davies 1995, Nettleton 1995, Opie 1997, Miers 1999). Bloor and McIntosh (1990) for example, in their study of health visiting and therapeutic communities, build on the idea of pastoral power by developing the concept of the 'therapeutic gaze'. This surveillance technique constitutes people as psychosocial beings and involves the observation, interpretation and redefinition of behaviour. They identify three different techniques of surveillance: covert or naturalistic surveillance, supervisory surveillance, and surveillance by proxy or by the encouragement of self-reporting. Whilst such surveillance can be construed negatively, Bloor and McIntosh (1990) demonstrate that surveillance is a necessary precondition for the conduct of both health visiting and therapeutic community practice. With reference to health visiting they argue that,

> "Health visiting is essentially a preventative service concerned with monitoring the physical and emotional well-being of infants and young children and with encouraging healthy lifestyles and 'appropriate' practices of childcare. Surveillance, we would argue, is an essential component of these preventative activities. This can be seen most clearly, perhaps, in the case of the monitoring of

> abuse and neglect and the assessment of children's current state of health and development. Obviously, the accomplishment of these tasks requires direct evidence of the child's well-being and of the adequacy of his or her environment. This information can only be obtained by means of surveillance" (Bloor and McIntosh 1990, p162).

Bloor and McIntosh (1990) argue however, that the surveillance functions of health visitors are more pervasive than this. Specifically, they are sceptical of health visitors' claims that, in their health education role, they are non-directive and non-judgmental. Health education is not neutral but contains a set of values that may or not be shared by health visitors' clients. Those values entail assumptions about what is 'good' and what is 'bad' parenting, what is 'healthy' and what is 'unhealthy' lifestyle. The aim of health visiting is to persuade parents to conform to the standards that are valued by health visitors. In short, health visiting involves the promotion or maintenance of those behaviours regarded as appropriate.

There was some evidence in this investigation that the values held by the service providers possibly coloured the way in which women with long-term mental health problems were perceived. For example, the promiscuity of some of the women was remarked upon, their vulnerability, their tendency to dress oddly, and their inability to be good mothers. Such value judgements would not arguably be made about male clients (theirs would be different), and they possibly reflect a more pervading societal view that 'normal' women are sexually monogamous, avoid situations where they might be exploited, dress appropriately and non-provocatively and are good enough mothers.

Furthermore Bloor and McIntosh (1990, p163) highlight one of the central ambiguities of health visiting. On the one hand, health visitors are expected to establish a caring and supportive relationship with families, while, on the other, they are charged with the responsibility of monitoring the occurrence of abuse, neglect, and inadequate parenting. The evidence from this investigation suggests that the conflict experienced by the service providers working with women with long-term mental health problems is similar (see chapter eight). Whilst there is a strong expectation that they develop meaningful, trusting, therapeutic relationships with the women; optimize their functioning in normal social roles; and increase their independence from services; they are also expected to closely monitor the women, protect them from their vulnerabilities and ensure public safety (Morrall 1998, Perkins and Repper 1998). A constant fear that any variation from recommended practice could lead to an incident resulting in an injury and the humiliation of being named in a report, inevitably results in service providers moving towards a protective mode of working (Muijen 1996, p152). The service providers in chapter eight for example worried that they would be blamed if a woman with long-term mental health problems should become pregnant. Such a protective way of working inevitably impacts on the lives of women with long-term mental health problems as service providers are increasingly reluctant to take the necessary risks entailed in promoting these women's inclusion into the community.

Whilst the contradictory nature of mental health policy creates tensions for service providers, the findings also suggest that the working practices of other professionals in the organization made it difficult for motivated service providers to maintain their women-centered discourse. For example, women's issues were often not seen as a priority, the knowledge about these women's particular needs was patchy, there were conflicting views on how best to deal with harassment, and the women's physical health problems were often seen as a manifestation of their mental illness. This situation can possibly be explained by the inevitable differences in the discursive practices of the different professional groups within and outside the RCCS which served to perpetuate differences rather than agreement between service providers. Opie (1997) has explored this issue in a recent study of multi-disciplinary teamwork using a Foucauldian perspective. She argues that a professional resistance to user-centered discourses can be explained with reference to the difficulties of multi-disciplinary teamwork. The difficulties she identified included,

> "Lack of professional trust resulting in complicated power relations between professionals; an overabundance of, or, alternatively, an absence of conflict; lack of clear structures and directions; unclear goals; the dominance of particular discourses resulting in the exclusion of others; the existence of tensions between professional discourses resulting in potentially unsafe practices; and the production of client discussions which, far from addressing client goals, marginalise them and contribute to the clients' disempowerment" (Opie 1997).

The exercise of power however, according to Foucault (1977) always produces resistance, as power and resistance are different sides of the same coin. Resistance was conceived by Foucault as the crux of his concept of freedom: power is pervasive and so freedom cannot exist in its absence, but rather as the possibility of practical revolt in reaction to it. Bloor and McIntosh (1990) drew on their data to identify a number of strategies of resistance adopted by mothers in the face of health visiting surveillance. These strategies included what they termed individual ideological dissent; hidden non-compliance with health visitors' advice; escape or avoidance, which involved mothers either stopping clinic visits or avoiding contact with the health visitor at home; and concealment and deception. In this investigation there were a number of strategies adopted by women with long-term mental health problems to resist the surveillance role of the service providers within the RCCS. Interestingly the strategies adopted were not as evident as those described by Bloor and McIntosh (1990). This possibly reflects the reliance of women with long-term mental health problems on the support provided within the RCCS, and because this investigation did not originally set out to explore surveillance and strategies of resistance. The resistance strategies adopted by the women included: the reluctance and / or refusal to engage in services which they either considered inappropriate to meet their needs, or which contributed to them feeling like a 'patient' rather than an 'ordinary' person; and continuing hopes and aspirations for things that the majority of women take for granted such as meaningful relationships, work, privacy and independence. Although it has been argued that the absence of such ordinary things in their lives emphasizes their marginalisation and difference; this pervading hope marks a powerful resistance to the attempts made by both services and the wider community to perpetuating their 'patienthood'. Such resistance was however more marked amongst the younger women. The older women with long-term mental health problems interviewed in chapter nine had limited aspirations for the future. Such a finding might suggest a gradual move from idealism towards realism as the women eventually come to terms with the disabling nature of their long-term mental health problems and their inevitable personal limitations. It may also reflect a degree of institutionalization. All of the older women interviewed had experienced long periods of hospitalization in the past and many currently lived in private registered homes or professionally supported housing. Such environments, particularly if the women have experienced a lack of control over decisions which concern them, can contribute to a lack of interest in the future, and having a resigned acceptance that things will go on as they are without changing (Ryan 1979).

To conclude. This section has highlighted that whilst current mental health policy offers women with long-term mental health problems the possibility on inclusion into the community, the process of exclusion remains powerful. Such women perceive themselves, and are seen by others, as different from their mentally healthy counterparts; they have to cope with the double disadvantage of profound social disabilities and their gender; and virtually every aspect of their public and private lives are monitored by the services on which they are dependent for treatment and support. The predicament of women with long-term mental health problems has to be understood within the current conflicts which exist within mental health policy; that is, the concern with ameliorating distress versus the need to control and manage deviant behaviour. The inevitable dilemmas for service providers in monitoring people with long-term mental health problems and protecting the public, as well as trying to promote individual choice and autonomy is becomingly increasingly discussed in the literature (c.f. Holloway 1994, O'Grady 1996, Breeze 1998, Chan 1998, Dyer 1998, Morrall 1998, Perkins and Repper 1998, Stainton 1998). However, the particular needs of women with long-term mental health problems continue to be marginalised with the continuing emphasis on a small group of predominately young, violent male clients who are perceived to pose a particular danger to themselves and to the public (c.f. Department of Health 1998b).

10.4 Implications of the findings on policy and practice

In December 1998, the new Labour government launched 'Modernising Mental Health Services' (Department of Health 1998b) which is the first comprehensive statement from any government about the future direction of mental health policy since 'Better Services for the Mentally Ill' (Department of Health and Social Security 1975). The strategy sets out a number of core priorities for service improvements which include strengthening comprehensive care (e.g. more acute and secure beds, the development of assertive outreach and crisis intervention teams); providing 24-hour access to services; developing, training and recruiting staff; improving the planning and commissioning of services; and developing partnership working. This strategy represents an attempt to deal with a range of competing pressures such as public concern about homicides by mentally ill people and the evidence of related service breakdowns; the government's desire to tackle social exclusion and modernise public services; and concerns that services are not sufficiently well resourced or well developed to meet needs, and that current levels of pressure cannot be sustained (Sainsbury Centre for Mental Health 1999). Running alongside the proposed service improvements are a review of the 1983 Mental Health Act, and the National Service Frameworks for mental health which are due to be issued in the Summer of 1999.

Although many of the recommendations outlined in 'Modernising Mental Health Services' (Department of Health 1998b) have been welcomed (c.f. Mahoney 1998), there are criticisms.

These primarily centre around the government's view that community care has failed, and the over emphasis on the risk and safety issues (Rowden 1998, Sainsbury Centre for Mental Health 1999). As Frank Dobson wrote in the foreword to the strategy,

> "Care in the community has failed because, while it improved the treatment of many people who are mentally ill, it left far too many walking the streets, often at a risk to themselves and a nuisance to others. A small but significant minority have been a threat to others or themselves... The law will be changed to deliver [this] protection for the public while at the same time respecting the civil rights of patients" (Department of Health 1998b).

While the strategy emphasizes the promotion of social integration and respecting the civil rights of people with mental health problems, the overriding emphasis on public safety continues to place service providers in the position of having to balance the two elements of care and control. Furthermore, people with mental health problems are overwhelmingly referred to as an homogeneous group with no differentiation made between the differing needs of women and men. Since completing the data collection for this thesis a further report has clearly shown that the particular needs of women are not being met in mental health services (c.f. Department of Health 1999). The findings of this thesis therefore remain pertinent.

