

Relative Views Of Madness:

Families' Experiences of Living With Mental Illness.

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ABSTRACT.

This study examines the experiences of relatives of people suffering from long-term mental illness.

The impetus and context for this study has been provided by the well publicised Regional Health Authority sponsored closure programmes of Friern and Claybury Psychiatric Hospitals. These planned closures have emerged from several decades of a fairly consistent, nation wide, shift of services from the old hospital sites to the community.

The study has taken place amid a certain amount of confusion about the future direction of Community Care policy. In an attempt to grapple with this, the particular focus for the thesis is the experiences of relatives of people who in past decades might have found their homes within the Asylums, had they not been closing. It is argued that study around this group provides valuable insight into current difficulties.

On a policy level it is argued that it has been, albeit largely unacknowledged, anxiety about 'the family' that has been significantly orchestrating the broad sweep of mental health policy changes, certainly since the middle of the last century.

A review and critique of previous models used to study 'families and mental illness' is provided. Their failure to capture vital aspects of the relatives' experiences is highlighted. The roots of this failure are charted within the dominant paradigms of social science and their social and political contexts.

Using material from in depth interviews the devices employed by relatives to construct and attach meaning to their experiences are explored. It is argued that relatives are involved in a negotiation of meaning within the discourses that surround them. The relatives' experiences are examined in terms of the complex grief process, the experience of shame and the encounter with stigma which all take place within the framework of meaning provided by 'the family'. Here, as these apparently intimate affects are explored, and their social significance highlighted it becomes clear that the traditional paradigms of social science that, for example make great distinction between psychological and sociological levels of understanding, are insufficient.

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Preface.

Any piece of research has its life history. Whilst it is not possible, or desirable, to fully document this there are key life events and influences on its development which deserve acknowledgement.

The roots of this work lie in my work as a Research Assistant on a project that aimed to evaluate psychiatric hospital closure. This was a largely quantitative study. My preparation for this work included a quite rigorous training in semi-structured interviewing. I also had experience of the analysis of large scale quantitative data-sets and the publication of such work in main stream psychiatric journals.

Despite the many benefits of this experience, I began to realise that although quantitative research had its uses, there was a great deal of people's experiences that was being missed in the effort of quantification. What was often important to people's lives did not seem to emerge from number crunching.

I then moved to work in a post that was jointly managed between the Social Science Department of South Bank Polytechnic (where I first heard the phrase 'qualitative research') and an NHS Psychology Department where I was first introduced to psychodynamically informed therapeutic work with people suffering mental health problems. I was given the freedom in this role to develop my interest in the so-called "new long-stay", it was then that I noticed and became interested in their families.

The obvious methodological concerns (and tensions) of this thesis are born through my struggle to reconcile my interest in a psychodynamic style of interviewing and approach to the generation of knowledge, with notions of 'qualitative research' which have been developed in social science disciplines (particularly sociology).

I am indebted to Dylan Tomlinson's friendship and creative diplomacy for making this project possible in the first place. I must also thank the late North East Thames Regional Health Authority for part funding the first two years of the project. An Economic and Social Science Research Council studentship then provided funding for

a further two years full-time study.

Professor Shulamit Ramon has provided supportive and challenging supervision throughout.

Eric Karas, Sue Carvalho provided me at different times with a very different kind of supervision - that of psychodynamic therapy. Although this was quite separate from this project it will be seen to have been influential.

My greatest debt is towards the people who talked to me, and told me about their experiences. I am sure that speaking as openly as they often did to a complete stranger was not without cost. I hope I can repay that effort by representing their stories and experiences as well as I can in the hope that families in similar situations in the future may be better understood.

Thanks must go to Nick Wright for continuous encouragement and incisive comment, much of it on licensed premises. Iain Murray, for friendship and the use of the printer (again). Catherine and Ian Gilchrist, for friendship, and (encouraging) reading. Thanks to Helen for proofing and putting up with it all (again). Thanks to Isobel for not really noticing.

INTRODUCTION.

The Struggle For Meaning.

Carol Peters¹ is in her mid-thirties. She is married and has two small children. She is also the sister of Donald, a man who has been treated for many years by the psychiatric services having been diagnosed as suffering from schizophrenia. In the passage below Carol expresses her frustration with professional mental health workers, followed by a series of poignant questions. The frustration and the subsequent questions can be regarded as an appeal for meaning.

There is anger at professionals for seeming to withhold meaning, by refusing to "label the illness" (1). Contrast is made with "normal nursing", and the apparent predictability of the course and treatment of cancer (2). Then there is the appeal for meaning, articulated through a series of questions (3), voiced in the face of the distress caused by the apparently irrational and deeply troubling behaviour (4).

"But they [professionals] also have this idea that, they don't label the illness (1), they don't like to label the illness so . . . they won't tell you what it is . . . that he's just ill. You see it's probably something in their training that they've got . . . It should be taken as far back as when they're all being trained for these jobs, as to how to deal with the families. I mean in normal nursing (2), when you're dealing with . . . like my father-in-law when he had that brain tumour, the nurse was wonderful with us. She took us into a room, she explained exactly what was happening, the fact that it was malignant; what was going to happen to him - at 76 hours he would be this - but that during that time he wouldn't have any recollection. She went through the whole bit. Now that's what you need in mental illness . . . You need somebody who will sit down and you can say- (3) "How can we deal with this? How are we meant to react? What do you want us to do?" We can only be there for Donald, and you go through these stages where Donald thinks he hasn't got a family, he doesn't want to know you, he'll throw you out of the place, he'll scream at you, he'll shout at you . . . You need somebody. When at times like that happen, you know you're not immune to it all- it hurts (4). "We know he's ill, can you explain to us

¹ Interviewed as part of this study.

what is going on in his brain that he is suddenly screaming and shouting at us, and abusing us and everything else, do you know why? . . . What can be done about it? And what do you want us to do about it?" - except make nuisances of ourselves, with both them and with him, because that's what you feel like."

This is a study of the experiences of people like Carol who have a relative who suffers from severe mental health problems. It is about the relatives' distress, and the difficulties that they face. Most of all this study is about their struggle for meaning in the face of what appears to be the breakdown of reason that we call madness. It is about the conflict which people like Carol encounter in finding that their experiences and their understanding of those experiences are not captured by the conventional methods of social science that operate within psychiatry and related disciplines.

Foucault (1967) argued that as a culture we have objectified and banished madness, designated it simply as disease so that "[I]n the serene world of mental illness, modern man no longer communicates with the madman" (xii-xiii). This is a study of the struggle of a group of people, like Carol Peters, for whom the disease model is undoubtedly attractive. Yet they are also trying to remain in dialogue, and find liveable arrangements, with 'madness'. Carol asks anguished questions which as a society we have not found satisfactory answers:-

How can we deal with this?

How are we meant to react?

What do you want us to do?

Hospital Closure.

The roots of this thesis lie in my interest in the welfare of a group of people who have been called the "new long-stay". This group is generally characterised as consisting of relatively young people typically being diagnosed as suffering from schizophrenia. In former decades they would perhaps, as their moniker suggests, have found themselves living in the long-stay hospitals. It is an important test of the policy

of Asylum closure that the needs of this group will be not be neglected. Concern has been expressed about their welfare in this country and their presence has been seen as an obstacle to hospital closure. American experience of deinstitutionalisation suggests that there are reasons to be concerned (for example Schwartz et al. 1981). What emerges from a review of the literature on this group (in Chapter 1) is the narrow foci of these studies. Many studies have estimated the prevalence of individuals fitting the characterisation of the group and described the apparent dependency and disability levels. There has been little consideration of the context or the processes that were highlighting such disabilities or producing such dependency. Some studies, including one that I was involved with (Jones and Margolius 1989, Thornicroft et al. 1993) did point to 'social factors' being involved in creating the status 'new long-stay'. It was an attempt to trace these 'social factors' that led to my interest in their families.

The Policy Background.

There is a great deal of public confusion surrounding the future direction of mental health policies within community care, such that Ramon (1992:xvi) is able to say:

What is striking in the current public debate on mental health services in Britain, Italy and the USA is the relative lack of vigour in defending hospitals or calling for their reinstatement, coupled with considerable scepticism that care in the community can work for people with serious mental health problems.

Underlying policies for people with mental illness are a host of unresolved issues, concerning the nature of society and of mental illness itself. There is often little consensus on the nature of mental illness itself between professionals, between service users or the general public. For these issues to be discussed openly would be difficult. As will be argued, the role of families in society, although quite central to social policy, is not explicitly discussed.

To date the British Government remains, ostensibly, committed to Asylum closure

and Community Care policy (HMSO 1990²). Yet even so there is clearly ambivalence. Of interest is the Conservative Government's reaction to the 1988 Griffiths Report "Community Care: An Agenda for action". Although initially enthusiastic supporters of the idea of institution closure, the Government took over 12 months to give a public response to the report. This delay is presumed to be due to the realisation that Griffiths proposed a large shift of resources to local authorities, which was greatly at odds with the ideas the Government had about reducing State spending and centralising what remained. This ambivalence to Community Care was further evidenced by the three year delay in the implementation of the subsequent Community Care Act. Responses to a series of very public crises such as the Supervision Register and the promotion of the Care Programme Approach have also served to highlight the ambivalence (DoH 1991, DOH 1996). The ambiguity that persists is particularly evident when the group of people who might be called the 'new long stay' population are considered.

Tomlinson (1989) writes of "administrative culture" whereby organizations find it very difficult to openly discuss issues that entail conflict. Mental illness and surrounding issues are certainly controversial. In this light, the Griffiths Report (1988) can be seen as being another in a line of government responses which propose organisational changes. The suggestion being that the right structure for the administration of care, will ensure the proper care of the mentally ill. This tactic avoids many difficult issues, such as the nature of mental illness, society and families. These crucial issues which might be of a social, political or psychological nature are, as Barham (1992:59-65) highlights, are often those which have the greatest impact upon people.

As the locus of care for people with long-term and debilitating mental health problems shifts from the old Asylums towards the 'community', questions are raised as to what is the nature of mental illness and of that 'community'?

² Department of Health (1990) "Caring for People: Community Care in the Next Decade and Beyond."

HMSO: London.

The Caring Family?

A large facet of that community is likely to be 'the family'. If the nature of community can be contested, so also can 'the family' and the meaning of care in the case of long-term mental illness. A key distinction is being made, at a policy level, between informal and formal care. Formal care is that which is provided, usually by professional workers, by the state or its institutions. Informal care is that which is thought to exist, 'naturally' in the community. Informal care networks, ideally, consist of the extended family, friends and neighbours.

An important policy debate revolves around the relationship between the formal and informal systems of care. Should they be seen as interchangeable? Should formal care only be involved when informal care has broken down, or should they be able to cooperate and support one another? To the latter end the concept of the interweaving of informal and formal care has arisen. Attention has been drawn to the difficulties of such a process (reviewed by Bulmer 1987), despite its obvious attractions.

It is increasingly being assumed, and supported by evidence, that it is families that actually provide the vast bulk of informal care in cases of chronic illness or disability (Bulmer 1987). Following this recognition, it seems important to examine the meaning ascribed to mental illness, and to the care of a sufferer, within the informal sector as represented by the family. It will be argued that this has been not only a neglected dimension of the policy debate, but also of the models that professionals bring to their work with families. The roots of this neglect can be traced to the dominant paradigms of social research which effectively disregard what amount to essential values which operate within the 'informal' social world of the family.

The Meaning of Family.

This study examines the role played by families in the support of this group. Unfortunately 'the family' is such a currently contested concept that consideration of where to even begin such a study is necessary. What this thesis is arguing is that the study of the 'family' within social science is problematic. This is so because 'family'

is such a central, organising feature in our perceptions, our identities and our society. Aspects of 'family' are so 'obvious', or commonsensical, that they are not questioned. Chapter 1 therefore charts the influence of ideas about families within the broad sweep of social and mental health policies that have nurtured and are now undermining the Asylums. Much of the research on families and mental illness, reviewed in Chapter 2, has been shaped by the quite ideologically informed notions of family life that have been apparent in policy decisions.