It has been argued throughout this thesis that women with long-term mental health problems are a profoundly disabled group who require support from a range of agencies to enable them to manage their lives on a daily basis. The findings of this thesis also concur with the views expressed by Penfold and Walker (1984) and Busfield (1996) that the delivery of mental health services are characterized by conflicts and tensions. That is, services have both regulatory and caring functions. The following recommendations for policy and practice acknowledge these inevitable conflicts. There is an attempt however, to keep the needs of women with long-term mental health problems to the fore, and to limit what might be construed as 'monitoring or controlling' strategies to those key areas in which the women are known to be vulnerable. Finally the recommendations reflect the researcher's view that it is not just the current organization of mental health services which contribute to the predicament experienced by women with long-term mental health problems, but also wider societal attitudes towards both women and mental illness.

10.4.1 Recommendations

- There needs to be a major public education campaign funded by the government, aimed at helping the population to better understand the realities rather than the myths of mental health problems. This campaign should involve both users and service providers, and must emphasize the different experiences of women, men, and people from black and ethnic minority groups, amongst others.

- Future mental health policy, reports and guidance must reflect the gendered experience of service users. There should be a move away from referring to people with mental health problems as an homogeneous group, towards acknowledging that the needs of women and men are different but equally important.

- Long-term community mental health services must aim to:

1. Decrease unevenness in attention to women's needs across services by:

- developing a strategic plan to include an equal opportunities policy, a sexual harassment policy, and a policy concerning the safety of women within the services;

- developing a staff training plan which would include information and awareness about gender issues, sexual harassment and equal opportunities training, and supervision to enhance skill development;

- facilitating access to mainstream health facilities to meet physical health needs.

2. Make the services more attractive so that women will want to use them by:

- providing a choice as regards the sex of their key worker for all women;
- providing a range of interventions and support to help women deal with domestic violence, childhood sexual abuse, and loss;
- creating a therapeutic environment which reflects as little as possible the conditions in society which demoralise women;
- providing a range of women-only facilities such as day facilities, supported accommodation, in-patient facilities, group and leisure activities;
- minimizing the problems of harassment both within and outside the services by providing personal alarms, help and support in reporting any abuse to the police and ensuring that a woman is available for the victim to talk to. This would include making sure that the women know that sexual harassment is not tolerated and that mechanisms are in place to challenge and change unacceptable behaviour;
- ensuring privacy by providing separate washing, bathing and toilet facilities, a quiet room to spend time away from men or to entertain visitors;

- inviting local women's organizations to run activities.

3. Support the agencies, services and public amenities in the community to accommodate women with long-term mental health problems by:

- educating those agencies providing services for women about the nature of their disabilities and how help might best be provided;

- providing practical support to access facilities;

- supporting agencies with, for example,a contact within the service should difficulties arise.

4. Assist women with long-term mental health problems to gain access to roles, relationships, facilities and opportunities in the communities of their choice by:

- compiling a directory of women's services available in the area and to circulate information about women-only events, courses and groups within the community;

- providing an opportunity for women to make informed choices about the options available to them to improve their lives;

- providing on-going support to help the women become established within the community of their choice such as company, encouragement, and an opportunity to talk about anxieties;

5. Enable the women to gain control of their problems and lives by:

- fostering opportunities to bring women together to enable them to gain solidarity and confidence through shared experiences, aspirations and action;

- exploring ways of working with women which specifically examine power relationships. (One approach which takes account of power in work with individuals has been developed by Hagan and Smail (1997). Their notion of 'power mapping' represents a way of conceptualizing power which clarifies the experiences of individual clients in terms of the operation of social power);

- helping women cope with the loss in their lives;

- helping women to get out of abusive relationships.

10.5 Final comments on methodology and directions for future research

This thesis has presented a number of methodological challenges. Many of these have already been discussed with reference to the six studies presented in chapters five to nine. There are however, three broad issues which have arisen from considering the evaluation as a whole. These are the size and scope of the evaluation, interviewing women with long-term mental health problems, and the attempts made to overcome the limitations of the pluralistic approach to evaluation. These will be considered in turn.

First, there is no doubt that the size and scope of this evaluation was ambitious. As was described in chapter four, the RCCS is a large, multi-faceted and geographically dispersed service which provides care for up to 500 people with long-term mental health problems. In addition the RCCS has links with a range of facilities provided by the voluntary, private and social services sectors. Considerable time was spent in the initial stages of the evaluation simply becoming familiar with the organization and structure of the service. Gaining access was also very time consuming as it did not only take place at the start of the evaluation but was a continuous process throughout the data collection period (see chapter four). The design of the six studies which make up the evaluation also required considerable fieldwork. The data collection period alone took over three years and necessitated constant perseverance, good time management, and organizational skills. Despite attempts to keep to a detailed planned timetable there were inevitable problems with collecting the data. Consequently the data collection for one study often overlapped with another. This not only made it difficult to reflect on the findings of one study before embarking on the next, but to consider the emerging findings as a whole.

These limitations however, do not detract from the fact that this is the first, and to the researcher's knowledge, the only pluralistic evaluation of the experiences of women with long-term mental health problems receiving care within a long-term community based service. The use of multiple methods of data collection to gather data from the service providers and women with long-term mental health problems generated findings which not only substantiated previous research but also generated new knowledge. For example, the findings of the six studies clearly highlight the ways in which the service was successful in meeting the needs of women with long-term mental health problems, and the many gaps in existing provision (see section 10.2). In addition the findings as a whole illustrate the impact of current mental health policy on the lives of these women and the range of forces which appear to determine their marginalised role and status within the community (see section 10.3).

Second, eliciting the views of women with long-term mental health problems presented a number of challenges. These included the problems of getting access to the women, the time spent gaining their trust and that of their key workers, and managing sensitive issues which were discussed in the focus groups (see chapter nine, section 9.4.2). The findings from chapter nine demonstrate that women with long-term mental health problems are able to talk in some depth about issues that concern them and make pertinent comments about existing services and ways they could be improved.

The very real problems of women with long-term mental health problems and the difficulties experienced by service providers trying to help them were reinforced by the many additional events which were observed during the data collection period and recorded in a fieldwork diary. For example, witnessing a group of service providers trying to decide whether or not to advise a female client to leave her abusive partner. Some of the staff felt strongly that the client should be helped to leave, whereas others felt that such interference infringed the woman's rights to choose her partners. Or, visiting a female client just before Christmas for one of the follow-up interviews described in chapter seven. The woman apologized for the lack of Christmas cards and decorations but said that there was little point bothering to make an effort as she had no friends or family to celebrate with anyway. Such events inevitably influenced the researcher's thinking. It could be argued however, that it would have been difficult to spend such a long time in the service without becoming involved in the day to day lives of the clients and staff. Furthermore, such experiences enabled this thesis to be written with feeling rather than detachment.

Third, the limitations of the pluralistic approach to evaluation raised a number of dilemmas concerning the selection of evaluation criteria, judging the success of the RCCS in meeting the needs of women with long-term mental health problems, and the role of the researcher in this process (see chapter four, section 4.3; chapter ten, section 10.2). These dilemmas stemmed from the fact that it was difficult to adhere rigidly to the principles of the pluralistic approach whilst attempting to avoid going round and round in circles rather than moving forward towards a 'reasonable' version of reality in order to make recommendations for policy and practice. These dilemmas are not peculiar to this evaluation but are increasingly being addressed in a growing critique of the limitations and problems of interpretivist approaches to evaluation (c.f. Cook and

Shadish 1986, Adelman 1996, Kushner 1996, Pawson 1996, Murphy et al 1998). This critique highlights that there is no perfect method of generating evaluation criteria (Cook and Shadish 1986); that although the stakeholders may see a service in different ways, there is no reason to avoid using a single set of evaluation criteria which can encompass multiple perspectives (Kushner 1996); that it is reasonable for the evaluator to defend choices regarding examples of good and poor practice (Kushner 1996); and that there is a level of reality that can be agreed on without compromising the notion of pluralism. Pluralism is then viewed as variation in perspectives which owes less to cognition and more to situational differences (Kushner 1996). The issue of needing to move towards a linear advance on the truth has also been emphasized by Pawson (1996), and with particular reference to health services research by Murphy et al (1998). The overall thrust of the critique is perhaps best summed up by Pawson (1996) when he suggests that the way forward for interpretivist evaluations is a "healthy dose of horses-for-courses pragmatism".

The pluralistic model of evaluation was therefore the starting point and main inspiration for this investigation. However, certain aspects of the model were modified in order to fit in with the unique combination of problems posed by the complexity of the RCCS and with the need to move beyond merely presenting the perspectives of each of the stakeholders (see chapter four, section 4.3). The work of Everitt and Hardiker (1996) was used to support the researcher's view that the voices and experiences of the women with long-term mental health problems should be at the forefront of this evaluation. The critique of interpretivist evaluation outlined above was drawn upon to support the approach taken to making decisions concerning the choice of evaluation criteria, judgements regarding the success of the RCCS in meeting the needs of women with long-term mental health problems which drew on evidence generated in the six studies presented in chapters five to nine, and recommendations for policy and practice.

The issues raised in this thesis suggest a number of directions for further research:

- Prior to an education campaign aimed at helping the public to understand the realities rather than the myths of mental health problems, there is a need to explore how women with mental health problems are viewed by the public. Are there differences in the way in which men and women with mental health problems are perceived ? Why are they perceived differently ?

- The complex role of service providers working with women with long-term mental health problems needs to further explored. How do they view their current role ? How do they view the impact of current mental health policy on the way they work with these women ? What kinds of tensions do they experience in their day to day work ? How do they manage and resolve these tensions ? Does the nature of their work impact on their private lives ?

- There is a need to explore the resistance by services towards inter-agency working (c.f. Department of Health 1999). Why are service providers in health settings often reluctant to meaningfully engage with a range of social care, voluntary and private facilities ? What are the barriers to inter-agency working ? Are there any differences in the level of collaboration between decision makers and grassroots workers, or between managers and professionals?

- The issue of domestic violence experienced by women with long-term mental health problems featured strongly in this evaluation. There is a need to further explore domestic violence by conducting a comprehensive exploratory study looking at prevalence, precipitating factors, risk factors, impact on the women, and responsiveness of services.