From the outset my point of view has been that the relatives of people with such severe, and apparently chronic, difficulties are a group of whom a great deal is being required, yet who have not been asked what they think, or what their experiences and difficulties are. There have been discernible moves toward the seeking of 'ordinary' participants' views for some decades now. It is, for example, around 40 years since Erving Goffman spent time in gaining an understanding of the inmates' and staff's view of the psychiatric Asylum (Goffman 1961). Despite such moves, as Chapter 2 stresses, although there have been many studies of 'families and mental illness', they have generally been of a very different ethos. They have usually not been seeking to understand the families' experiences or communicate their point of view.

As Chapter 1 will highlight, the fact that 'the family' has in different ways been an important factor in the story of the Asylum reinforces the importance of the question as to why such little effort has gone into asking families what they think and experience. One partial explanation may be the degree of confusion about what 'the family' is. As Chapter 1 emphasises, 'the family' is a complex entity that is expected to include not only economic and social functions such as caring for the dependent, and the transmission of cultural rules and values, but is seen as containing the often enigmatic sides of human nature (most notably the world of sexuality).

Methodology.

The core of this thesis consists of in depth interviews with relatives. I was interested in how they felt about having a relative suffer in this way, what impact it had on

them and their lives. The rationale of the study has been that the emotional difficulties of being in that position have been largely ignored.

As I have been working on this thesis my attention has been increasingly drawn to a hiatus within the world of empirical social science. On the one hand there are the studies that are based in positivism, that seek to break down and quantify the social worlds that they study. In this they seem often to miss crucial aspects of people's experiences. Such methods have been profoundly criticised for some years now (certainly within sociology: Schutz 1954, Kuhn 1962, Gouldner 1970, Phillips 1973). On the other hand, and despite the strength of the rationale for non-positivistic research, a great deal of empirical research seems dogged by confusion over what should replace positivistic research. There are still many unresolved issues concerning what the appropriate role of interpretation and reflection should be (see, for example, the range of disparate views in the edited volumes by Berger Gluck and Patai 1991 and Stanley 1994). Much of this thesis is therefore, necessarily, concerned with methodological critique. Chapter 3 is a general discussion of methodology; a critique of the influence of positivism on qualitative research and a formulation of some principles gleaned from psychoanalytic practices which are argued to provide a useful framework for carrying out research. Chapter 4 is a description of the particular method of this study.

The Cartography Of The Social World.

There will be occasions in the chapters that follow that I seem to stray far from Carol Peters' plaintive questions (p8). This is not (I hope) through a frivolous need to travel, but because the domestic (traditional Anglo-American) language of conventional social science has had difficulty in hearing her concerns. Hence there seemed to be a need to travel in areas not covered by the traditional maps of social science. The maps of the social world have been plotted as busily and assuredly as the cartographers of past centuries eagerly charted the remote seas and sketched the landmasses of the dark continents and new worlds described (and subjugated) by their colonial adventurers. By tradition the human world has been divided between what might be called the sociological and the psychological territories. It will be argued

through this thesis that this partition is an artificial one that leads to a failure to outline crucial aspects of our worlds (Giddens 1976).

In an attempt to overcome this disciplinary fragmentation this thesis makes recourse to paradigms that might be seen as odd bedfellows. The most conspicuous 'foreign' language in this thesis will be that of psychoanalysis. Recourse is made to psychoanalysis in an attempt to bridge the gap between psychological and sociological understandings of people's experiences. That psychoanalysis may be able to play this role and exist on the apparently uncomfortable and alien terrain between paradigms is suggested by the contradictions that are within psychoanalysis. Freud is described³ as being one of the three "masters of suspicion" alongside Marx and Nietzsche, who have together stimulated radical change in philosophical thought. Yet to others Freud is the bourgeois psychologist of adaptation (Poster 1978, for example). This apparent contradiction is clear within this thesis. On the one hand, psychoanalytic theory is used for its valuable and questioning ideas about how communication between people can be understood. On the other, psychoanalytic ideas have fed some of the more normative models of families which are argued to be unhelpful within Chapter 2.

A rather different language, less conspicuous perhaps, but influential on this thesis has been post-structural sociology - shaped chiefly by the work of Michel Foucault. It is through this mode of thought that questions about the marginalisation of the families' points of view, over a period when concerns about the family have been an important strand of social and mental health policies can begin to be understood. The perspective of Chapter 1 owes something to Foucault's (1967, 1977) concern to scrutinise the human sciences and expose their political foundations. It is also through this mode of thought that the relatives' experiences and the meanings they impute can be understood within the cultural frameworks that shape them, which are themselves shaped in turn by those meanings.

³ Vincent Descombes, for example uses the phrase, in his outline of "Modern French Philosophy".

The Formulation of Rationality and Irrationality.

An important argument of the thesis will be that there are aspects of people's experiences operating within the family relationships studied which are not fully apprehended by conventional social scientific understandings of social relations. It will be argued that the social sciences have systematically privileged rational explanation at the expense of those explanations which focus on understanding (or meaning).

Whilst the definition of rationality and irrationality might be open to dispute it can be argued, tautologically, that irrationality consists of aspects of experience which fall outside the realm of rationality. Thanks to the evolution of a very technological definition of instrumental rationality (as discussed and 'debated' at length by Weber, Foucault and Habermas - see Habermas 1987, Brubaker 1984 and Simons 1995), irrationality might be further seen as consisting of all modes of understanding that are not tied to a positivistic understanding of the world. On this basis irrationality includes instinct, intuition, and the entire universe of human emotions - affection, hate, anger, sadness, happiness and desire. For as Giddens succinctly puts it: "reason has no place for emotion" (Giddens 1992:40). It is these aspects of human experience that have been seen as falling outside the reach of conventional social science methods. This, it will be argued, has led to a rather desiccated, and ultimately misleading, conception of human relations.

In order to understand how it should be that affective meaning has been systematically marginalised by the mainstream social sciences, it is necessary here to put briefly the perspective of the human and social sciences into historical context.

Just as the charting of the physical globe was not an entirely innocent pastime but one that served the needs of colonial powers; the mapping of the social world has been propelled by stronger forces than the benign enquiry of curious scholars. Michel Foucault (1967, 1974) has argued that alongside the growth of Enlightenment thinking in the Western World (which he places at around the turn of the 15th and 16th centuries) the marginalisation of irrationality began. This process, Foucault claims,

was made plain in the segregation and 'great confinement' of the insane. As technologisation progressed, along with the assertion of rationality and positivistic knowledge the active repression of the irrational became inevitable: the insane had to be set apart from society. Insanity had to become an object of rationality. It is the psy-complex (Ramon 1985), most obviously the psychiatric profession, which was given the job of rendering insanity 'intelligible'.

Rationality, much as described by Max Weber (Snyder 1955 for example) emerged as the dominant mode of thinking around the 17th century, as it successfully drew previously divine or magical natural phenomena to within the mastery of humanity. As Bierstedt (1979) stresses, in his discussion of the roots of sociological thought, rationality itself, wrought through Enlightenment thinking, came to be formularised as concerning only instrumentally useful knowledge, becoming inextricably linked to a technological model of nature. By the 19th century the success of this project, apparently leading to industrial and technological progress undreamt of by previous generations, led to the tautological view that reality itself was a rational (technological) system. It was then but a short walk to the claim of scientism that only that which is available to a particular form of rational enquiry (soon to be formalised into positivistic empirical method) could possibly constitute useful knowledge. The social sciences, emerging into the sooty light of the industrially and socially revolutionary cities of Western Europe of the 19th century were born of and into this system. Auguste Comte who coined the term Sociology expressed his vision of social science in the famous dictum "Savoir pour prévoir, prévoir pour pouvoir" ("To Know is to be able predict, to predict is to be able to control"). It is the contention of this thesis that the search for explanation as a means to control reality has led the mainstream social sciences to places where it often barely hears, let alone understands, vital constituents of its topic of study. As Bleicher (1982:1) complains of his own discipline of sociology:

I would argue that the tendency within sociology towards the gathering of instrumentally useful knowledge and away from the generation of practically relevant insight relates to the trained inability to take account of the hermeneutic dimension operative in the study of social phenomena and the reluctance on the part of sociologists to engage in

hermeneutic (self-) reflection.

This thesis argues that the lack of emphasis on reflection which Bleicher identifies can clearly be seen at a methodological level in the bulk of studies that have concerned themselves with mental illness and families (reviewed in Chapter 2). The family's role in the story of mental illness has been construed in instrumental terms, there has been little attention paid to the understanding of the experience of families who themselves are groping for meaning in the half-lit world of unreason that is madness. As Carol put it:-

"can you explain to us what is going on in his brain that he is suddenly screaming and shouting at us, and abusing us and everything else, do you know why?".

This study takes up the theme of the marginalisation of the irrational in arguing that our current thinking about families is consistent with a discourse that effectively submerges this element by focusing only on the rational and conscious aspects of social life. The language of rationality that is used to formulate family relationships is that of the marketplace and technological systems (Brubaker 1984). Studies, borrowing language from anthropological studies of 'simple' societies, in the areas of social science or social policy are furnished in the language of instrumentality and exchange. Finch and Mason (1993), for example, base their highly influential study of contemporary British family life on the search for the rules of either obligations or of reciprocity which might govern patterns of help within families. This approach is unlikely to be sufficient for understanding families and their relationship to mental illness.

The Challenge of the Study of the Family.

It will be argued that study of families presents a challenge because the family is not only a complex and multifaceted creature but that there are ideals (or fantasies) about family life which run through research models, policy assumptions, professional models, and people's every day expectations. These ideals make understanding of

real, ordinary families a challenge. This study, therefore, has several related purposes:

- 1) To examine the experiences of relatives of people who have come to be seen as suffering from severe mental illness in such a way that the emotional aspects of events and relationships, and the meanings that they hold, can be apprehended.
- 2) To offer insight into the experiences of those families in order that those concerned with formulating and implementing mental health policies may be better able to constructively work with those families.
- 3) To trace the influence of families and ideas about families in the mental health system. On the one hand ideas about families have influenced the research models and policy aims, whilst on the other families themselves have shaped practices through their own responses to mental illness.
- 4) To explore a methodology which may provide a useful way of making contribution to the understanding the social significance of contemporary family life.

A Note on Writing, Science and Knowledge.

Much of the intellectual labour of the past few decades have been undermining the Enlightenment project. What has variously been termed post-modernism, post-structuralism, or even super-structuralism (Harland 1987) has had the consequence of bringing into question the legitimacy of any particular claim to 'truth', whether the claim is being made through art, literature, science or 'native' discourse. All such claims, it is now argued, must be interpreted as representing only one particular construction of reality. The impact of this vision has been particularly great on the social sciences. The Ph.D. thesis cannot be immune to this critique.

In writing this thesis I became aware, and indeed it was pointed out by others when drafting the thesis, that I was writing in two distinct styles. One is an obviously narrative style, written with the 'I' clearly present. The other seemed to represent the

formal voice of academic social science - impersonal, referenced, with the 'I' removed. Stylistic clumsiness is no doubt a part of this. However the two different voices usually arise in the context of very different material. The former occurring when I am discussing the interview material, where I am mingling my thoughts and observations with the words of my interviewees. The latter can in some ways be heard as not really being my voice at all, but it is the voice of academia, of social science. It usually makes its appearance when discussing 'the literature'. I raise this matter here as it is not merely a matter of style, but is an issue that runs to the heart of some of the concerns of the thesis.

Writing and Authority.

Writing, viewed as being embedded in systems of knowledge, can be understood as narratives which can be categorised as belonging to either the explicitly narrative tradition (such as story telling) or to the "logico-scientific" tradition. Richardson (1990) argues that since the 17th century "the world of writing has been divided into two separate kinds: literary and scientific. From the 17th century onward, literature was associated with fiction, rhetoric, and subjectivity, whereas science was associated with fact, 'plain language' and objectivity." (p13-14) The two voices distinguishable in this thesis are related to these traditions. The presence of two styles is not merely the signal of stylistic clumsiness but points out fundamental concerns of this thesis. There are at least three different voices in this thesis:-

- 1) The voices of the people interviewed.
- 2) My own voice, as researcher and writer.
- 3) The voices of the various social science traditions.

The first group are really only heard through me. Their words appear apparently in their own right in the chapters that contain sections of verbatim interviews. However, it was me that supplied the context for the interview and the sections of interviews that appear are the ones that I have chosen. I have also put my interpretations on their words. This aspect of social research is dealt with in the Methodology section. My own use of the "I" is an attempt to be very clear about what is going on here - which

amounts to no more than my own attempts to make sense of the things that were being said to me. There is nothing objective about that process. At other times in this thesis I adopt the traditional impersonal tones of academia. It is a style which in many ways facilitates communication, it is certainly recognised and understood by the community for whom this thesis is written. In this I am happy to comply with tradition. It is however a tradition whose assumptions must be put under scrutiny. There is a danger that this style will be seen as being of greater authority. In writing 'science' as authors adopt the impersonal tone, they are also donning the mantle of objective authority. In removing the speaker there is an effort to appear to be speaking from a higher, independent authority. So although my voice is not necessarily recognisable when I am reviewing and criticising other people's work, it would be an illusion to suggest there was a greater authority being referred to.

Chapters 5 to 9 all contain a great deal of material from interviews with relatives. This follows from my concern to reflect as well as make sense of their experiences. Hence the emphasis on their words and their stories, interlaced by my interpretations of those narratives.

CHAPTER 1.

The Family, Madness and the Asylum.

Introduction.

It is the family and its relationship to mental illness in an era of Asylum closure which is the focus of this thesis. There is now a burgeoning literature on Asylum closure (Busfield 1986, Glennerster and Korman 1985, Hall and Brockington 1991, Murphy 1991, Carrier and Tomlinson 1996). This thesis is written in the tradition of those (Barham 1992, Ramon 1992, Tomlinson 1992, Scull 1979) who see the securing of decent existences for those people with enduring mental health problems as raising wider social challenges than the administration of a set of medical and social services (important though they may be). This chapter will, therefore, be wide-ranging in its scope: from contemporary psychiatric research literature to ideas about family history and change. The family has now become, it will be argued in this chapter, a significant part of the environment in which mental illness resides.

This chapter will set out the grounds for making this particular study of a group of people who have a relative who could be called 'new long-stay'. These are people (discussed in the Introduction) who have only recently become long term users of psychiatric beds, who seem to have long-term needs, but who are not to be directly reprovided by the hospital closure programme (Tomlinson 1992). The 'new long-stay', due to the policy of hospital closure, will be the first people for over a hundred years who although deemed to be suffering from long-term mental illness, may live largely outside the shadow of the Asylum. There is an urgent need therefore to come to a better understanding of the outside community in which they will live. It will be argued that it is important to gain an understanding of the families, not simply because the families' voices ought to be heard in the interests of decency and fairness, but because their experiences and their understanding help shape the social fabric in which this group of patients and ex-patients live.

The first part of the chapter will demonstrate that enough is known about the group

of people who fall into the descriptive category of 'new long-stay' to say that their future welfare is uncertain and that effort is required to understand the social contexts in which they will live. This group most poignantly raises the issue of what kind of services and expectations should be replacing the old Asylums.

Secondly, it will be argued that the families of this group form an extremely important aspect of the social world that surrounds the closing Asylums. Ideas about families have been deeply implicated in the world of mental illness. Families and ideas about 'the family', what it can do, and what it should do are a significant feature of the social milieu which first of all shaped the growth of the Asylums, and then prepared the ground for their demise. There is now quite a large body of research literature on 'families and mental illness'. The ideological importance of the family has, however, ensured that (as will be explored further in Chapter 2) this work has not been aimed at understanding their experience or point of view. Families have been seen, for example, as being the cause of mental illness.

Thirdly, it will be argued that although 'the family' can be understood on many different levels of analysis, it is important that such a study is able to apprehend the affective understanding that family members have of what has happened, and the emotional nature of their relationship to the person seen as suffering from a mental illness. The family can no longer be conflated as 'the household', or understood as a productive unit to be understood in instrumental terms. These families, as examples of the 'modern Western family', are complex entities that entwine together a great deal of cultural symbolism wrapped around often convoluted emotional ties.

1) Community Care and the New Long-Stay.

The study takes place within a London Borough affected by the reprovision of psychiatric services from hospital towards the community. In 1983 North East Thames Regional Health Authority announced that they planned to close Friern and Claybury Psychiatric hospitals. Between them they had a total population of over 1,700, many of whom had spent the greatest parts of their lives there - 20, 30, 40 or

more years.

In many ways this was a dramatic and brave decision (Tomlinson 1992). Both hospitals had in their own ways, and at different times, been particularly prominent. Claybury had been involved in experiments as a therapeutic community, Friern had always had a high profile serving large sections of the population of the centre and north of the capital, originally known as the Colney Hatch Asylum.

It was planned to be a well funded, clearly observed and researched closure. A research team was set up in 1985 with initial funding from the King's Fund, the Department of Health and Social Security and North Thames Regional Health Authority to monitor and evaluate the closures. Their findings have continued to be encouraging about the improvement in the lives of the residents of the hospitals as they have moved out to new accommodation (TAPS 1989, 1990).

A consistent shadow over these optimistic reports of the resettlement of Asylum residents has been cast by concern over a group of people who have been known in psychiatric circles for some years as the 'new long-stay'. From the perspective of the Health Service providers, the most salient task of hospital closure is to re-provide for the current occupants of the long-stay hospitals. A longer term, and more challenging task however, is to provide for those people whose future care might have been in the old Asylums had they not been closing. In the British psychiatric literature these people have been termed the 'new long-stay' (usually defined according to their length of stay in hospital - for example between 1 year and 5 years).

This definition draws attention to a conceptual problem, since it relies upon the notion of bed occupancy to identify the group. As services shift from traditional institutions to the new community services there will increasingly be the problem of defining chronicity, as it "can no longer be defined on the basis of hospital stay, but rather on the basis of dependence on the psychiatric and social service system" (Rud and Noreik 1982:4). In other words, although the moniker 'new long-stay' may be useful in the short-term, to actually define the group in these terms is insufficient.

These are the people for whom in past decades the Asylum may well have become their 'home'. Now that the Asylums are closing, there is debate over where they shall live. Their current plight seems to raise most plaintively the questions: Why were the Asylums built? Why are they closing? Do we need a replacement?

American Experience of 'new chronicity': Issues of Definition.

The United States of America (US) is generally further along the road of de-institutionalisation than Britain. Research papers from the US are consequently more customarily concerned with the aftermath of de-institutionalization. The conceptual problem of how to define chronicity in the absence of long-stay beds is very clear from examining the US literature. In the research literature vague descriptive definitions tend to be used. Holcomb et al. (1987:625) study "a random sample of 611 severely impaired young adult patients". Pepper et al. (1982) described the selection of a sample of 294 young adult chronic patients "through chart reviews", they were "readily identifiable as having a characteristic configuration of functional disabilities and of treatment and social services needs" (p464). In all these no further details are given, it is as though the description has become the definition.

Unfortunately, this problem of definition appears to be mirrored in problems of service provision. It seems that the group only becomes identifiable when its members have dropped out of conventional social structures: often when they have fallen into homelessness, vagrancy, and petty crime. A priority might be to identify these people sooner in order that help may be offered to arrest this decline. That is: how can the people with the greatest needs be quickly identified, and how can they best be served?

Schwartz et al. (1981), in another American article, quite critical of the new services, refer to how the process of hospitalization did allow people to become "more firmly engaged in the system of care after discharge" (p474). There seems to be an important argument here about how the process of hospitalization has acted as an official sanctioning of dependency; only when people are recognized as being needy

will they qualify for society's support. Much of this work on 'young adult chronic patients' has seemed to overshadow the earlier, and influential, optimistic reports of deinstitutionalisation (Harding et al. 1987, Mosher and Burti 1989, Warner 1985).

British Research On The 'New Long-Stay'.

The British studies are usually concerned with in-patient populations and define the group according to how long they have been in hospital. For example, Mann and Cree (1976) define a sample of 'new long-stay' (NLS) as having been in continuous in-patient care for greater than one, but less than three years. Many papers are concerned with arguments over whether or not it is a good idea to close the hospitals. Several authors have sought to demonstrate that so far as service providers are concerned the NLS are really indistinguishable from the 'old long-stay' (OLS) (Babiker 1980, Bewley et al. 1981, Christie-Brown et al. 1977, Ebringer and Christie-Brown 1980, Freeman and Choudrey 1984).

Other researchers focus solely on NLS, without attempting to compare them to any 'old long-stay' group, and emphasise the group's needs for care (Measey and Smith 1973, Todd et al. 1976, Mann and Cree 1976) whilst concluding that hospital replacement is problematic.

The Need for Further Research.

An examination of the British and US literature suggests that the circumstances of this so called 'new-long stay' group need to be studied. They are the people for whom the Mental Health Services of the future will have to cater. That they have considerable needs, in terms of accommodation and care, is also a difficult conclusion to resist on reviewing this data. Whether such services need to be identical to those most suitable for the OLS who are currently being decanted from the large psychiatric hospitals is a crucial issue.

There is significant consensus that the OLS have considerable needs, whether these are due to years of institutionalisation or the presence of deteriorating organic

conditions. Their transfer from Claybury and Friern has been facilitated by the adoption of the "dowry" or "Revenue Transfer" system in 1984 (Tomlinson 1988). A certain sum of money is allocated to the accepting Health Authority when a bed is closed and the patient transferred. Re-provision of the OLS was monitored by the Regional Health Authority. Such clear planning and evaluation programmes do not seem to be in place for the 'new long-stay'.

The issue of the 'new long-stay' is one which exposes unresolved issues which run to the very heart of current philosophical debate not only in psychiatry but in Community Care in general. It raises fundamental questions about the nature of psychiatric problems: are they most appropriately addressed as illnesses (which might be cured), handicaps (which might require long-term care) or as social phenomena (which might be alleviated by consideration of the dynamics of society, family life and the individual)?

Many of the British authors imply that because the NLS studied by them are cognitively and socially impoverished, they are like the OLS. Thus the argument is that institutionalization is mythical and these are features that are intrinsic to the mental affliction. The Lancet (1982) for example argues that "[t]hey [the NLS] are only new in the sense that their chronicity of stay dates from after the general adoption of non-institutional policies by English psychiatric hospitals after about 1970" (p1135). However, Bachrach (1982), an influential American researcher, argues for the acknowledgement of "their uniqueness as a patient population" (p189). Pepper et al. (1981) turn the argument on its head and suggest that just as in the past institutional life was examined in terms of its contribution to 'social breakdown syndrome', now "we must explore the roles played by the family and society in the formation and persistence of our young chronic patients' repetitive behaviour" (p465).

Need for Wider Scope.

Whilst a brief review of this literature demonstrates the importance of research in this area, it also becomes clear that a different quality of work is called for. Most of the published research has tended to focus on the characteristics and disabilities of the

individual. However, a broader approach which attempts to understand individuals within their context seems indicated.

Demographic data, such as measures of social under-privilege, have been repeatedly shown to influence rates of psychiatric morbidity (Hirsch 1989). Much of the data reviewed here implicate social factors as being involved with an individual's prolonged stay in hospital (Ebringer and Christie-Brown 1980, Freeman and Choudrey 1984, Jones and Margolius 1989, McCreadie et al 1983, Rud and Noreik 1982, Kastrup 1987). Ebringer and Christie-Brown (1980:46) suggest in their survey of short-stay psychiatric patients that many "have lost their community supports by the time they reach hospital", as witnessed by the rates of unemployment, and the number of people living alone and in transitory accommodation. Jones and Margolius (1989) found a significant correlation between the rates of "new long-stay" accumulation and the Jarman Ranking of the estimation of the degree of social under-privilege in the Health District of admission. Kastrup (1987), in Denmark, found that patients admitted from relatively large urban communities were significantly more likely to become long-stay patients (of greater than 12 months stay). Unmarried and formerly married people show a greater tendency to become long-stay. Individuals with a lack of education after school, and patients described as socially isolated at the time of admission were also more likely to become long-stay.