10.6 Conclusion

This thesis has presented a pluralistic evaluation of the services provided for women with long-term mental health problems receiving care and support within the RCCS in Nottingham. The rationale for beginning this research was that, whilst the specific problems experienced by women with long-term mental health problems had been extensively documented in the literature (see chapter two), little was known about their experiences within mental health services (c.f. Perkins and Rowland 1991), and even less about what the women themselves feel about the services they receive. The thesis has contributed to current knowledge about the experiences of such women in the following ways.

First, this is the only pluralistic evaluation of the experiences of women with long-term mental health problems receiving care and support within a long-term community based service. The findings of the six studies which make up the evaluation clearly highlight the ways in which the service was successful in meeting these women's needs, and the many gaps in existing provision. It has also been demonstrated that women with long-term mental health problems can give coherent and comprehensive accounts of their experiences and their voices should therefore be included in future evaluations of community based services.

Second, the findings illuminate the current predicament of women with long-term mental health problems which is that they remain excluded and marginalised from the communities where they are now living. The process of exclusion takes many forms but includes the perpetuation of 'difference', the double disadvantages of gender and profound social disabilities, stigma, the increased surveillance into every aspect of their public and private lives, the current policy emphasis on public safety which creates conflicts for service providers wanting to promote these women's inclusion into the community, and the differences in the discursive practices of service providers which inhibits the development and maintenance of a women-centered discourse.

Third, a number of recommendations for policy and practice have been identified. These go beyond the previous recommendations for 'women friendly' services which treat women with mental health problems as a homogeneous group (c.f. MIND 1992, 1993a), towards suggestions which pertain specifically to women with long-term mental health problems. These recommendations will be useful for clinicians and managers wanting to develop services to better meet these women's needs, and as criteria for the future evaluation of services.

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Appendix A

Data collection tool - Form A

Socio-demographic characteristics

Client's full name: --

Client's current address: --

I.D. Number: (   )

Care manager: ----------------------------------

Date of Birth: ----------------------------------

Age: ----------------------------------

Gender:
1.male, 2.female (   )

Marital status:
1.single, 2.married, 3.cohabiting, 4. separated, 5.divorced, 6.widowed (   )

Ethnicity:
1.White, 2.Afro Caribbean, 3.Asian, 4.African, 5.Other (   )

Type of accommodation (current or usual)
1.independent accommodation without professional support as part of housing. 2.community supported accommodation with professional support as part of housing. 3.hospital. 4. Private registered homes, hostels. 5.homeless (   )

Who does the client live with ?
1.alone(inc.hostel,hospital), 2.with friends, 3.with spouse/cohabitee, 4.with spouse/cohabitee and children, 5.lone adult and children, 6.with parents, 7.with other family, 8.N.F.A. (   )

Has the client any children and where do they live ?
1.with client, 2.with relative, 3.in-care/fostered, 4.adopted, 5.other

Child one:	**age**	**( )**	**Where living**	**( )**
Child two	**age**	**( )**	**Where living**	**( )**
Child three:	**age**	**( )**	**Where living**	**( )**
Child four:	**age**	**( )**	**Where living**	**( )**

What was the client's last job ? ....

When did they last work ? ....

Work:
1.in paid work, 2.in unpaid work, 3.in sheltered work, 4.retired,
5.student, 6.houseperson, 7.unemployed. ( )

Work arrangements:
1.full-time, 2.part-time, 3.casual ( )

Appendix B

Data collection tool - *Form B*

Psychiatric diagnosis and history

Client's full name: ------------------------------------

I.D. Number: ( )

Primary Diagnosis:
0.unknown, 1.none, 2.schizophrenia, 3.major depression,
4. manic depressive disorder, 5.schizo-affective disorder,
6.mental retardation, 7.alcohol dependency, 8.other drug dependency,
9.organic brain syndrome, 10.other psychosis,
11.non-psychotic mental disorder ( )

Secondary Diagnosis:
(code as above) ( )

Section of Mental Health Act:
1.unknown, 2.none, 3.s.2, 4.s.3, 5.s.37, 6.s.37/41,
7.guardianship order, 8.other ( )

Year of first psychiatric contact: -----

Number of psychiatric admissions: -----

Duration of longest admission (months): -----

Total duration of admissions (months): -----

Please list current prescribed medication:

1.____

2.____

3.____

4.____

5.____

Has this client any chronic medical conditions or physical disabilities ?
(Please specify)

1.____

2.____

3.____

4.____

Has this client a record of drug or alcohol abuse ?
(Please specify)

Has the client a record of violence towards people or property ?
(Please specify)

Has the client ever been in prison or in a special hospital ?
(Please give details)

Appendix C

Data collection tool - Form C

Service use

Client's full name: ....

I.D. Number: ( )

Please list the services this client uses at present as comprehensively as possible; include frequency.

Residential:

1.____

2.____

3.____

Day Care:
(Eg. NHS, social services, drop-ins, family first, voluntary services etc).

1.____

2.____

3.____

4.____

Outreach:
(Eg. case management, DISH, district nurse, home help, physiotherapy, meals on wheels, voluntary services worker etc)

1.____

2.____

3.____

4.____

Appendix D

Life Skills Profile

Instruction:

Please complete the form (on the inside pages) as you assess __________'s general functioning (i.e. not during crises when he or she is ill, or becoming ill, but his or her general state over the past three months).

Answer all items by circling the appropriate description.

Example:

For example, if you consider that the person generally shows a particular behaviour only 'rarely' you would place a circle as below:

Always Usually [✓ Rarely] Never

For rights, permissions, forms and scoring manuals, contact Professor G. Parker or Dr A. Rosen at the School of Psychiatry, University of New South Wales, The Prince of Wales Hospital, Randwick 2031, Australia.

1. **Does this person generally have any difficulty with initiating and responding to conversation?**

No difficulty with conversation	Slight difficulty with conversation	Moderate difficulty with conversation	Extreme difficulty with conversation

2. **Does this person generally intrude or burst in on others' conversation (e.g. interrupts you when you are talking)?**

Not intrusive at all	Slightly intrusive	Moderately intrusive	Extremely intrusive

3. **Does this person generally withdraw from social contact?**

Does not withdraw at all	Withdraws slightly	Withdraws moderately	Withdraws totally or near totally

4. **Does this person generally show warmth to others?**

Considerable warmth	Moderate warmth	Slight warmth	No warmth at all

5. **Is this person generally angry or prickly towards others?**

Not angry at all	Slightly angry	Moderately angry	Extremely angry

6. **Does this person generally take offence readily?**

Doesn't take offence	Somewhat ready to take offence	Quite ready to take offence	Extremely ready to take offence

7. **Does this person generally make eye contact with others when in conversation?**

Appropriate eye contact	Slightly reduced eye contact	Moderately reduced eye contact	Extremely reduced or no eye contact

8. **Is it generally difficult to understand this person because of the way he or she speaks (e.g. jumbled, garbled or disordered)?**

Not at all difficult	Slightly difficult	Moderately difficult	Extremely difficult

9. **Does this person generally talk about odd or strange ideas?**

No odd ideas	Slightly odd ideas	Moderately odd ideas	Extremely odd ideas

10. **Is this person generally well groomed (e.g. neatly dressed, hair combe**

Well groomed	Moderately well groomed	Poorly groomed	Extrem poorly groom

11. **Is this person's appearance (facial appearance, gestures) generally appropriate to his or her surroundings?**

Unremarkable or appropriate	Slightly bizarre or inappropriate	Moderately bizarre or inappropriate	Extreme bizarre inappropria

12. **Does this person wash himself or herself without reminding?**

Generally	Occasionally	Rarely	Nev

13. **Does this person generally have an offensive smell (e.g. due to body, breath or clothes)?**

Not at all	Smells slightly	Smells moderately	Smel a l

14. **Does this person wear clean clothes generally, or ensure that they are cleaned if dirty?**

Maintains cleanliness of clothes	Moderate cleanliness of clothes	Poor cleanliness of clothes	Very poo cleanlines of clothe

15. **Does this person generally neglect her or his physical health?**

No neglect	Slight neglect of physical problems	Moderate neglect of physical problems	Extrem neglect physic problem

16. **Does this person generally maintain an adequate diet?**

No problem	Slight problem	Moderate problem	Extrem probler

17. **Does this person generally look after and take her or his own prescribed medication (or attend for prescribed injections on time) without remindi**

Reliable with medication	Slightly unreliable	Moderately unreliable	Extremel unreliabl

18. **Is this person willing to take psychiatric medication when prescribed by a doctor?**

Always	Usually	Rarely	Neve

19. **Does this person co-operate with health services (e.g. doctors and/or ot health workers)?**

Always	Usually	Rarely	Neve

20. Is this person generally inactive (e.g. spends most of the time sitting or standing around doing nothing)?

Appropriately active	Slightly inactive	Moderately inactive	Extremely inactive

21. Does this person generally have definite interests (e.g. hobbies, sports, activities) in which he or she is involved regularly?

Considerable involvement	Moderate involvement	Some involvement	Not involved at all

22. Does this person attend any social organisation (e.g. church, club or interest group but excluding psychiatric therapy groups)?

Frequently	Occasionally	Rarely	Never

Can this person generally prepare (if needed) her or his own food/meals?

Quite capable of preparing food/meals	Slight limitations	Moderate limitations	Totally incapable of preparing food/meals

24. Can this person generally budget (if needed) to live within his or her means?

Quite capable of budgeting	Slight limitations	Moderate limitations	Totally incapable of budgeting

25. Does this person generally have problems (e.g. friction, avoidance) living with others in the household?

No obvious problems	Slight problems	Moderate problems	Extreme problems

What sort of work is this person generally capable of (even if unemployed, retired or doing unpaid domestic duties)?

Capable of full-time work	Capable of part-time work	Capable only of sheltered work	Totally incapable of work

27. Does this person behave recklessly (e.g. ignoring traffic when crossing the road)?

Not at all	Rarely	Occasionally	Often

28. Does this person destroy property?

ot at all	Rarely	Occasionally	Often

29. Does this person behave offensively (includes sexual behaviour)?

ot at all	Rarely	Occasionally	Often

30. Does this person have habits or behaviours that most people find unsociable (e.g. spitting, leaving lighted cigarette butts around, messing up the toilet, messy eating)?