There is evidence, however, that more in depth studies are required which explore the events underlying these correlations:-

(a) Simple social indicators such as social class, employment, accommodation, and education level are too often equally well explained by assuming that things are either prognostically significant indicators or are a function of the illness. More work is required on what actually lies behind these data in order to try and understand the mechanisms.

(b) The challenge is to study chronicity in the absence of long-stay beds (Rud and Noreik 1982). This means looking within the

community, at who the people are with long term mental health problems, how they are functioning in that community, and attempting to study individuals within the context of their environment. In selecting study samples definitions that are entirely reliant on length of stay in hospital will become increasingly inadequate.

(c) Little is known about the views and wishes of the direct and indirect users (such as the families) of services. Service providers will need to take these into account, indeed the Carers Act (DoH 1995) explicitly gives carers the right to have their needs assessed.

Removing the Asylum seems to be leaving a vacuum of sorts. In order to better understand what the loss of the Asylum means, as other commentators have pointed out (for example Barham 1991) it is necessary to understand what function the Asylum was serving, what role it was fulfilling. There have been many different versions of the story of the Asylums and how they came to be built (Castel 1988, Chesler 1972, Digby 1985, Doerner 1981, Donnolly 1983, Foucault 1967, Grob 1983, Jimenez 1987, Mackenzie 1992, Porter 1987, Rothman 1971, Scull 1979, Skultans 1979, Tomes 1994). It will be argued that one often neglected (Mackenzie 1992) factor that both shaped the Asylum and laid the ground for its decline has been ideas about 'the family'.

2) The Family, the Asylum and Community Care.

Community Care and The Family.

Hospital populations have been in decline in England and Wales since 1954 (Tooth and Brooke 1961). The cause of this decline has been subject to some considerable debate (Busfield 1974). The development of phenothiazines (Clare 1976, for example), changing philosophies of hospital care (Jones 1972), and fiscal crisis (Scull 1984) have all been argued for.

What is now clear is that the policy of hospital run-down became explicitly embedded within the wider Community Care policy initiative (DHSS 1981). It is also apparent that the greater involvement of informal care, with families being key participants here (Bulmer 1987), is seen as an essential plank of Community Care policy (Griffiths 1988). This is despite the fact that there might be some debate about how moves away from the institutional care of the long term ill and disabled, which began during the middle of the century, directly assumed the greater involvement of families (Busfield 1986, Finch and Groves 1984).

Within the area of mental illness, however, the formulation of practices which would bring about the greater involvement of families is problematic. Certainly within professional models there has been a great deal of ambivalence towards the role of families. This is an ambivalence which has resulted in the views and experiences of families being neglected, despite a wealth of literature on Asylum closure. Biegel et al. (1990:173) for example, in reviewing the research literature on families observe that: "Unlike caregivers of other diseases . . . , family caregivers of the mentally ill have been blamed as causal agents of the disease."

It will be argued here that the omission of families from the planning and research agenda is unfortunate. It is likely that families will have some impact on the ultimate shape of the alternatives to Asylum. Four aspects of families' involvement in mental health policy issues will be considered in this section.

Firstly, families can be viewed as being users of the Asylum and active participants in their proliferation as they deposited their relatives within them. It is therefore likely that families will shape the alternatives to the Asylums. Secondly, some of the motivation for initial Asylum building, embodied in the principle of 'Moral Treatment', assumed that the notion of 'family life' was of importance to mental health. This assumption is, it can be argued, germane to understanding aspects of contemporary Community Care policy. The third section will argue that an important factor in the demise of the Asylums was the development of the welfare state, which assumed a great emphasis on the importance of family life (Finch 1988, Land 1978, Wilson 1977). The fourth section will argue that the family has been the object of a considerable amount of professional attention as they have been examined for the part they may play in creating mental illness.

All this suggests that attention needs to be turned towards the families themselves. If, as is presumed by recent legislation (notably the 1995 Carers Act), professionals are to consult and work in partnership with carers, then they need to have a good understanding of their perspective. Yet to date research (reviewed in Chapter 2) has been dominated by policy and ideological concerns rather than an effort to understand the perspective of those families (Hatfield and Lefley 1988).

i) Families As Users of the Asylum.

It will be argued here that families were a significant factor in the growth of the Asylums because they were utilising them by placing their relatives there.

The reasons for the growth of the Asylums and of their populations have been subject to considerable debate. The Liberal-Scientific view on the growth of the Asylums was that they grew naturally from the recognition that 'madness' was an illness, much like any other, whose victims needed care and treatment (Hunter and MacAlpine 1963, Jones 1972). This perspective has been under sustained attack for some time. The thrust of the criticism has been that Asylums need to be understood as a product of often competing social forces and interest groups. It will be argued here that one

such significant interest group have been the families of those deemed 'insane'.

Foucault (1967) produced the most notable and influential dent in the Liberal Scientific view with his ambitious attempt to link the identification and incarceration of the insane to the development of an instrumental 'Western' rationality which had no place for madness in its social order. Scull (1979) has constructed a material economic framework around this argument through his influential thesis on the growth of the English Asylums. He argued that Asylums reflected a need for the emerging market orientated economy to control a deviant underclass who were no longer being regulated within their communities. The developing market economy brought two parallel movements which had implications for family life-

i) As feudal systems of patronage broke down, social and geographic mobility accelerated the fracture of community bonds, with their informal systems of support (Perkin 1969, in England⁴). MacDonald (1981), for example, writes of the demise of the traditions and obligations of almsgiving from the 16th century as the philosophy of individualism progressed. The nuclear family thus became the crucial unit of social support (Aries 1962, Parsons 1955, Shorter 1976, Stone 1977).

ii) The introduction of wage-labour made it difficult for individual families to cope with non-productive (sick and disabled) members. As Grob (1983:10) wrote of the foundations of the American Asylums:

For many families mental illness raised severe economic problems. The afflicted individual was usually unable to work, and the family was obliged to provide continuous care. Mental illness as a result was intimately related to the problem of dependency.

Society was thus presented with the problem of how to care for people and how to protect itself from the threat to order posed by potentially large numbers of people living outside conventional structures, who might join what was seen as a growing

⁴ It is the perception of these changes and anxiety about them which arguably provided the impetus to establishment of the study of society - sociology.

vagrant underclass (Foucault 1967, Scull 1979). The Asylum, Scull (1979) argues, alongside its cousins the workhouse and the prison, suggested itself as an answer. Whether one sees the emphasis of the growth of the Asylums as being on care or control is perhaps a matter of ideological perspective (Ingleby 1985). It is certainly clear, and well documented, that the Asylum movement can be seen as being continuous with Poor Law legislation and the development of workhouses in England (Allderidge 1979, Jones 1972).

The involvement of families in the confinement of their relatives in Asylums has been directly addressed by Walton (1985) and Mackenzie (1992) in Britain, and Tomes (1994) in America. Walton examines records from the Lancaster County Asylum and decides that those admitted were "not so much 'inconvenient people' ... as impossible people in the eyes of families, neighbours, and authorities". The Asylum provided: "relief for desperate families rather than an easy option for the uncaring." (Walton 1985:143).

Nancy Tomes (1994) presents a detailed study of the 18th and 19th century history of the Pennsylvania Hospital for the Insane, including analysis of letters written by relatives to the hospital staff. She argues that families were active partners (she refers to them as "the patrons") in shaping the development of the Asylum. It is they who wanted somewhere to put their aberrant relatives who could not behave properly in the newly emerging private domestic space of the family.

Charlotte Mackenzie (1992) through her study of the development of the private Ticehurst Asylum in England, documents in detail the intimate involvement of family members in the decision to admit to the Asylum, in the monitoring of treatment and the decision to discharge. She comments in her conclusion:

Given the central role of the family in choosing forms of care, it is surprising that, with the exception of Tomes's study of Pennsylvania Hospital for the Insane, it is a dimension which has been relatively neglected in the histories of the asylum movement. (Mackenzie 1992:214).

Whilst Mackenzie is right to highlight this relative neglect, there have been other

studies which, whilst not dwelling on the families' perspective, have noted their involvement. Castel (1988), details the rights of families to have relatives detained in pre- and post revolutionary France. Grob (1983:9) also notes that most commitments to American Asylums were by the families: "The diagnosis of insanity often did not involve the community. Nor were most commitments begun by law enforcement personnel. Proceedings were usually initiated by the immediate family." Jimenez's study of the initial development of the New England Maclean Asylum also notes that the inmates came from families (Jimenez 1987). Arieno (1989) produced figures from English Asylum records suggesting that the inmates were indeed coming from families. Finnane (1996) notes the involvement of families in the Irish Asylums. There is evidence, therefore, that families were actively participating in the Asylum movement by confining relatives who they were unwilling or unable to cope with.

ii) Anxiety about the amoral family: Moral Treatment.

If the Asylum was serving the needs of families, they can also be seen as being shaped by the perception that families (or at least some families), seen as a crucial component of the social order, were failing in their task to create "the bourgeois ideal of the rational individual" (Scull 1979:68). Foucault (1967) had already identified the family as implicated in the definition of reason and madness. To Foucault, however, the family, rather than being an active partner in this endeavour is better seen as a "battleground of the conflicts from which the various forms of madness would arise" (quoted by Sheridan 1980:28).

There was certainly vigorous debate in England about the effects of industrialisation and urbanisation on the moral climate and upon family life in particular. Fears about the breaking of sexual codes of conduct were prominent. City life was seen as breaking down conventional barriers between people. Introducing:-

. . temptations, hazards, and incitements far beyond those which approach the rural cottage; ignorant and largely depraved, they are likewise capable of combination; (Fletcher 1847:193)

The availability of factory work which took women out of the home, to possibly earn

more than men, would lead to the violation of "all the decencies and moral observances of domestic life" (Gaskell 1836:89). The Victorian MP Edward Jenkins (1874:55) evoked a hellish urban landscape where domestic space is squeezed out by over-crowding and poverty. 'The family' is pushed onto the street and into the gin palaces. Mothers and fathers are too drunk to bring up their children with any sense of morality:

The families get into cellars, or encroach on the narrow space of other families, until, at higher rents, they have in some mysterious way, found holes, like rabbits, where it would seem that every inch of the warren was already overstocked. Intolerable are the conditions of life, horrible the perils, moral and physical, dismal indeed the experiences of a population packed like that. . . . boys of nine or ten with old, hard fixed features and cunning eyes, taking their brandy and cigar.

David Rothman's (1971) portrayal of the rise of the North American Asylum lays great stress on the role of the perception of the family as the crucial socialising force. He argues that with the perceived atomization of the community during the early 19th century and the declining influence of the church, the family was discerned to be left isolated as the only means of instilling virtue into members of society. Reasoning then followed that if the family background of an individual was defective, that individual would fall into sin, crime and madness. If people had become insane (or criminal), the answer was to remove them from their defective families and sin-ridden communities and place them in institutions that could provide a setting in which people could learn a self-regulating discipline. Vieda Skultans (1979) also highlights the importance given to 'Moral Management' of the insane within English Asylums which would induce self control and discipline in individuals.

Even Andrew Scull (1979), who is scathing about the ultimate form that the Asylums took, acknowledges that 'Moral Treatment' was influential as an impetus to the building of the Asylums. People like Pinel at the Bicêtre in Paris at the end of the 18th Century and the Tukes at the York Retreat through the 19th century, were influential in popularising the idea of 'Moral Treatment'. The expectation of which was that if people were treated kindly and with respect they would be more likely to effect a recovery and would thus be able to return to a normal life. Doerner (1981:80)

draws attention to the emphasis the English reformer Samuel Tuke put on the creation of a family environment within the York Retreat, away from the corruption of the outside world. The insane were to be subject to the natural authority of the family like setting within the institution. That is, they were to be treated like children - subject to prompt punishments and rewards, taught that their behaviour had moral repercussions in that it disrupted the rest of 'the family'. The use and importance of the familial metaphor to the development of the York Retreat is discussed by Digby (1985).

Daniel Tuke, writing in 1882, finished off a summation of the important aspects of the York Retreat by noting ". . . that from which the first has been regarded as a most important feature of the institution, is its homishness - the desire to make it a family as much as under the peculiar circumstances of the case is possible" (quoted in Skultans 1975). Donnelly (1983:46) argues that, although the Tukes were unusual in so directly associating the idea of 'family' with the Asylum, "moral pressures, exerted with a force close to the intensity of a parent's bond to a child, were the fundamental motor of the new plan of 'management' in Asylums and its most telling symptom." The creation of dedicated, State monitored, Asylums would allow for Moral Treatment to accomplish cure (after the fashion of the York Retreat and similar private establishments).

Therefore whilst data from Arieno (1989), Finnane (1996), Grob (1983), Jimenez (1987), MacKenzie (1992), Tomes (1994) and Walton (1985) suggest that it was indeed often families unable to cope who were delivering their relatives to the Asylum gate, it was also anxiety about the moral state of the family which helped shape the growth of the Asylum, and the emphasis on 'Moral Treatment'. Unfortunately, Rothman (1971) and Scull (1979) are able to report how quickly the reforming institutions in North America and England respectively degenerated into merely custodial ones. Chesler (1972) also highlights the importance given to 'family life' in the Asylum. In her radical feminist story, however, there is no hint of any contradiction between 'Moral Treatment' and subjugation: "mental asylums are families bureaucratized: the degradation and disenfranchisement of self, experienced by the biologically owned child (patient, woman) takes place in the anonymous and

therefore guiltless embrace of strange fathers and mothers." (1972:34)

iii) The Asylum's Demise And The Rise Of The Welfare State.

If the family can be implicated in the rise of the Asylums they can also, it will be argued here, be seen as participants in its demise through their location in the scheme of the welfare state and their quite explicit place in Community Care policies.

The causes of the decline of the Asylum have been subject to similar forms of debate as the rise of the Asylum. To some, the decline is yet another symptom of the relentless forward march of scientific knowledge and progressive thinking. The factor most often emphasised in the traditional psychiatric literature (see Clare 1976 for example) is the introduction of the phenothiazines (major tranquillisers). This is disputed by those (such as Scull 1984 and Ramon 1985) who point out that the chronology is wrong, that the phenothiazines only started becoming widely available during the 1960s. Pilgrim and Rogers (1993) also note that the number of beds in many European countries increased over this same period, despite the spread of phenothiazines.

Meanwhile others see hospital closure as a cynical exercise in cost-cutting. Scull (1984) argues that economic crisis coupled with the industrial world's increasing commitment to welfarism rendered the Asylums too costly compared to care in a community which was already receiving benefit from the state. However, Busfield (1986) points out that the chronology of Scull's argument appears incorrect. The fiscal crisis was a 1970s phenomenon, whereas the populations of the Asylums were in decline from the mid 1950s. Scull is certainly not able to present convincing evidence for any great savings being made through deinstitutionalisation.

Chronologically the fall of the Asylum population fits very well with the establishment of the welfare state, which Gough (1979) refers to as being a product of the 20th century, "in particular, of the period since the Second World War". Scull (1984) refers to the growth of welfarism only as a drain on state resources. However,

it will be argued here that consideration of the assumptions and actions of the welfare state is helpful in highlighting again the involvement of ideas about families within mental health policies. Meanwhile, one of the instrumental actions of the welfare state (the provision of public housing) has helped enable the Asylums to close and has had important impact on the actual involvement of families.

Post-War Anxiety About The Family and the Welfare State.

The second world war is often viewed as a key watershed in British social history (Hill 1993, Deakin 1987, Midwinter 1994, Lewis 1992, Wolfram 1987), with much of the reordering that has become plain since the 1960s in gender and family relations being mooted in this period (Turner and Rennell 1995). In the immediate post-war period, on both sides of the Atlantic, there was concern about the family, and particularly women's place in the family as opposed to the workplace. Many family conflicts were being created as families were re-united after the war (Turner and Rennell 1995). In England and Wales the number of divorce petitions rocketed from a pre-war level of 9,970 in 1939 to 34,443 in 1949 (Wolfram 1987). Across the Atlantic there was a similar surge, with 1946 628,760 marriages being dissolved in the United States (just over four per thousand of population) which represented one in 55 of all marriages existing in 1946. Similarly high rates were not achieved again until the early 1970s (Phillips 1988). There was anxiety about the number of women in the workplace on both sides of the Atlantic. In an effort to bolster traditional family forms, women were being encouraged out of the factories and back into the home (although with little success - Lewis 1992). These anxieties were part of a conducive environment that allowed a sufficient political consensus to nurture the growth of the welfare state (Gough 1979). Wilson (1977) argues that this growth had at its heart the reinforcement of 'traditional' gendered family relationships. Wilson (1977), and other feminist critics (Land 1987 for example) point out that many of the state's welfare activities are designed to buttress and support the family:

First and foremost today the Welfare State means the State controlling the way in which the woman does her job in the home of servicing the worker and bringing up her children . . . (Wilson 1973:39)

Community Care policy, seen as an evolution of state welfare strategies, appears to be intimately linked to the ideological construction of the nuclear family as the fundamental unit of society. The emphasis on the role of the family in Community Care is indeed very clear (Bulmer 1987, Busfield 1986, Finch and Groves 1984, Land 1978). The decline of the Asylums has taken place, therefore, in a period where Government policies have concerned themselves with resourcing and strengthening the family in order that they can care for their 'own' dependents.

The more subtle ideological importance given to the family within the specific workings of community care policy were picked up by Christine Perring (Perring 1990, 1992, McCourt-Perring 1993) in her study of the community care homes to which ex-Friern patients were moved. She noted "[t]he model is one of a substitute family where carers are viewed in a quasi-maternal role, their managers as paternal and the residents as child-like" (Perring 1992:161). Such observations make the continuity of the linkage between ideals of family life and mental health very clear.

iv) Searching for the Cause of Mental Illness Within the Family.

Families can therefore be identified as being direct and indirect participants in the shaping of the broad sweep of mental health policies through the Asylum's rise and demise. On the one hand they were delivering their relatives who were deemed to be mentally ill to the Asylum door. On the other hand, anxiety about social change, and doubts about the moral rectitude of family life in particular, can be considered to have supplied some of the impetus to the Asylums and to the principle of 'Moral Treatment'. However, it in the period following the second world war, the era of 'welfarism' and the decades of the Asylum's decline, where the spotlight of critical professional attention was most conspicuously fixed on the family (Rose 1989). Family genes have been implicated, their behaviour assessed and their communication styles analysed by those that have assumed that the roots of mental illness lie somewhere within the family background of the sufferer (Biegel et al. 1990). More recently families have been studied for the degree of burden they take on as they assume greater responsibility 'in the community' (Perring et al. 1990). The findings of those studies that have looked at families and mental illness will be considered in

more detail in Chapter 2. The important point to be grasped here is that the direction of the bulk of the research has meant that there are considerable gaps in our understanding of the experiences of families.

The hardest physiological theory of serious mental illness is the hereditary one. The idea that insanity was a hereditary disorder has quite deep historical roots. Morel's 19th century theory that insanity was the product of degenerate reproduction is a good example (see Castel 1988). This idea has been taken up in a more sophisticated way by modern genetic models of transmission (Tsuang and Vandermeij 1980). Here the roots of mental illness are placed firmly within the family.

Families have more centrally been the target for attention by those constructing the major psychological models of mental illness. Freud and psychoanalytic theory are customarily seen as having established the principle of the primacy of childhood experience as a determinant of psychological health. It was the psychoanalyst Frieda Fromm-Reichman, who coined the phrase 'schizophrenogenic mother' (Fromm-Reichman 1948). This is a mother who was seen as being very cold and withholding of affection from the young baby, which according to Fromm-Reichman, caused the child to go on to develop schizophrenia later in life. However, the vast majority of the psychoanalytic effort has been applied to neurotic, rather than psychotic disorders. The fuller theorisation of the familial causation of psychosis took place mainly within the Family Therapy movement, which has been responsible for the vast majority of the research on families and mental illness.

Family Therapy and the Dysfunctional Family.

A group of researchers, based in different research centres in the United States (see reviews by for example Barker 1986, Nicholls and Schwartz 1991), emerged as a group in the post-war period who can collectively be called the Early Family Therapists. They had the common goal of hunting for the roots of schizophrenia in the behaviour and communication styles of the immediate family (usually the parents). Here the linkage between ideals of family behaviour and sanity become entirely explicit.

The similarity with the preoccupations of the 19th century advocates of 'Moral Treatment' is striking. Sanity is seen as being nurtured by the orderly conduct and clear communications occurring within the family. This linkage was picked up in Britain most notably by Laing (Laing 1959/1965, Laing and Esterson 1964). Although Laing's work had a radical edge of social criticism, the linkage of family and sanity explored by most of the Early Family Therapy researchers can be seen as being provoked by familiar anxiety about the place of the family within the arena of social change - this time made clear by the upheaval of the second world war in Europe and the United States.

Nathan Ackerman, one of the leading figures in Early Family Therapy research who was concerned to understand schizophrenia within the context of disordered family relationships (Ackerman 1954), writing in 1958 has clear concerns about the direction and impact of social change:

Blatantly in evidence are the disorganising trends in contemporary family life, the conflicts and failures of complementarity in man-wife relations, the signs of disintegration of the moral and ethical core of family relationships. (1958:335).

Here, plainly, we find anxiety about the disintegration of the family. As the above quote suggests, Early Family Therapy case studies often adhere to highly normative values of family functioning. Many ideological assumptions are made about gender roles in particular (see examples from Lidz and Bowen, in Chapter 2). These assumptions are indeed often very explicit. Transgressions of traditional gender roles are seen as pathogenic. Theodore Lidz (1963), another pioneer in Family Therapy research wrote:-

It becomes increasingly evident scientifically, as it has been through common sense, that children require two parents with whom they interact and who optimally are of opposite sexes in temperament and outlook . . . It appears that women having won their emancipation, recognise that women's self-realisation is linked to marriage and child bearing. (p26)

The Early Family Therapy literature has, not surprisingly, been criticised for its normative class, gender and ethnocentric values (the model is the two parent nuclear

family, with clear gender roles; any transgression from this being aberrant).⁵

Future Policy and The Family.

Therefore families themselves, or ideas and anxieties about the assumed importance of families, can be seen to be an important engine of change within mental health policies. It is families who used and encouraged the growth of the Asylum, it is the welfare state, in part fuelled by concern to bolster the family which has encouraged and allowed the Asylums to decline.

There is a great paradox being raised here. Whilst it can be shown that families have been important directors of change, and their involvement in the provision of care is a strong assumption of Community Care policy (Bulmer 1987), they have also been the objects of some considerable suspicion within professional models. As Chapter 2 will demonstrate, although families have been subject to a considerable amount of research, this research has not had the goal of helping professionals understand their experience, or point of view. Therefore the integration of family carers within a network of caring that includes professionals which is certainly an explicit goal of the Carers Act (DoH 1995) is likely to be problematic.

Having established that it is important to understand something of the families of people who are seen as suffering from long-term mental illness, the question arises as to what aspect or aspects of those families would most usefully be studied? This is the question addressed by the third and final part of this chapter.

⁵ Books such as Perelberg and Miller's (1990) "Gender and Power in Families" are a sign of increasing awareness of this issue.

3) The Evolution of the Affective Family and the Social Order.

It will be argued that it is important to apprehend an understanding of the affective and symbolic aspects of relationships within the families. It is these which are of particular contemporary cultural importance.

Even a cursory glance at the literatures on 'the family', reveals a considerable array of alternative perspectives from foci on highly instrumental dealings to the seemingly more personal emotional ties that exist within family relationships. Sociological, and indeed anthropological, perspectives have tended to focus quite exclusively on the structure and functions of the family, whilst regarding as largely analytically irrelevant the concerns of psychologists and psychiatrists who focus on the subjective nature of family life. Freud has most notably spotlighted the family as being at the very epicentre of our subjective and emotional lives. This pursuit has been taken up voraciously by the various caring professions and what others have called the 'technologists of the soul' (Rose 1989). The psychologists and therapists stand accused by critics of having a solely ahistorical understanding of the place of the family, ignoring evidence that the family has changed and altered over time and that its apparently natural form has been shaped by social forces.