Not at all	Rarely	Occasionally	Often

31. Does this person lose personal property?

Not at all	Rarely	Occasionally	Often

32. Does this person invade others' space (rooms, personal belongings)?

Not at all	Rarely	Occasionally	Often

33. Does this person take things which are not his or hers?

Not at all	Rarely	Occasionally	Often

34. Is this person violent to others?

Not at all	Rarely	Occasionally	Often

35. Is this person violent to him or her self?

Not at all	Rarely	Occasionally	Often

36. Does this person get into trouble with the police?

Not at all	Rarely	Occasionally	Often

37. Does this person abuse alcohol or other drugs?

Not at all	Rarely	Occasionally	Often

38. Does this person behave irresponsibly?

Not at all	Rarely	Occasionally	Often

39. Does this person generally make and/or keep up friendships?

Friendships made or kept up well	Friendships made or kept up with slight difficulty	Friendships made or kept up with considerable difficulty	No friendships made or none kept up

Appendix E

Codebook: Variable description and codes for study describing and comparing men and women with long-term mental health problems using the Rehabilitation and Community Care Service

Variable name	Values	Value names	Variable labels
ID	1 to 500		client name code
age			age as of 1/1/94
sex	1 2	male female	sex of clients
marital	1 2 3 4 5 6	single married cohabiting separated divorced widowed	marital status
ethnic	1 2 3 4 5	white afro/caribbean asian african other	ethnicity
accom	1 2 3 4 5	unsupp (ind, family, DISH) comm-supp hosp non prof supp homeless	current or usual type of accommodation
work	1 2 3 4 5 6 7	paid unpaid sheltered retired student houseperson unemp	
workarr	1 2 3 4	full part casual not applicable	work arrangements

primdiag	1 2 3 4 5 6 7 8 9 10 11	unknown / none schiz depression mandep schizaff mentretard alch drug org otherpsych nonpsych	primary diagnosis
secdiag	1-11	as above	secondary diagnosis
mha	1 2 3 4 5 6 7	unknown / none sec 2 sec 3 sec 37 sec 37/41 guardian other	section of mental health act
yfpc			year of first psychiatric contact
admis			number of psychiatric admissions
durad			duration of longest admissions (months)
totad			total duration of admissions (months)
livarr	1 2 3 4 5 6 7	alone (inc indep, hosp, hostel) friends spouse/cohabitee spouse/cohabitee/kids kids parents othfam	who client lives with
child	1 2	yes no	children
child1ag			child age as 1/1/94
child1lv	1 2 3 4 5 6	client relative incare adopted other not applicable	Where child lives
child2ag			child age as 1/1/94

child2lv	1-5	as above	where child lives
child3ag			child age as 1/1/94
child3lv	1-5	as above	where child lives
child4ag			child age as 1/1/94
child4lv	1-5	as above	where child lives
lastjob	1 2 3 4 5 6 7 8	professional employer/man intermed/nonman junior/nonman skilledman semiskill unskilledman never worked	last job
lastwork	1 2 3 4 5 6 7	< 1 year 1-2 years 3-5 years 6-10 years 11-20 years > 20 years not applicable	years since last worked
psychmed	1 2 3 4 5	majtranq mintranq antidep combine, majtranq, antidep none	currently prescribed psychotropic medication
chronmed	1 2	yes no	chronic medical condition
physdis	1 2	yes no	physical disability
histabus	1 2	yes no	history of drug or alcohol abuse
histviol	1 2	Yes no	history of violence
histpris	1 2	Yes no	history of prison/special hospital
resid	1 2 3 4	hosp comm prof comm priv/charity none	residential services
mansman	1 2	Yes no	daycare: RCCS day centres

span	1 2	Yes no	daycare: skills and practical activity network
socserv	1 2	Yes no	daycare: social services
volserv	1 2	Yes no	daycare: voluntary organizations, charity, self help
educ	1 2	Yes no	daycare: education and training
careman	1 2	Yes no	outreach services: community rehabilitation teams (care management)
dish	1 2	Yes no	outreach services: community support teams (dish)
acutekey	1 2	Yes no	outreach services: acute sector key worker
discnurs	1 2	Yes no	outreach services: district nurse / auxiliary
volchar	1 2	Yes no	outreach services: private sector or charity worker, volunteer
socserv2	1 2	Yes no	Outreach services: home help, meals on wheels
ot	1 2	Yes no	outreach services: community OT
selfcare			LSP - self-care
nonturb			LSP - non-turbulence
socont			LSP - social contact
commun			LSP - communication
respons			LSP responsibility
lsptotal			LSP total score
Transformations			
agepsych			age at first contact with the psychiatric services
child18	1 2	under 18 over 18	dependent children

childlv	1 2 3 4 5 6	client relative incare adopted other not applicable	where children under 18 are living
daycare	1 2 3	one two or more none	number of day care services used
outreach	1 2 3	one two or more none	number of outreach services used
maritnew	1 2	single, separated, divorced, widowed married, cohabiting	marital status
marital 3	1 2	single married, cohabiting, separated, divorced, widowed	past and current marital status
worknew	1 2	employed unemployed, sheltered work, retired	employment status
livenew	1 2	alone with friends, spouse, kids, parents, family	living arrangements
diagnew	1 2 3	other schizophrenia major affective disorder	Primary diagnosis
residnew	1 2 3	hospital supported housing none	residential services
mhanew	1 2	no section section 2, 3 etc	section of the mha
caredish	1 2	yes no	attached to community rehabilitation teams (care management) or community support teams (dish)

Appendix F

Results from study describing and comparing men and women with long-term mental health problems using the Rehabilitation and Community Care Service.

1. Socio-demographic characteristics of the clients (N=480).

		Men		Women	
Number:		65.8%	316	34.2%	164
Age:	Mean	48.34		51.10	
	SD	14.92		15.31	
	Range	63.00 (19-82 yrs)		65.00 (21-86 yrs)	

(Number of missing observations = 0).

		Men		Women	
Marital status:	Single	81.3%	257	61.6%	101
	Married	5.7%	18	7.3%	12
	Cohabiting	-		0.6%	1
	Separated	1.9%	6	1.8%	3
	Divorced	10.1%	32	17.7%	29
	Widowed	0.9%	3	11%	18

(Number of missing observations = 0)

		Men		Women	
Marital status:	Single, sep, div,wid	94.2%	295	91.8%	134
	Married, cohabitating	5.8%	18	8.2%	12

(Number of missing observations = 0)

		Men		Women	
Marital status:	Single	81.3%	257	61.6%	101
	Currently or previously married	18.7%	59	38.4%	63

(Number of missing observations = 0

		Men		Women	
Ethnicity:	White	89.2%	282	90.2%	148
	Afro/caribbean	7.3%	23	4.9%	8
	Asian	1.6%	5	4.3%	7
	African	0.3%	1	-	
	Other	1.6%	5	0.6%	1

(Number of missing observations = 0)

		Men		Women	
Accommodation:	Unsupported	39.2%	124	40.2%	66
	Comm-supported	7.6%	24	16.5%	27
	Hospital	15.5%	49	11.0%	18
	Non-prof supp	37.3%	118	32.3%	53
	Homeless	0.3%	1	-	

(Number of missing observations = 0)

		Men		Women	
Work:	Paid	2.2%	7	1.2%	2
	Unpaid	0.3%	1	-	
	Sheltered	2.8%	9	2.4%	4
	Retired	15.5%	49	24.4%	40
	Student	0.3%	1	0.6%	1
	Houseperson	0.3%	1	1.8%	3
	Unemployed	78.5%	248	69.5%	114

(Number of missing observations = 0)

Employment status:	Employed	2.2%	7	1.2%	2
	Unemployed	97.8%	309	98.8%	162

(Number of missing observations = 0)

Work arrangements:	Full time	1.6%	5	0.6%	1
	Part time	3.8%	12	3%	5
	Casual	-		-	
	Not applicable	94.3%	298	96.3%	158

(Number of missing observations = 0)

Last job:	Professional	2.6%	8	1.3%	2
	Employer / manager	1%	3	0.6%	1
	Intermediate / non-manager	4.6%	14	3.8%	6
	Junior / non-manager	6%	18	13.9%	22
	Skilled manual	13.6%	41	4.4%	7
	Semi-skilled manual	15.6%	47	4.4%	7
	Unskilled manual	21.2%	64	21.5%	34
	Never worked	35.4%	107	50%	79

(Number of missing observations = 20)

Years since last worked:	< 1 year	1.7%	5	2.5%	4
	1-2 years	1%	3	1.3%	2
	3-5 years	5.3%	16	4.5%	7
	6-10 years	9.9%	30	6.4%	10
	11-20 years	22.2%	67	14%	22
	> 20 years	24.2%	73	19.7%	31
	Not applicable	35.8%	108	51.6%	81

(Number of missing observations = 21

	Men		Women	
Who the client lives with				
Alone (inc. hospital, hostel etc)	82.2%	249	74.7%	118
Friends	1.3%	4	3.8%	6
Spouse / cohabitee	4.3%	13	10.1%	16
Spouse / cohabitee / children	2%	6	1.3%	2
Alone with children	-		1.9%	3
Parents	9.6%	29	6.3%	10
Other family	0.7%	1	1.9%	3

(Number of missing observations = 19)

		Men		Women	
Living arrangements:	Alone	82.5%	250	76.6%	121
	With family, friends	17.5%	53	23.4%	37

(Number of missing observations = 19)

	Men		Women	
Number of clients with children	16.0%	50	28.8%	47

(Number of missing observations - 20)

	Men		Women	
Number of clients with dependent children	4.6%	14	10.3%	17

(Number of missing observations = 20)

	Men		Women	
Where the dependent children live				
With client	14.3%	2	35.3%	6
With relative	71.4%	10	29.4%	5
In care	7.1%	1	23.5%	4
Adopted	7.1%	1	11.8%	2

2. Psychiatric diagnosis and history (N = 480)

	Men		Women	
Primary diagnosis				
Schizophrenia	71.6%	217	68.4%	106
Depression	4.6%	14	8.4%	13
Manic depression	8.9%	27	6.5%	10
Schizo-affective disorder	0.3%	1	-	
Mental retardation	0.7%	2	0.6%	1
Alcohol dependency	1.3%	4	0.6%	1
Drug dependency	-		-	
Organic psychosis	2.6%	8	0.6%	1
Other psychosis	1.7%	5	3.2%	5
Non-psychotic mental disorder	8.3%	25	11.6%	18
Unknown / None	-		-	