This final section of the chapter will argue that an understanding of the affective values and the meanings of family relationships gives access to elements of sociological significance. Far from being of mere private concern the feelings that people have for one another are, it will be argued, an important aspect of that social structure. One significant aspect of that structuration (in which family life is both immersed within and contributes to) are definitions and understandings of madness.

Alternative Perspectives on 'The Family'.

Three distinctive perspectives on the family can be identified: the family as a functional instrumental network (ie, a network that facilitates the exchange of goals and services); the family as a household unit; and the family as an affective unit. It will be argued that two things in particular need to be understood about the

contemporary family. Firstly that it is not spatially contained within the household. Secondly that the emotional relationships that operate within families are of great cultural significance.

1) The Shrinking Family?

Any attempt to define succinctly "the family" is clearly problematic. Traditionally, sociologists make a distinction between the nuclear and the extended family. The nuclear family consists of children and parents living together in one household, the extended family consisting of parents, children, and other kin living together in a household (Gittins 1985). The evolution of 'the family' in the industrial world has been seen in terms of a shift from the extended form to the nuclear (Popponoe 1988). This story, however, can now be seen as too simplistic. Abundant debate has surrounded the history of the changing size of the English household, with argument as to whether since the advent of the industrial revolution the average household size has shrunk, representing the weakening of intergenerational bonds as fewer generations lived together (Anderson 1997, Seccombe 1992, Laslett and Wall 1972).

Since the second world war it is clear that there has been persistent and marked decrease in the size of the average household, as fertility has fallen (Lewis 1984, Seccombe 1992) and more people live alone (Buck et al. 1994, Social Trends 1995). It is the provision of social housing that rapidly increased after the second world war (Burnett 1978, Malpass and Murie 1987) which has aided the process by which people are able to live in smaller units, allowing family relationships to spill beyond the walls of single households. This might be regarded, by some, as a somewhat ironic outcome of welfarist policies which were aimed at bolstering the family unit.

An understanding of the role of social housing helps resolve a potential conundrum presented by the facts that although the Asylum populations have fallen, a repeated observation in the mental health literature is actually how few users of services actually live with their families (Ebringer and Christie-Brown 1980, Goldie 1986, and Rogers et al. 1993). The fact that mental health service users often do not live with

families has perhaps aided the process whereby families have been ignored in research on Asylum closure. Relatively few studies that have looked at families have included relatives who were non-co-resident (see Chapter 2, Creer 1975 and Simmons 1990). The exclusion of non-resident relatives is, it will be argued, based on an artificial association of the household with the family.

It is certainly not clear that the decreasing size of households does represent a diminution of the significance of 'the family'. Those who suggest there is a connection (Popone 1993) are assuming that there is a meaningful correspondence between the notion of 'the household' and that of 'the family'. Whilst such an assumption is historically uncertain, it is likely that the association carried into contemporary debate is unhelpful. As Bourdieu (1996:21) critically points out: "The dominant, legitimate definition of the normal family (which may be explicit, as it is in law, or implicit, in for example the family questionnaires used by the state statistical agencies) is based on a constellation of words - house, home, household". The increasing rate and visibility of divorce, separation, step-families and part-time parenting mean that the association is no longer tenable (Batchelor, Dimmock and Smith 1994). It will be argued that family relationships, freed from the connection with production, are better understood as being dependent upon feelings and are thus unbound from the walls of the household and are able to operate beyond those walls (Grieco 1987, Gubrium and Holstein 1987).

2) The Rise of the Affective Family.

Writers as diverse as Aries (1962), Shorter (1976), Stone (1977) and Parsons (1955) agree that the emotional significance of the family has greatly increased since the middle ages⁶. However, care needs to be taken to avoid a too simplistic picture of the pre-industrial family as being an emotionally arid environment. It is a picture that has been refuted forcefully by Macfarlane's (1986) extensive historical survey and through MacDonald's (1981) highly innovative, intensive study of the notes of the

⁶ There are differences in how this change is regarded. Shorter, Stone and Parsons celebrate the positive emotional benefits of private family life, whilst Aries mourns the loss of vital community life as the foci of people's lives shifted from the community towards the privatized family.

17th century physician Richard Napier who provided portraits of the lives of his patients through the problems they brought to him. However it is possible to see, even in MacDonald's descriptions of individuals' emotional turmoil from the 17th century, that greater importance was put on community, rather than intimate family, relations. Gillis (1985, 1987) argues that the emotional impact of personal relationships was great in pre-industrial times, but that alliances were more structured by community conventions, and relations outside of the conjugal were of greater significance to individuals than is usual in contemporary Western societies.

This rise of the affective family has taken place over time where there is again a discernible consensus that the Western family has lost many productive economic functions (Aries 1962, Parsons 1955). The family is no longer responsible for the organisation of agriculture, industry or education. Many of these functions have now been taken over by the state or other corporations (Turner 1969).

Although the family may have become less of an explicitly productive economic unit, it should still be noted that the family still has economic significance, a point highlighted particularly by feminist writers (Barrett and McIntosh 1982, Wilson 1977). Indeed the financial costs of caring can be considerable (Ungerson 1990). However, even for those who would argue that the *raison d'être* of the family is an economic one rather than to provide emotional support for individuals, the emotional investment in families that individuals make, still needs explanation. To live within families is the choice of many, although families may be exploitative (particularly towards women) and it may be questionable as to how real the choices are for individuals (Barret and McIntosh 1982).

It can be argued that the loss of functions and the ascension of the emotional life of the family were interdependent. Phillippe Aries (1962) argues that the development of state organisations (health services, education) allowed the family to develop as an affective unit, as opposed to an economic or educational one. The Asylums arose during a period when the family was becoming an emotional unit. They can be seen as being part of a development of the state that allowed the privatized family to

develop.⁷

Love and Order.

The emotional aspects of family life are subject to a significant contradiction. There is a highly visible public discourse that suffuses a range of psychological tomes and self-help manuals, radio talk shows, magazine articles, that implies that those feelings are of essentially private concern (Gubrium and Holstein 1987, Rose 1989). It will be argued here that this conundrum is resolved when it is understood that those feelings themselves have a significance which operates at a public, structural level. Feelings now provide a degree of order and control that was once the domain of more explicit rules and ties.

Kinship, Sexuality and Order.

There are accounts of the social significance of sexuality which can provide a useful framework for understanding the public role of the emotional relationships within families (and no doubt beyond). Foucault's work on the significance of sexuality to the Western world and Schneider's anthropological account of 'American' kinship both highlight the cultural significance of sexuality as a web which links and orders relations between individuals and thus provides a significant degree of social order.

The meaning of Western kinship patterns and behaviour have received remarkably little attention (Strathern 1992, Wolfram 1987). In this respect Schneider's anthropological analysis of Western kinship deserves some attention. Schneider (1980) explicitly examines contemporary American kinship and family in terms of a symbolic order.⁸ Whilst not directly ordering economic and political life (in the way that kinship structures in simple societies are argued to), he finds the notion of the family is still pivotal in contemporary American society through its containment of sexuality.

⁷ The question of the development of the privatized family as a means by which the State could exert control is taken up in detail by Donzelot (1980).

⁸ This is an analysis which the British anthropologist Marilyn Strathern (1992) considers highly applicable to Britain.

Schneider (1980) describes the cultural beliefs about the family as revolving around the symbol of sexual intercourse which "provides all of the central symbols of American kinship" (1980:114). The rules of kinship determine that sexual intercourse is sanctioned within the conjugal relationship and is outlawed from other relationships (particularly those within the family). Through its containment of the sexual, the family provides a means of reconciling the desire of a culture to see itself as rational and civilised with its natural and 'animal' underbelly. It is the family which balances the world of reason and culture with the irrational world of nature (1980:36-37).

Schneider's location of sexuality at the heart of cultural practice is echoed in Foucault's (1979) work on the deployment of sexuality⁹. Foucault argues that the last few centuries have witnessed a shift from a system of "alliance" to one of "sexuality". The system of alliance which, Foucault argues, dominated European societies before the 17th century was based on a system of more or less explicit rules concerning "a system of marriage, of fixation and development of kinship ties, of transmission of names and possessions." (Foucault 1979:106). Although involving family and sexual relations the emphasis was on the community rules of kinship, which tied in with the economic and productive functions of the community (much as Gillis 1985, Perkin 1969 and other historians have argued). This is analogous to the anthropologists' concept of kinship which has been used to analyze human societies. In observing 'simple' or 'primitive' societies there has been consensus that the organisation of kinship ties is fundamental to the structure of society (for example Levi-Strauss 1969). A distinction was made between societies which were seen as simple and those complex (including contemporary Western societies, Fox 1967). The notion of kinship in simple societies can be seen as constituting Foucault's law of alliance.

Anthropologists have seen the patterning of kin relations in our own society as being less relevant in the face of class arrangements, bureaucratisation, and corporate structure (Strathern 1992). Foucault agrees that in our own society the power of the cannons of alliance and kinship have diminished but argues that increasingly over the last few centuries we are being governed by the "deployment of sexuality". That

⁹ Sheridan in his translation of Foucault, prefers the word 'machinery', to deployment.

over that last few centuries, in accompaniment to "the social redistributions of the classical period" there "was a steady proliferation of discourses concerned with sex" (1979:18). This "discursive explosion" led to the creation of sexuality, where before there had simply been sex. It is the observance of sexual priorities which now govern us more effectively than those explicit rules of conduct and obligation (Finch 1989).

In outlining the 'deployment of sexuality', Foucault (1979) is describing the fabric from which the modern nuclear family is fashioned. Foucault identifies four related threads: the location of the medicalised and sexualised female body at the heart of society through its articulation of family space and women's relationships to children; rules concerning children's sexuality; the governance of reproduction (through rules concerning family support and the availability of contraception); and the identification, categorisation (and marginalisation) of minority sexual practices.

Foucault should be taken seriously in two respects: firstly, in pointing out that sexuality, far from being repressed, is provoked and forms a significant aspect of the cultural landscape (at least since Victorian times); and secondly, that there are now two interrelated systems deployed:- one of the rule of law, and one of sexuality around which relations between individuals revolve. In modern Western society the rule of sexuality has become more important. This is certainly in keeping with Schneider's anthropological analysis of contemporary American society (1980), and is echoed in Giddens' later work (Giddens (1991, 1993) and also by Beck and Beck-Gerhshheim (1995) and Luhmann (1986).

Thus, it can be argued that the family is now not merely required to fulfil the function of raising children, or the benign provision of emotional sustenance, but that these emotions bear a significant weight of social regulation. As there has been a diminution of the power of 'the community' in ordering social relations a corresponding burden of social management has fallen onto families (Aries 1962, Rothman 1971). As Rose (1989:126) has written on the contemporary British family:

'Familialization' was crucial to the means whereby personal capacities and constructs could be socialized, shaped, and maximised in a manner that accorded with the moral and political principles of liberal society.

In the field of mental illness the assumed role of the family in promoting the development of orderly individuals becomes quite visible. As the earlier discussion of 'Moral Treatment' and the 'Early Family Therapy' research made clear, the family is now seen as responsible for the transmission of many cultural rules and the establishment of orderly conduct. Perelberg (1983) studied the family events surrounding the admission of a patient to an acute psychiatric ward as "a privileged moment for an anthropological investigation of the relationship between the individual and society as the social rules are being tested and applied" (p138). Perelberg observed that the 'accusation' of mental illness by parents of their children occurs as various rules were broken (Perelberg also looked at inter-spouse accusations). Perelberg identified three topics which commonly arose between parents and someone who came to be identified as mentally ill:- 1) Lack of respect for parental authority. 2) The mental patient was seen as taking over control, and 3) The ideology of family unity and privacy became threatened. It is noteworthy that Perelberg observed that the breaking of sexual boundaries was often problematic. Perelberg (1983) is describing the order of modern families being disrupted by the presence of mental illness and the active involvement of families in defining (by 'accusation') the problem in terms of mental illness. A study of families' involvement in mental illness needs, therefore, to be able to grasp the ambiguity that in studying the affective worlds of meaning and relationship, an important thread of the social fabric is also being studied, which will help us understand the world in which mental illness resides.

Summary.

This chapter has argued that the rise and current demise of the Asylum (whilst the precise product of multifarious forces) can be seen as influenced by ideology, and anxiety, concerning the family. Community Care policy explicitly supposes the greater involvement of families in the future care of people with long term mental health difficulties. It will very likely lead to greater responsibilities falling upon families (see Bulmer 1987), particularly the women in these families.

The real test of hospital closure policies will come in their provision of adequate support for the group of people who have become known as the 'new long-stay'. There is a need to understand more of the circumstances of this group. This study will therefore comprise an investigation of family members who have a relative who might be seen as fitting into this category. Care will need to be taken in defining a suitable sample, however, since the practice of defining the group according to length of stay in hospital will no longer be adequate as services shift from hospital to the community.

In studying relatives of this group, we are studying the contemporary family which is a complex creature. As the importance of community networks and formal social rules have withered, many social control functions have fallen upon the family. Increasingly, the family has become an important receptacle for the conveyance of cultural practice. As part of this transformation the family developed as a unit that has enormous affective significance for individuals.

Any attempt to understand family relations needs to be aware of the two systems discussed here. There are 'rational' forces that operate through a system of obligation and kinship, but there is also a more subterranean one involving the psychic and emotional lives of individuals (including the particularly intangible emotions to do with, for example, sexuality). Traditionally sociologists have tended to regard the latter as being the preserve of psychology and of being of minor importance (if not irrelevant) compared to the study of social structures. Foucault's analysis is sociologically significant in raising the possibility that it is through the study of intimate psychic worlds that we gain access to social structures which actually command through their ability to penetrate and 'create' the individual social actor. What is particularly highlighted is the blurring of the distinction between the social and emotional levels. It should also be noted that a study of 'the family' must study the family beyond the household. This is consistent with observations that many people with mental health problems do not live with families. This does not weaken the case for studying families but emphasises how the affective rather than merely the instrumental aspects need to be understood.

The important questions that are raised are: What are the challenges that face families who care for someone with long-term mental illness, and how can their experience be better understood? Unfortunately, as the next chapter will show, a great deal of the research into families and mental illness has been driven by the same concerns that have directed the involvement of families in mental health policies. There are on the one hand concerns about families being inadequate and failing to create rational citizens, whilst on the other the family members are seen simply as caretakers of a dependent group. There has been little effort to understand the families' experiences.

CHAPTER 2.

The Previous Research On Families Of People With Mental Illness.

Introduction.

Reviews of the literature concerned with families and serious mental illness (Biegel et al. 1990, Hatfield and Lefley 1987 and Perring et al. 1990) reveal a great volume of research, but also a dearth of material that sheds light on the experience, or the perspective, of families. This stands now in contrast to the growing literature that explores the perspective of the mental health service user (Barham and Hayward 1991, Rogers, Pilgrim and Lacey 1993, McCourt-Perring 1993). The apparent paradox can be understood within the context of the issues discussed in the previous chapter. Families hold an important ideological location through their assumed shaping of the subjective and affective lives of individuals (Foucault 1979, Donzelot 1980, Rose 1989) and their more formal importance within social policies (Wilson 1977, Lewis 1992). This chapter will review the literature on families and mental illness. The very important point to note here is how little of it focuses on the emotional experiences of the families. Yet as Chapter 1 has argued, it this area which may be of crucial importance, since within it lies the source of the incongruity that Community Care policy seems to require so much of families, and yet within the mental health field families often seem ignored or viewed with suspicion by professionals and planners.

There are four branches of research to consider:

1) The greatest amount of work has been carried out within the model that can be broadly called 'Family Therapy', and the first part of this chapter is concerned with this paradigm. The originators of the movement of 'Family Therapy' were concerned with severe mental illness affecting children (usually adolescents and young adults) within families. The focus of the great majority of this research was to seek the cause of mental illness within the behaviour of the family of the sufferers (Kreisman and Joy 1974). Some of the ideological concerns of this paradigm were discussed in the

previous chapter. The aim of this research has not been to provide insight into the experiences of the families themselves.

2) The major alternative paradigm may be called 'burden research'. This style of research has been reviewed in detail by Perring et al. (1990), who observe that it has tended to highlight the practical problems of caring, or the characteristics of carers as they affect the course of illness. The rationale behind this research has been the instrumental policy aim of finding out how the caring burden can be reduced and caring made more effective. The approach can be understood as growing directly from policy decisions which are likely to increase family 'burden'.

3) These two paradigms have, to an extent, come together in some more recent developments in family therapy. These might be called the 'psychoeducational' strategies - such as the "Problem Solving" and "Expressed Emotion" approaches. Whilst the blame directed at families for causing the illness has been attenuated, the aim of these approaches is to instruct families to cope better. Again, these developments can be understood as being part of a social policy shift which requires families to provide more care.

4) The small number of studies that have focused more upon the experience of family carers will be considered. They have drawn attention to the emotional difficulties experienced by relatives and the often difficult relationships they have with care agencies (Creer 1975, Mills 1962, Shepherd et al. 1992, and Strong 1997).

1) Early Family Therapy.

In discussing Family Therapy here reference is not being made to all therapeutic efforts which might happen to be made with a family, but a quite specific construction of the family as being the cause of illness within one of its members (Barker 1986, Foley 1974). Within this paradigm much effort has been expended in tracing the roots of schizophrenia.

Family Therapy has been influential in forming thinking about families and mental illness. It is certainly the largest body of research to have considered the families of people suffering from long-term severe mental illness. For these reasons it is worth dwelling on and examining some of the assumptions being made by Family Therapy.

The Disordered Family.

Family Therapy research gained prominence in America in the late 1940s and through the 1950s. The primary assumption of the early Family Therapy research was that schizophrenia as a disease, or a set of symptoms, was in some way being created within the environment of the family, particularly through the parental behaviour (Hatfield and Lefley 1988, Kreisman and Joy 1974). Much of the early research involved very intensive, acute observation of families where one member of the family, invariably one of the children (as an adolescent or young adult), had been diagnosed as suffering from schizophrenia.

It will not be possible to comprehensively review the various schools of Family Therapy here. The history of the movement can be read in several accounts produced by adherents (Barker 1986, Foley 1974, Goldenburg and Goldenburg 1991, Nicholls and Schwartz 1991) a good example being Lyn Hoffman's (1981) book *Foundations of Family Therapy*. In a celebratory prologue to this book (an excerpt of which is presented below), Hoffman brings attention to several crucial aspects of Family Therapy. In the passage, the exaltation of objectivity can first be noted, with the one-way screen being used by the researchers to observe the families (1). The researchers can remain behind the screen, the observer is separated from the observed. There is also the wish for Family Therapy research to be associated with the technology and paraphernalia of Enlightenment science, the initial metaphor being the discovery of the telescope (2), before then shifting from astronomy to the biological sciences (3). There is then the very definite statement about schizophrenia not being an illness but as being behaviour which can be regarded as 'understandable' in the context of the family environment (4).

"This book is a journey to a newly discovered kingdom, the world

behind the looking glass. For me, the advent of the one-way screen (1), which clinicians and researchers have used since the 1950s to observe live family interviews, was analogous to the discovery of the telescope (2). . . the screen became a stake-out place from which to view the fauna (3) of a realm that had always been before as yet never truly seen. One of the early discoveries made by those who first viewed families with schizophrenics was that what were thought to be mental illnesses belonging to individuals might not be illnesses in the medical sense. In fact, they might not be disorders at all. Rather, they could be seen as orderly manifestations that had meaning in the families or other social setting in which they occurred.(4)" (p3-4)

Whilst there was not one inventor of the Family Therapy approach, certain names appear ubiquitous in the many histories of Family Therapy (for example Barker 1986, Hoffman 1981, Foley 1974, Goldenburg and Goldenburg 1991, Nicholls and Schwartz 1991). There were the psychiatrists Theodor Lidz, and Nathan Ackerman (psychoanalytically trained psychiatrists). The research team based at Palo Alto, originally led by Gregory Bateson and including Jay Haley, John Weakland and eventually Don Jackson. Lyman Wynne and Murray Bowen came somewhat later, but developed important concepts.

The various ideas underlying Family Therapy models can be considered under three, overlapping, categories:-

i) Functionalism.

Functionalism underlies most schools of Family Therapy. This is consistent with the dominant paradigm of American sociology through the 1950s and after (Parsons and Bales 1955). The basic tenet of this functionalism was to view social groups as systems, with the various components of the system being understood by considering the roles that they fulfil in maintaining that system. In families with a member suffering mental illness, the family is considered as such a system. It is then assumed that the symptoms of the identified patient serve some purpose useful to the family

system.

Functionalist thinking in Family Therapy theory can be illustrated by a typical example from Murray Bowen (1960). Bowen worked by looking in detail at the dynamics of the family relationships before him and then by attempting to alter them. In this account of family therapy, the identified patient is the young daughter, suffering from a psychotic breakdown. Bowen construed the 'real' problem as being the dysfunctional relationship between the parents, and not the daughter's supposed psychosis. The mother and daughter were seen as being unhealthily involved with each other, with the daughter's 'illness' serving to draw attention away from the dysfunctional relationship between the parents (where the real problem lay). The values and norms which are operating here are instructive:-

The father remained on the periphery in an inadequate position. Gradually the father began to participate in the family problems. The conflict shifted to the mother-father relationship. As the father began to take some stands against the over-adequate mother, she became much more anxious, challenging and aggressive towards him. Eventually he assumed a position as head of the family, in spite of her marked anxiety, tremulousness and protest. In a few days she rather quickly changed to a kind, motherly, objective person. She said "It is so nice finally to have a man for a husband. If he can keep on being a man, then I can be a woman." (p369)

Eventually, the parents became much closer, the daughter losing the "close symbiotic relationship" with the mother-and went on to "make some solid progress."

This notion of the symptom serving a family system function has been taken up as a central principle of the more recent and quite popular Milan systemic school which will be discussed later.

ii) Emotional Disturbance.

Another way of looking at families was as though they suffered from some form of emotional disturbance which was making, or had made, the identified patient mentally ill. Under this view schizophrenia was seen to be a response to emotional deprivation, such as the loss or absence of one or other parent, or the plain odd, eccentric behaviour of the parents.

A good example of this approach is found in a study by Lidz and Lidz (1949). They look at the family environment of some schizophrenia patients and consider five different categories of factors which might be relevant: the loss of one parent through death or divorce; the incompatibility of parents (special emphasis seems to be given to religious differences); the instability of parents; particulars of "Raising"; and occurrences of "Mental illness in family" . Factors which are picked out for this particular group as being possibly relevant are instructive. Factors include everything from overt mental illness in the parents to such comments as:-

"Father hypochondriacal and mother always nervous and irritable."

or " Mother moody, thoughtless, rigid."

or "Peculiar marriage of poor Protestant barber to wealthy Catholic heiress who was disowned and disinherited."

or "Parents married only because of the pregnancy. No mutual life. Father took no interest in pat. and found interests out of home. Mother silly."

Lidz and Lidz conclude that "The study of the histories of these patients impresses forcefully that one patient after another was subjected to a piling up of adverse intrafamilial forces that were a major factor in moulding the misshapen personality . ." (:343). Through the focus on early family trauma the influence of psychoanalysis is clear. Some of the leading protagonists (such as Bowen, Lidz and Jackson) were indeed trained in psychoanalysis (Hoffman 1981).

iii) Communication Dysfunction.

Another way of looking at the families was as though they suffered from communication dysfunctions. Here the schizophrenic symptoms were seen as being an inevitable result of confusing communications within the family. Gregory Bateson's theory of the 'double bind' is the best known example (Bateson et al. 1955). A typical example is the mother who asks her son why he does not show her affection, and when he goes to put his arm around her, she shrinks away. The son is thus getting contradictory messages on different 'channels'. The overt verbal communication is 'come close to me', the covert (non-verbal) communication is 'stay away'. To Bateson et al. a way out of such confusion was to become schizophrenic.