(Number of missing cases = 22)

		Men		Women	
Primary diagnosis:	Other	14.5%	44	16.8%	26
	Schizophrenia	71.9%	218	68.4%	106
	Major affec. disorder	13.5%	41	14.8%	23

(Number of missing cases - 22)

Secondary diagnosis

Schizophrenia	2%	6	1.9%	3
Depression	0.7%	2	2.6%	4
Manic depression	1.7%	5	0.6%	1
Schizo-affective disorder	0.7%	2	1.3%	2
Mental retardation	3.3%	10	8.4%	13
Alcohol dependency	-		1%	2
Drug dependency	0.7%	2	-	
Organic psychosis	1.3%	4	3.9%	6
Other psychosis	1.3%	4	2.6%	4
Non-psychotic mental disorder	5.3%	16	3.2%	5
Unknown / none	83.2%	252	74.2%	115

(Number of missing cases = 22)

Section of Mental Health Act

None	95%	288	96.8%	150
Section 2	0.7%	2	0.6%	1
Section 3	3.3%	10	1.9%	3
Section 37	-		-	
Section 37/41	0.7%	2	0.6%	1
Other	0.3%	1	-	

(Number of missing observations = 22)

Section of Mental Health Act

Section	5%	15	3.2%	5
No Section	95%	288	96.8%	150

(Number of missing observations - 22)

Age at first contact with the psychiatric services

Mean	27.48	28.95
SD	10.30	11.40
Range	4-64 (60 years)	3-70 (67 years)

Number of psychiatric admissions

Mean	3.36	3.62
SD	3.10	2.80
Range	19 (0-19)	15 (0-15)

(Number of missing observations = 22)

	Men		Women	
Duration of longest admission (months)				
Mean	46.34		51.14	
SD	93.27		111.29	
Range	671 (0-671 mths)		594 (0-594 mths)	
(Number of missing observations = 22)				
Total duration of admissions (months)				
Mean	54.23		57.99	
SD	98.05		113.07	
Range	671 (0-671)		594 (0-594)	
(Number of missing observations = 22)				
Currently prescribed psychotropic medication				
Major tranquillizers	64.2%	194	64.8%	103
Minor tranquillizers	0.7%	2	1.9%	3
Anti-depressants	5.3%	16	5.7%	9
Combination of major tranquillizers & anti-depressants	12.6%	38	12.6%	20
None	17.2%	52	15.1%	24
(Number of missing observations = 19)				
Reported chronic medical condition	29.1%	88	34.2%	54
(Number of missing observations = 20)				
Reported physical disability	8.6%	26	5.7%	9
(Number of missing observations = 20)				
Reported history of alcohol, drug or solvent abuse	20.9%	63	14.6%	23
(Number of missing observations = 20)				
Reported history of violence towards people or property	40.4%	122	21.5%	34
(Number of missing observations - 20)				
Reported history of prison or special hospital	16.6%	50	8.2%	13
(Number of missing observations = 20)				

3. Use of psychiatric services (N = 480)

(Number of missing observations = 20)

	Men		Women	
Use of residential services				
Hospital	18.2%	55	9.5%	15
Community supported accommodation with professional support as part of housing	7.6%	23	12%	19
Private registered homes and voluntary agencies with non-professional support as part of housing	20.8%	63	19%	30
None	53.5%	162	59.5%	94
Use of residential services				
Hospital	18.2%	55	9.5%	15
Supported housing	28.4%	86	31%	49
None	53.5%	162	59.5%	94
Use of day care services (RCCS day centres)	32.8%	99	24.1%	38
Use of day care services (SPAN)	17.2%	52	12%	17
Use of day care services (Social Services)	9.3%	28	9.5%	15
Use of voluntary organizations, self-help groups, drop-ins	12.9%	39	8.2%	13
Use of education and training facilities	2%	6	2.5%	4
Number of daycare services used				
None	53.6%	162	60.8%	96
One	33.1%	100	29.1%	46
Two or more	13.2%	40	10.1%	16
Use of outreach services (Community Rehabilitation Teams, Care management)	89.1%	269	87.3%	138
Use of outreach services (Community Support Teams, DISH)	12.3%	37	16.5%	26
Attached to Community Rehabilitation Teams or Community Support Teams:	95.4%	288	98.1%	138
Use of outreach services (acute sector key worker)	-		-	
Use of outreach services (district nurse / auxillary)	1%	3	3.8%	6

	Men		Women	
Use of outreach services (private sector or charity worker, volunteer)	6.3%	19	5.1%	8
Use of outreach services (Social services - home help, meals on wheels)	5.6%	17	6.3%	10
Use of outreach services (community occupational therapist)	5%	15	6.4%	10
Number of outreach services used				
None	4.3%	13	1.9%	3
One	75.8%	229	76.6%	121
Two or more	19.5%	59	21.5%	34

4. Level of functioning:

(Measured by Life Skills Profile, Parker & Rosen 1989)

(Number of missing observations = 21)

	Men	Women
Life skills profile: total score		
Mean	118.19	119.67
SD	16.77	17.00
Range	101.00	77.00
Life skills profile: self-care		
Mean	28.69	29.73
SD	6.29	6.25
Range	38.00	27.00
Life skills profile: non-turbulence		
Mean	40.21	40.50
SD	6.06	6.07
Range	31.00	26.00
Life skills profile: social contact		
Mean	14.17	14.38
SD	4.58	4.09
Range	34.00	17.00
Life skills profile: communication		
Mean	18.91	18.85
SD	3.55	3.60
Range	18.00	15.00
Life skills profile: responsibility		
Mean	16.12	16.33
SD	2.80	3.17
Range	13.00	22.00

5. Differences between the men and the women

Variable	Type of data	Statistical test	Result
Age as of 1/1/94 (age)	interval	Independent sample t-test	p=0.06
Marital status (marital)	nominal	chi-square	$X^2=37.68$, df=5 p=<0.001
Marital status (maritnew)	nominal	chi-square	$X^2=0.99$, df=1 p=0.31
Past and current marital status (marital3)	nominal	chi-square	$X^2=22.20$, df=1 p=<0.001
Ethnicity (ethnic)	nominal	chi-square	$X^2=5.42$, df=4 p=0.25
Work (work)	nominal	chi-square	$X^2=10.10$, df=6 p=0.12
Employment status (worknew)	nominal	chi-square	$X^2=0.58$, df=1 p=0.44
Work arrangements (workarr)	nominal	chi-square	$X^2=1.55$, df=3 p=0.67
Last job (lastjob)	nominal	chi-square	$X^2=33.51$, df=7 p=<0.01
Years since last worked (lastwork)	nominal	chi-square	$X^2=12.88$, df=6 p=0.45
Who the client lives with (livarr)	nominal	chi-square	$X^2=18.11$, df=6 p=<0.05
Living arrangements (livenew)	nominal	chi-square	$X^2=2.32$, df=1 p=0.12
Number of clients with children (child)	nominal	chi-square	$X^2=10.92$, df=1 p=<0.001
Number of clients with dependent children (child18)	nominal	chi-square	$X^2=0.74$, df=1 p=0.34
Where the dependent children live (childlv)	nominal	chi-square	$X^2=5.56$, df=3 p=0.13
Primary diagnosis (primdiag)	nominal	chi-square	$X^2=8.80$, df=8 p=0.36

Primary diagnosis (diagnew)	nominal	chi-square	$X^2=0.64$, df=2 p=0.72
Secondary diagnosis (secdiag)	nominal	chi-square	$X^2=20.32$, df=10 p=<0.05
Section of mental health act (mha)	nominal	chi-square	$X^2=1.21$, df=4 p=0.88
Section of the mental health act (mhanew)	nominal	chi-square	$X^2=0.73$, df=1 p=0.39
Age at first contact with the mental health services (agepsych)	interval	Independent sample t-test	p=0.37
Number of psychiatric admissions (admis)	interval	Independent sample t-test	p=0.66
Duration of longest admission (durad)	interval	Independent sample t-test	p=0.31
Total duration of admissions (totad)	interval	Independent sample t-test	p=0.37
Currently prescribed psychotropic medication (psychmed)	nominal	chi-square	$X^2=1.75$, df=4 p=0.78
Reported chronic medical condition (chronmed)	nominal	chi-square	$X^2=1.23$, df=1 p=0.26
Reported physical disability (physdis)	nominal	chi-square	$X^2=1.25$, df=1 p=0.26
Reported history of drug, alcohol or solvent abuse (histabus)	nominal	chi-square	$X^2=2.71$, df=1 p=0.09
Reported history of violence towards people or property (histviol)	nominal	chi-square	$X^2=16.49$, df=1 p=<0.01
Reported history of prison or special hospital (histpris)	nominal	chi-square	$X^2=6.08$, df=1 p=<0.05
Use of residential services (resid)	nominal	chi-square	$X^2=8.21$, df=3 p=<0.05
Residential services (residnew)	nominal	chi-square	$X^2=6.05$, df=2, p=<0.05
Daycare, RCCS day centres (mansman)	nominal	chi-square	$X^2=3.78$, df=1 p=<0.05
Daycare, Skills and Practical Activity Network (span)	nominal	chi-square	$X^2=2.14$, df=1 p=0.14
Daycare, Social Services (socserv)	nominal	chi-square	$X^2=0.0$, df=1 p=0.94

Daycare, voluntary organizations, self-help groups, drop-ins (volserv)	nominal	chi-square	X^2=2.27, df=1 p=0.13
Daycare, education and training (educ)	nominal	chi-square	X^2=0.14, df=1 p=0.70
Number of daycare services used (daycare)	nominal	chi-square	X^2=2.28, df=2 p=0.31
Outreach services, Community Rehabilitation Teams (careman)	nominal	chi-square	X^2=0.30, df=1 p=0.58
Outreach services, Community Support Teams (dish)	nominal	chi-square	X^2=1.55, df=1 p=0.21
Attached to Community rehabilitation Teams or Community Support Teams (caredish)	nominal	chi-square	X^2=2.18, df=1 p=0.13
Outreach services, district nurse/auxillary (discnurs)	nominal	chi-square	X^2=4.25, df=1 p=<0.05
Outreach services, private sector,charity worker, volunteer (volchar)	nominal	chi-square	X^2=0.28, df=1 p=0.34
Outreach services, home help, meals on wheels (socserv2)	nominal	chi-square	X^2=0.09, df=1 p=0.76
Outreach services, community OT (ot)	nominal	chi-square	X^2=0.39, df=1 p=0.53
Number of outreach services used (outreach)	nominal	chi-square	X^2=2.45, df=3 p=0.48
Life skills profile - total score (lsptotal)	interval	Independent sample t-test	p=0.26
Life Skills Profile - self care (selfcare)	interval	“	p=0.07
Life Skills Profile - non turbulence (nonturb)	interval	“	p=0.56
Life Skills Profile - social contact (socont)	interval	“	p=0.53
Life Skills profile - communication (commun)	interval	“	p=0.85
Life Skills Profile - responsibility (respons)	interval	“	p=0.38

Appendix G

Interview Schedule - Rehabilitation and Community Care Service Staff Survey

1. Name of service:

2. Please could you supply any booklets or pamphlets regarding the services that you provide, or briefly explain the nature of the services, (for example, people who use the service, the support and care provided, referral procedures and funding, any special policies or criteria relating to women).

3. What are the special needs or problems of the women who use your services ?

4. What specific services do you provide for these women ?

5. What do you do when women reveal needs or problems not specifically addressed by the service ?

6. Have you had any particular problems with uptake or implementation of specific services for women ? If so, could you give details.

7. Have you any additional comments you would like to make ?

Appendix H

Matrix
Rehabilitation and Community Care Service Staff Survey

Core category: services provided for women	Residential Services: 5 staff gps	Day care services: 4 staff gps	Outreach teams: 2 staff gps	Residential partnership schemes: 5 staff gps
No specific policies for women	3	1	-	4
Equal opportunities policy	1	2	-	1
Women-only house	1	-	-	-
Choice of sex of key worker	2	-	2	1
Women's group	1	4	2	-
Sexual harassment policy	-	1	-	1
Posters advertising specific women's groups and other information	-	-	-	1
Policy on gender awareness	-	1	-	-
Gender awareness training for staff	5	4	2	5
Individualized care	-	-	-	3
Sexuality forum	-	-	1	-
Flexible workshop times to accommodate children	-	2	-	-
Supporting women to access male dominated workshops	-	2	-	-
A women-only woodwork group	-	1	-	-

Core category: strategies for dealing with issues outside the remit of the service	Residential services: 5 staff gps	Day care services 4 staff gps	Outreach teams 2 staff gps	Residential partnership schemes: 5 staff gps
Usually manages issues within the facility	6	3	-	1
Refers on to appropriate outside agencies when need cannot be met within	3	3	2	3
Use of GP for screening purposes	-	-	-	2
Suggest that women contact Nottingham Advocacy Group	-	1	-	-
Outside input can conflict with inside work	-	-	1	-

Sub category: nervousness or wariness of men	Residential services 5 gps staff	Day Care services 4 gps staff	Outreach services 2 gps staff	Residential Partnership Schemes 5 gps staff
Some clients are wary of men	-	-	1	-
Many women are unused to men, little awareness of men	-	-	-	1
Get nervous surrounded by men	-	-	-	1
Often find it difficult sharing accommodation with men	1	-	-	-

Sub category: vulnerability to abuse and violence	Residential services 5 gps staff	Day care services: 4 gps staff	Outreach services 2 gps staff	Residential Partnership schemes 5 gps staff
Pestered by male clients for money and cigarettes	2	-	-	-
Give sexual favours in return for money and cigarettes	1	-	-	1
Many have history of abuse, childhood abuse and/or abusive relationships with men	1	-	-	-
Get asked personal and sexually explicit questions by male clients	1	-	-	-
Vulnerable to abuse both within and outside the services	-	2	1	2
Coerced into sexual relationships they do not want	-	1	-	-
Verbal abuse directed towards appearance, eg. witch	-	-	1	-
Protecting women form abuse can conflict with ideas of integration which staff feel can be a positive experience particularly for men	-	1	-	-
Stereotyped attitudes of male clients - expect women to clear up and do the housework, tend to regard women as second class	1	1	-	1

Sub-category: low confidence and self esteem	Residential services: 5 gps staff	Day care services: 4 gps staff	Outreach teams: 2 gps staff	Residential partnership schemes: 5 gps staff
Low confidence	-	1	1	-
Lack assertiveness skills	-	1	-	-
Low self esteem	-	-	1	-
Loneliness, little family support, lack of stability	-	-	1	-

Sub category: difficulties in finding an appropriate role in life	Residential services: 5 gps staff	Day care services: 4 gps staff	Outreach teams: 2 gps staff	Residential partnership schemes: 5 gps staff
Miss the opportunity to care for others, flock over staff members' babies, want to know about staff's lives	-	1	-	-
Loss regarding not having any children	1	-	-	-
Want to do things for male clients	-	1	-	-
Feels as if they have missed out due to illness	1	-	-	-
Often take on domestic role willingly	1	-	-	-
Delayed teenage needs, friendship, body image, shopping, boyfriends	-	-	1	-

Sub category: physical health issues	Residential services: 5 gps staff	Day care services: 4 gps staff	Outreach teams: 2 gps staff	Residential partnership schemes: 5 gps staff
Reluctant to attend well woman clinics for cervical smears and contraception	1	-	-	-
Lack of attention by staff to physical health needs such as breast screening, cervical smears, menopause	1	-	-	-

Sub category: minority of women in the service	Residential services: 5 gps staff	Day care services: 4 gps staff	Outreach services: 2 gps staff	Residential partnership schemes: 5 gps staff
Minority of women in the service	3	3	2	2
More men referred to the service than women	2	3	2	-
Male culture unwelcoming	-	1	-	-
Few 'traditional' female activities available	-	1	-	-
Men are sent to work to get better, women tend to get pushed into domestic pursuits	-	1	-	-
Domination of men in some activities	-	2	-	-
Much of the work is orientated around gender stereotypes - crafts, arts and catering groups mostly attended by women, woodwork and upholstery groups dominated by men	-	2	-	-

Appendix I

Questionnaire - Survey of organizations outside the Rehabilitation and Community Care Service

1. Name of service:

2. Please could you enclose any booklets or pamphlets regarding the services that you provide, or briefly explain the nature of the services, (for example, people who use the service, the support and care provided, referral procedures and funding, any special policies or criteria relating to women).

3. What are the special needs or problems of the women who use your services ?

4. What specific services do you provide for these women ?

5. What do you do when women reveal needs or problems not specifically addressed by the service ?

6. Are there any women currently using your service who have long-term mental health problems such as schizophrenia or manic depression ?

Yes / No

7. If not, is there are a particular reason for this ?

8. If there are, are you able to adequately meet their needs ?

9. Please feel free to make any additional comments.

Appendix J

Matrix
Survey of organizations outside the Rehabilitation and Community Care Service (n=38)

Core category: specific provision made for women	Registered residential homes (n=7)	Registered charities (n=6)	Voluntary organizations and self help groups (n=10)	Projects funded by Social Services, County Council, Health Authority (n=15)
Only provide service to women	1	3	8	8
Provide a service to men and women	6	2	2	6
Do not make any special provision for women	4	1	-	1
Women-only residential home	1	-	-	-
Needs met on individual basis	3	2	1	5
Free creche	-	-	2	2
Women's groups	-	2	5	8
Women's space and facilities	-	1	3	4
Lesbian group	-	-	-	2
Sessional work with prostitute outreach workers	-	-	-	1
Breast screening	-	-	-	1
Provide a service to women from ethnic minority groups	-	1	1	3
Information and advice on services for women, welfare rights, rights as a patient, physical health	-	2	5	6
Counselling, general support, telephone contact, psychotherapy	-	5	9	11
Refuge for victims of domestic violence	-	1	-	-
Group for women who have been sexually abused	-	-	1	-
Psychological and practical support for women at home with children	-	-	1	2

Alcohol advisory service	-	1	-	-
Social care and support for homeless people	-	1	-	-

Core category: the extent to which services are used by women with long-term mental health problems	**Registered residential homes (n=7)**	**Registered charities (n=6)**	**Voluntary organizations and self help groups (n=10)**	**Projects funded by Social Services, County Council, Health Authority (n=15)**
Currently offer a service to women with long-term mental health problems	5	3	3	14
Prepared to offer a service if able to use the help on offer	2	2	2	1
Do not offer a service to women with long-term mental health problems	-	2	4	-
Cater for women who are not in touch with the statutory mental health services	-	1	1	-
Not geared up to meet the complex needs of women with long-term mental health problems	-	1	1	-
Unknown whether women with long-term mental health problems were using the service	-	1	3	1
Do not ask about women's mental health history	-	1	1	1
Never been approached	-	1	1	-

Core category: the role of services in meeting the needs of women with long-term mental health problems	Registered residential homes (n=7)	Registered charities (n=6)	Voluntary organizations and self help groups (n=10)	Projects funded by Social Services, County Council, Health Authority (n=15)
Assumption that the care manager was coordinating care	7	1	2	8
See themselves as part of an overall package of care	7	1	2	11
Providing a service which is related to clients position or role as women	-	2	4	1

Core category: facilitating the use of services by women with long-term mental health problems	Registered residential homes (n=7)	Registered charities (n=6)	Voluntary organizations and self help groups (n=10)	Projects funded by Social Services, County Council, Health Authority (n=15)
Services unsure about how to facilitate access to women	5	3	3	1
Lack of training and/or information regarding women's particular needs	-	1	1	2
The desirability of working more closely with mental health services as part of an overall package of care	-	1	2	10
Few such women referred	5	-	1	-
Care managers or women do not know about the service	-	1	1	1

Core category: knowledge of needs and problems of women with long-term mental health problems	Registered residential homes (n=7)	Registered charities (n=6)	Voluntary organizations and self help groups (n=10)	Projects funded by Social Services, County Council, Health Authority (n=15)
No needs or problems identified	2	3	4	9
Minority of women using the service, few women referred	5	1	2	2
Isolation, lack of family support, loneliness, miss female company and friendship	2	-	7	3
Vulnerable - harassed for money, cigarettes, sex, company by men, general abuse, domestic violence, sexual abuse	2	1	2	2
Looking after children with little support, fear of children being taken into care	-	2	2	-
Poverty, unemployment, lack of transport, poor housing	-	1	1	2
Low self worth and self esteem, wary of men, lack a role and purpose in life, stigma	2	2	1	1
Relationship difficulties - heterosexual and lesbian	-	-	1	2

Appendix K

QUALITY OF LIFE INTERVIEW

Name of Client ....

Date: ....

Start time of interview: .... End time of interview ....

Name of interviewer: ....

Number of attempts to interview: 1 2 3

Understanding of English ....

0 = good
1 = some difficulty
2 = considerable difficulty

Spoken English ....

0 = good
1 = some difficulty
2 = considerable difficulty

Overall quality of interview ....

0 = good
1 = some difficulty
2 = considerable difficulty

Name of any other person present ....

INTRODUCTION

(As an introduction, begin by checking data collected on sheets A and C)

I am interested in what your life is like, your health, what you do from day-to-day, and how you feel about things. I have some questions about different parts of your life. There are no right or wrong answers, so please relax and take your time in answering.

Before we start, do you have any questions?

SECTION A: GENERAL LIFE SATISFACTION

Please look at this card. (HAND SUBJECT THE DELIGHTED/TERRIBLE SCALE). This is called the Delighted/Terrible Scale (D/T Scale)

The scale goes from Terrible, which is the lowest ranking of 1, to Delighted, which is the highest ranking of 7. You can see that all the points have descriptions below them.

READ POINTS ON THE SCALE.

During the interview we'll be using this scale from time to time to help you tell me how you feel about different things in your life. All you have to do is tell me what on the scale best describes how you feel. For example, if I ask, "how do you feel about chocolate ice-cream" and you are someone who loves chocolate ice-cream, you might point to "Delighted". On the other hand, if you hate chocolate ice cream, you might point to "Terrible". If you feel about equally satisfied and dissatisfied with chocolate ice-cream, then you would point to the middle of the scale.

Do you have any questions about the scale? Please show me how you feel about chocolate ice-cream. Let's begin.

The first question is a very general one.

1. How do you feel about your life as a whole? (DT/SCALE) _____

SECTION B: LIVING SITUATION

2. Now I am going to ask you some questions about your living situation: **(Questions refer to most recent residence if patient is currently in the hospital). Skip if homeless or only home is hospital.**

How do you feel about:

A. The home you live in? _____

B. The privacy you have there? _____

C. Whether you can come and go as you please _____

D. The prospect of staying on where you currently live for a long period of time? _____

3. Not using your scale for a moment. Is there any aspect of your home that you would change if you were able?

4. Now look again at the D/T Scale and answer the following:

How do you feel about:

A. The people who live near you? _____

B. The outdoor space there is for you to use outside your home? _____

C. How safe you feel living in this neighbourhood? _____

SECTION C: DAILY ACTIVITIES AND FUNCTIONING

5. Now let's talk about some of the things you did with your time in the past week. I'm going to read you a list of things people may do with their free time. For each of these, please tell me if you did it during the past week. Did you ... (READ OPTIONS A-M)?

(No = 2, Yes = 1, Don't know/refused = -1)

A. Go for a walk? _____

B. Go to the cinema or theatre? _____

C. Watch television? _____

D. Go shopping? _____

E. Go to a restaurant or coffee shop? _____

F. Go to a pub? _____

G. Read a book, magazine or newspaper? _____

H. Listen to a radio? _____

I. Prepare a meal? _____

J. Play a sport? _____

K. Go to a meeting of some organisation or social group? _____
(INCLUDE CARE-RELATED MEETINGS)

L. Go to a park? _____

M. Go to a library? _____

6. Overall, how would you say you are able to function in home and social settings at the present time? Would you say your functioning in these areas is excellent, good, fair or poor?

EXCELLENT 1
GOOD 2
FAIR 3
POOR 4
DK ....-1

7. Now please look at the Delighted/Terrible scale again. How do you feel about (READ OPTIONS A-D)?

A. The way you spend your spare time? ____

B. The amount of time you have to do the things you want to do? ____

C. The amount of fun you have? ____

D. The amount of relaxation in your life? ____

SECTION D: FAMILY

The next few questions are about your relationship with your family.

8. Please look at the Delighted/Terrible scale. How do you feel about: (READ OPTIONS A-C)?

A. Your family in general? ____

B. How often you have contact with your family? ____

C. The way things are between you and your family? ____

SECTION E: SOCIAL RELATIONS

Now I'd like to know about other people in your life, that is, people who are not in your family.

9. Look at the Delighted/Terrible scale. How do you feel about

A. The things you do with other people? ____

B. The amount of time you spend with other people? ____

C. The way you get along with other people in general? ____

D. The amount of friendship in your life ____

E. Your sex life ____

10. If you have a problem have you anyone you can confide in? _____

(No = 2, Yes = 1, Don't Know/Refused = -1)

11. Is there somewhere you go to meet people other than a mental health service of some kind? _____

(No = 2, Yes = 1, DK/R = -1)

12. Do you have any close friends who are not family members? _____

(No = 2, Yes = 1, DK/R = -1)

SECTION F: FINANCES

13. Do you receive benefits at present? _____

(No = 2, Yes = 1, DK/R = -1)

14. Can you remember what the benefits are? (List the response)

15. Now, I'd like you to use the card for the Delighted/Terrible scale again. In general, how do you feel about (READ OPTIONS A-C)?

A. The amount of money you get? _____

B. The amount of money you have to cover basic necessities such as food, housing and clothes? _____

C. The amount of money you have available to spend for fun? _____

SECTION G: WORK AND SCHOOL

16. Do you have a job at the moment? _____

(No = 2, Yes = 1, DK/R = -1)

17. If yes, are you paid for the job? _____

(No = 2, Yes = 1, DK/R = -1)

18. If yes, how much do you get paid per week? _____

19. IF EMPLOYED (Use D/T Scale) How do you feel about:

A. Your job? ____

B. The people you work with? ____

C. What is it like where you work
- the physical surroundings? ____

D. The number of hours you work? ____

E. The amount you get paid? ____

20. How old were you when you left school? ____

21. What qualifications have you got? ____

1 = none, 2 = CSE/GCSE/O Levels,
3 = Vocational Qualifications, 4 = A Levels, 5 = Degree

SECTION H: LEGAL AND SAFETY ISSUES

22. Please look at the Delighted/Terrible scale again. How do you feel about:

Your personal safety on a day to day basis? ____

23. During the last two years have you had any involvement with the police for any reason? ____

No = 2, Yes = 1, DK/R = -1

24. If yes, in what way? ____

1 = Victim, 2 = Witness, 3 = Suspect, 4 = Charged, -1 = DK/R

25. Can you say a bit more about the experience?

SECTION I: HEALTH: MEDICAL OUTCOME STUDY QUESTIONNAIRE

Now I'd like to ask you about your health.

26. In general, would you say your physical health is:

EXCELLENT 1
VERY GOOD 2
GOOD 3
FAIR 4
POOR 5
RF/DK ....-1

27. These questions are about how you feel and how things have been with you <u>during the past month</u>. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the past month:

(1 = All of the time, 2 = Most of the time, 3 = A good bit of the time, 4 = Some of the time, 5 = A little of the time, 6 = None of the time)

A. did you feel full of life? _____

B. have you been a very nervous person? _____

C. have you felt so down in the dumps that nothing could cheer you up? _____

D. have you felt calm and peaceful _____

E. did you have a lot of energy _____

F. have you felt downhearted and blue? _____

G. did you feel worn out? _____

H. have you been a happy person _____

I. did you feel tired _____

J. has your health limited your social activities (like visiting with friends or close relatives) _____

SECTION J: SATISFACTION WITH SERVICES

28. Look at the Delighted/Terrible scale. How do you feel about:

A. the mental health services you are receiving at present? _____

B. the amount of choice you have about the services you receive? _____

C. the amount of control you have over the services you receive? _____

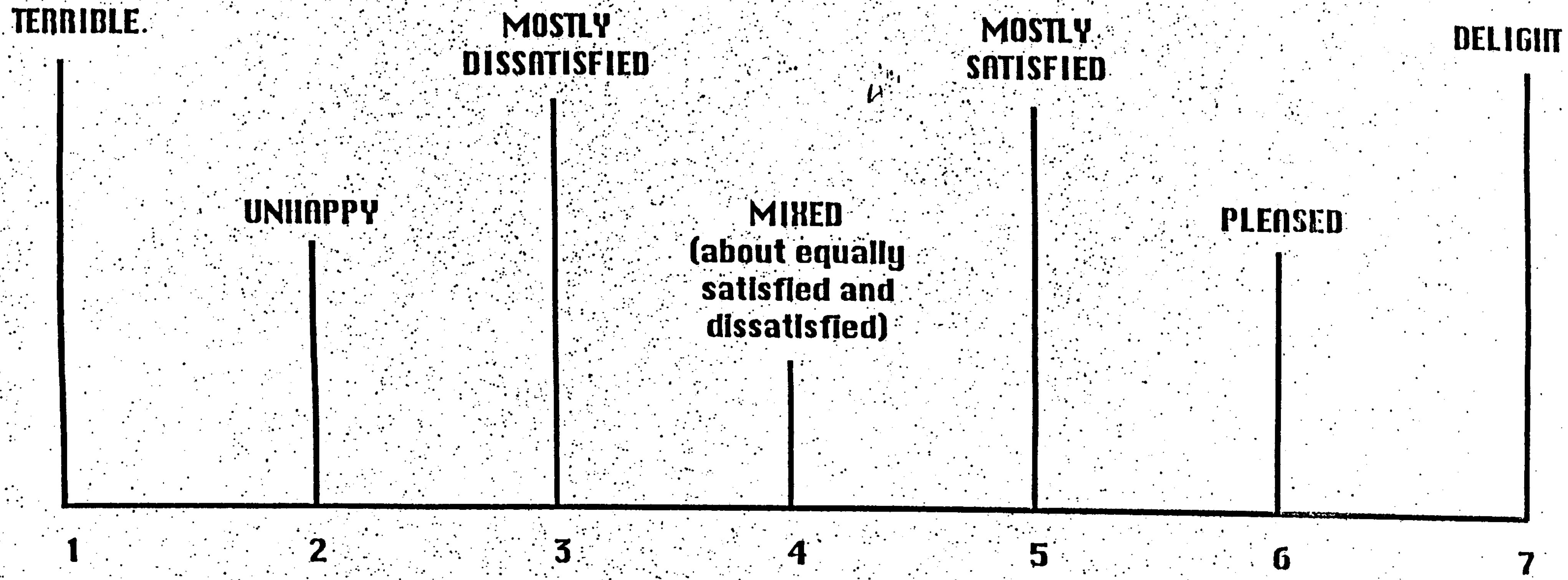
D. the chance you have to talk to a staff member you trust _____

SECTION K: GLOBAL RATING

29. And a very general question again.

Looking at the Delighted/Terrible scale,
How do you feel about life as a whole? _____

DELIGHTED/TERRIBLE SCALE



Appendix L

Data Collection Document - Monitoring Service Use Over Time

(Monthly follow-up through care manager or key worker)

The following information to be obtained:

- Have there been any changes during the last month to the educational, social, health or other services that the client is receiving ?
- If yes, what changes have been made ? Why have the changes been made ?
- If no, why have no changes been made ?

Contact No: Date: Informant:

Contact No: Date: informant:

Appendix M

Information Sheet

(To be explained to the client by the researcher prior to obtaining their consent)

I am looking into the way that mental health services are provided for people in Nottingham and as part of this I am asking a number of people, whose care is organized by the Rehabilitation and Community Care service (RCCS), a set of questions. These questions refer to how you see your quality of life, social supports, service provision, health and problems.

The interviews will last for one hour and anything you say will remain confidential and will be used for research purposes only.

Please say if you do not wish to be interviewed, you will continue to receive services in just the same way whether you are interviewed or not.

If you wish to stop the interview at any stage, you may do so. Please inform me if you wish to stop or if anything else troubles you.

If you would like to think about whether to be interviewed or not, I shall return another day.

My name is:

I am based at:

If you have any questions, please do not hesitate to contact me.

Thank you for your help.

Appendix N

Consent to be a Research Subject

I understand that the aim of this research is to look into the way mental health services are provided for people in Nottingham.

I agree to be interviewed for about one hour.

I understand that anything that I say will remain confidential and will be used for research purposes only. I can stop the interview at any time and this will not affect the services I currently receive in any way.

I, -------------------------------------- have read the information above and have been given a separate information sheet which has been explained to me. My signature indicates that I have been informed and have decided to participate.

Signature of client and date: --

Signature of researcher and date: --

Appendix O

Codebook: Variable description and codes for longitudinal study investigating the effectiveness and responsiveness of services provided for women with long-term mental health problems.

Variable name	Values	Value names	Variable labels
ID	1 2 3 4	menbefor menafter wombefor womafter	client name code
age			age at first interview
sex	1 2	male female	sex
marital	1 2 3 4 5 6	single married cohabiting separated divorced widowed	marital status
ethnic	1 2 3 4 5	white afro/caribbean asian african other	ethnicity
accom	1 2 3 4 5	unsupp (ind, family, DISH) comm-supp hosp non prof supp homeless	current or usual type of accommodation
work	1 2 3 4 5 6 7	paid unpaid sheltered retired student houseperson unemp	
workarr	1 2 3 4	full part casual not applicable	work arrangements

primdiag	1	unknown / none	primary diagnosis
	2	schiz	
	3	depression	
	4	mandep	
	5	schizaff	
	6	mentretard	
	7	alch	
	8	drug	
	9	org	
	10	otherpsych	
	11	nonpsych	
secdiag	1-11	as above	secondary diagnosis
mha	1	unknown / none	section of mental health act
	2	sec 2	
	3	sec 3	
	4	sec 37	
	5	sec 37/41	
	6	guardian	
	7	other	
agepsych			age at first contact with the psychiatric services
yfpc			year of first psychiatric contact
admis			number of psychiatric admissions
durad			duration of longest admission (months)
totad			total duration of admissions (months)
livarr	1	alone (inc indep, hosp, hostel)	who client lives with
	2	friends	
	3	spouse/cohabitee	
	4	spouse/cohabitee/kids	
	5	kids	
	6	parents	
	7	othfam	
child	1	yes	children
	2	no	
child18	1	under 18 years	dependent children
	2	over 18 years	
childlv	1	client	where children under 18 are living
	2	relative	
	3	incare	
	4	adopted	
	5	other	

lastjob	1	professional	last job
	2	employer/man	
	3	intermed/nonman	
	4	junior/nonman	
	5	skilledman	
	6	semiskill	
	7	unskilledman	
	8	never worked	
lastwork	1	< 1 year	years since last worked
	2	1-2 years	
	3	3-5 years	
	4	6-10 years	
	5	11-20 years	
	6	> 20 years	
	7	not applicable	
psychmed	1	majtranq	currently prescribed psychotropic medication
	2	mintranq	
	3	antidep	
	4	combine, majtranq, antidep	
	5	none	
chronmed	1	yes	chronic medical condition
	2	no	
physdis	1	yes	physical disability
	2	no	
histabus	1	yes	history of drug, alcohol or solvent abuse
	2	no	
histviol	1	Yes	history of violence towards people or property
	2	no	
histpris	1	Yes	history of prison/special hospital
	2	no	
resid	1	hosp	residential services
	2	comm prof	
	3	comm priv/charity	
	4	none	
mansman	1	Yes	daycare services, 702 mansfield road, manor road
	2	no	
span	1	Yes	daycare services, span
	2	no	
socserv	1	Yes	daycare services, social services
	2	no	
volserv	1	Yes	daycare services, voluntary organizations, charity, self help
	2	no	

educ	1 2	Yes no	daycare services, education and training
daycare	1 2	Yes no	in receipt of day care
careman	1 2	Yes no	outreach services, care management
dish	1 2	Yes no	outreach services, dish
acutekey	1 2	Yes no	outreach services, acute sector key worker
discnurs	1 2	Yes no	outreach services, district nurse / auxillary
volchar	1 2	Yes no	outreach services, private sector or charity worker, volunteer
socserv2	1 2	Yes no	Outreach services, home help, meals on wheels
ot	1 2	Yes no	outreach services, community OT
outreach	1 2	Yes no	in receipt of outreach services
selfcare			LSP - self-care
nonturb			LSP - non-turbulence
socont			LSP - social contact
commun			LSP - communication
respons			LSP responsibility
lsptotal			LSP total score
qolife			general life satisfaction
qolhome			feelings about home
qolneigh			feelings about neighbourhood
qolwalk	1 2	yes no	daily activities - walk
qolcine	1 2	yes no	daily activities - cinema, theatre
qoltele	1 2	yes no	daily activities - television
qolshop	1 2	yes no	daily activities - shopping

qolcafe	1 2	yes no	daily activities - restaurant or cafe
qolpub	1 2	yes no	daily activities - pub
qolbook	1 2	yes no	daily activities - reading
qolradio	1 2	yes no	daily activities - radio
qolmeal	1 2	yes no	daily activities - prepare a meal
qolsport	1 2	yes no	daily activities - play a sport
qolmeet	1 2	yes no	daily activities - go to a meeting or social group
qolpark	1 2	yes no	daily activities - go to a park
qollib	1 2	yes no	daily activities - go to a library
qolfunct	1 2 3 4	excellent good fair poor	functioning in home and social settings
qoleisur			feelings about leisure activities
leisnumb			number of leisure activities
qolfam			feelings about family
qolsrel			feelings about social relationships
qolprob	1 2	yes no	a person to confide in
qolgo	1 2	yes no	somewhere to go to meet people other than a mental health service
qolclose	1 2	yes no	close friends who are not family members
qolbenef	1 2	yes no	in receipt of benefits
qolmoney			feelings about finances
qoljob	1 2	yes no	job
qolage			age left school

qolqual	1 2 3 4 5	None CSE / GCSE / O levels vocational qualifications A levels degree	qualifications
qolpersa			feelings about personal safety
qolpolic	1 2	yes no	involvement with the police over last two years
qolvic	1 2 3 4	victim witness suspect charged	nature of contact with the police
qolphys	1 2 3 4 5	excellent very good good fair poor	self assessment of physical health
wellment			well-being, mental health
energy			well-being, energy / fatigue
qolimit			feelings about health limiting social activities
qolserv			satisfaction with services
Transformations			
marital2	1 2	ever married never married	marital status
diag2	1 2 3	other schizophrenia major affective disorder	primary diagnosis
mha2	1 2	no section section (2,3,37,41)	section of mha
livarr2	1 2	living alone (inc. hosp, hostel living with partner, friends	living arrangements
ethnic2	1 2	white afro/caribbean	ethnicity
caredish	1 2	yes no	attached to community rehabilitation teams or community support teams

Appendix P

Semi-structured Interview Schedule - Service Providers

1. What kind of difficulties or problems do women with long-term mental health problems have in your experience ?

(Probe: sexuality, relationships, physical health, self-esteem)

2. Are there any particular groups of women with long-term mental health problems who have special needs or difficulties ?

(Probe: women from ethnic minority groups, lesbians, older women, younger women)

3. What provision do you make for women within the service / unit that you work ?

(Probe: uptake of services, staff support, staff resistance)

4. Are there any other services or approaches that you would like to see developed for women that are not currently provided ?

Appendix Q

Discussion Guidelines - Focus Groups

1. Introduce self
   Explain purpose of study
   Encourage women to introduce themselves

2. When did your mental health problems start and how has it affected your life ?

(Probe: hospital, work, relationships, children, daily living)

3. What do you want to get out of life now ?

4. Are you getting the help you need to do those things ?

5. What sort of help are you getting ?

6. What other sorts of help would you like ?

7. What do you think about the services you are getting now ?

(Probe: good things, bad things)