Summary Of Assumptions Of The Early Family Therapy Research.

1) Consistent with psychoanalytic thought, the early family background of the individual is assumed to be of significance for psychological development. However, in a move consistent with the development of psychoanalytic theory in America (Brown 1964, Frosch 1987, Kovel 1988, Quen et al. 1978), more emphasis is given to the external social environment and later influences on development, rather than intra-psychoanalytic conflict and maturation.

2) There is great concern with "actual reality" and objectivity reflecting the empirical techniques of behavioural psychology (Brennan 1986) rather than orthodox psychoanalytic method with its focus on 'internal world' and fantasy.

3) An assumption is made that families had caused schizophrenic behaviour. What is striking about the Family Therapy research is the highly pejorative, moral tone that is taken. Some of the acute observation of the kinds of destructive cycles that people can get into might be useful and interesting. However, alternative hypotheses which are equally supported by their data are not taken seriously. For example, Lidz and Lidz (1949) recognise that their data could support a genetic hypothesis. However they comment only that the problem is difficult to resolve, and that "[t]he problem will not be debated here ...". (p344). The impression gleaned from reading these

papers is that the culpability of families in causing schizophrenia was plain and self-evident. Lidz (1963:11), for example, comments :- "My interest in the family arose from the clinical finding that schizophrenic patients had always been raised in seriously disturbed family settings . .".

It might be then that the Family Therapists were simply reflecting a very rudimentary anxiety about the fragility of family life and that the origins of mental illness lie within the boundaries of aberrant family life. The enmeshment of our perception of mental illness and family roles was discussed earlier in Chapter 1. It would certainly explain why the early Family Therapists did not seek to justify their assertions.

Subsequent Developments in Family Therapy.

Family therapy has now become a considerable industry with many different schools continually emerging, merging and dividing. Whilst the early research work had been with families and people suffering from psychosis, the focus has shifted during the subsequent years, in particular to poor and disadvantaged families, the sort of people, according to Hoffman (1981) "who did not always have so much trouble with 'what is real' as with 'what is right' according to the mores of the larger society" (p. 71). The element of social control in family therapeutic interventions here becoming particularly clear (Donzelot 1980, Rose 1989).

Many other 'family therapies' do not have the same strong epistemological roots, but perhaps use various concepts from psychodynamic or Rogerian theory for example (Satir 1967 for example). The various schools need not be reviewed here. They are not directly concerned with the families of those diagnosed as suffering from serious mental health problems.

A couple of family therapy movements have concerned themselves with psychosis and need to be mentioned. R. D. Laing was influential in Britain and was partly responsible for popularising the ideas of the Early Family Therapy researchers. More recently the Milan systemic school has been having some influence.

British Family Work: R.D. Laing and R.D. Scott.

R.D. Laing, working in Britain, developed theories based on assumptions that were, in essence, very similar to the earlier Family Therapy work in America. Indeed, he refers to some of that research work (Laing 1959/1965). Laing saw schizophrenia as being a sane reaction to an insane world, in particular the world of the family (Laing and Esterson 1964). Laing's critique did, however, extend beyond the unit of the family to contemporary society. He was also highly critical of the institutions and premises of psychiatry. Laing's views, however, lacked overall coherence. His early anti-family stance underwent a complete reversal so that by the early 1970s Laing was far from celebrating *The Death of the Family* (in the words of his former collaborator David Cooper) but was going "all out to prove that the family was, on the contrary, alive and well and living near Belsize Park" (Sedgwick 1982:108).

In spite of these reconsiderations, one of the most salient legacies of his work, through the popularisation of the early Family Therapists' work in Britain, has been the "Laingian family" who drive their children mad.

Also worth a mention, although less influential, is the work of the Napsbury Hospital team, headed by Richard Scott. Their work was also influenced by the American Family Therapists in that they took a family pathology perspective for granted (Scott and Ashworth 1967). Although they did develop an approach with the potential to develop an understanding of the families' point of view by emphasising the patients' own agency in the production of psychosis (Scott 1973, for example), and were interested in the impact of hospitalisation on family relationships, the final impression is of parents who are the source of many of the patient's problems.

Milan Family Therapy.

The Milan school of family therapists (Boscolo et al. 1987, Selvini-Palazzoli 1978) need to be discussed, since they take their theoretical stance from the early Family Therapy research, particularly from Bateson's work, and claim therapeutic success with schizophrenia. They share the early worker's interests in objectivity by using

one-way screens. They also view the family as a system.

They seem, on the face of it, to avoid blaming families, by replacing the concept of linear causality with circularity. Instead of assuming that a state of affairs is caused by something, they " ... would see communications and behaviours from everybody present, composing many circular causal loops that played back and forth, with the behaviour of the afflicted person only part of a larger recursive dance." (Hoffman 1981:6-7)

The claim for neutrality, which Hoffman refers to as the most likely signature of the Milan Associates (Hoffman 1981:302), is hard to sustain, however. For example, Boscoli et al. (1987) reproduce the transcripts of the team discussions of a therapy. This is a typical example from the treatment of a family with a teenage boy who has had a recent 'psychotic' breakdown, it seems clear where blame is really being apportioned:

The boy is being attacked by all these people [the family] who are trying to give him labels. You get to the point where even if you're a good child, it's a label. So you're not a human being any more, you're just a label." (p43)

The approach shares the problematic aspect of earlier family therapy that the basic premise that families cause mental illness has not been substantiated. Studies that have looked at the efficacy of treatment have not been very encouraging (Mashal et al. 1989, Howe 1989). The robustness of the claims to be non-blaming through the notion of circularity appears to be in doubt. As workers have attempted to work with families that have physically or sexually abused their children, the conceptualisation of circularity looks dubious (Walrond-Skinner 1987). Milan workers are now having to take serious account of power issues within families (Dell 1989).

The psychosocial interventions, such as the "Expressed Emotion" approach and the psychoeducational models, also have roots in family therapy but will be discussed in the next section, as their dominant features have come from other frameworks.

Summary.

Kreisman and Joy (1974) identified the key assumptions of Family Therapy as being that the family environment causes mental illness and that the evolution of the family environment is not considered. The initial claims of the early researchers have foundered. With hindsight it would seem that strong claims were made in the absence of clear evidence (Hirsch and Leff 1975). To quote a recently published text-book on family therapy - "family therapy has not proven effective with schizophrenic families." (Nichols and Schwartz 1991:216). The work has not helped elucidate the experience of psychosis or even what it is like to live with someone who experiences psychosis. Perhaps an unfortunate consequence of this quest for the aetiology of schizophrenia within the families of sufferers has been the re-enforcement of the alienation of carers from professionals. Agnes Hatfield has written:

Family therapists apparently recognise the problems, for many of them that we reviewed were adamant in their criticism of other therapists who blamed families and produced painful dysfunctional guilt, but predictably, they used terms just as critical of families and just as likely to exacerbate family problems. What is not recognised is that as long as the focus is on deficiencies of families, they will feel blamed, It also suggests that much of the problem lies in the concept of therapy, for in it there is no way to absolve the family from being at fault in some way. (1984:317)

It is only fair to say that much of the research has involved acute observation of the kinds of destructive cycles which people and families can become involved with. There is some convergence of observation that families with a member with a diagnosis of schizophrenia do have particular problems. More work needs to be done to try and understand the development of these situations.

2) Burden Research.

Following Grad and Sainsbury's (1963) conceptualisation, 'burden research' can be described as a more psychiatrically orientated literature. These studies set out to describe, or measure, the effects of mental illness on the family. This work can be viewed as being reactive to a lot of the Family Therapy work. It takes the view that a mentally ill person is a burden inflicted upon the family. It asks the question: what ill effects are caused in the family members, by the mentally ill person? In other words, this is the contrary view of the early Family Therapists.

Stephen Platt reviewed much of this work in 1985. He draws particular attention to attempts to distinguish objective from subjective burden.

Objective burden involves practical matters, anything that occurs as an obviously disrupting factor in family life owing to the patients' condition. This can be anything from financial effects to the disruption of routines and of previous roles. These elements are generally easily measurable, almost by definition, in that they involve perceived burden or difficulties. Subjective burden involves the feelings engendered by the objective burden which is a far less easily measurable concept.

Platt (1985) reviews the problems occurring in the measurement of subjective burden. The main difficulty is of course the very nature of the data - it can only be collected from the person feeling the burden, and it is hard to assess and measure since it is subjective. The problem, however, is that this subjective burden is crucial since this is how people actually experience and are affected by the objective burdens that are being catalogued. Apparently similar 'burdens' will mean different things to different people in different contexts. This raises concerns lying at the heart of this thesis which are explored in the Methodology chapter.

Objective Measures of Stress.

Some studies have documented the stress suffered by relatives, using objective measures of illness and stress. The study published by the "The Scottish

Schizophrenia Research Group" (1987) is a particularly clear example of this approach. They use self report questionnaires (the "General Health Questionnaire" and the "Social Adjustment Scale") which they administer to relatives. They demonstrated very high levels of stress, with anxiety based symptoms being prominent. Again these researchers are not attempting to provide insight into the experience of relatives, they are satisfied to simply document the apparent toll on relatives.

3) Psychoeducational Approaches.

The psychoeducational approaches involve the provision of information, which is usually quite medically orientated, and reassurance for the families that they are not to blame. Kazarian and Vanderheyden (1992) review psychoeducational approaches, and are rather equivocal about their success.

These approaches do not involve research into the experience of families as such, although the fact that they take a more neutral stance is notable.

Expressed Emotion.

The expressed emotion (EE) approach can be regarded as a variant of the psychoeducational approach. It evolved in Britain and has become well known, with many studies carried out and reported regularly in the psychiatric journals. Leff and Vaughan (1985) describe its development from an observation that people discharged from hospital with diagnoses of schizophrenia who returned to families were more likely to be re-admitted than those discharged to other environments. They decided that the problem within some families was the expression of negative emotion and criticism and a high degree of emotional involvement (high Expressed Emotion: high EE). Having developed interview schedules to detect and measure the degree of EE, they found that where this high EE was present the identified patient was more likely

to relapse. Further work, which involved intervening and providing the family with advice about the illness and how to cope, suggested that where the EE was decreased, the relapse rate was reduced.

The EE researchers have been a lot more circumspect about actually blaming the family for causing schizophrenia. They have however been criticised for providing yet another stick with which to beat families. Hatfield (1987b:61) wrote:- "High EE and low EE are seen as labels that once again depict families as "good families" and "bad families" - usually the latter". It has also been argued that EE is no more than an indicator of stress and that the family interventions work because they do provide some support and advice which reduces that stress (Hatfield 1987a).

Problem Solving.

An example of a less well known approach operates in Buckinghamshire and is described in Falloon and Fadden (1993). This approach entails a team of mental health workers working with families in the community in a very practical way. They set up practically orientated programmes and interventions that revolve around the idea of problem solving. This has been running for a short time apparently successfully. Critics point out that it operates on a rather small scale, and the rural location means they do not have to deal with the same problems as inner city areas.

4) Non-Illness Orientated Studies.

Perring et al. (1990) in lamenting the dearth of studies that actually examine what it is like to care for someone, argue that the paucity of such research might partly be explained by the strong medical bias, which has meant the experience of people (particularly those not actually 'ill') has been ignored in the quest for 'cure', and through the typical medical science reliance on quantitative methods. Studies of families where there is mental illness present which do not attempt to identify the cause, or alter the course, of mental illness are indeed few and far between. There

have been a couple of sociological studies carried out in the 1950s which make interesting observations.

A study by American sociologists Clausen and Yarrow (1954) looked at the wives of people suffering mental illness. The perspective taken by the study was actually quite a traditional medical model. It was concerned with examining how mental illness came to be recognised as such by the family members. Its conclusions are about how public education might quicken this recognition and thus make families request medical help sooner.

British sociologist Enid Mills (1962) carried out a study of mental illness in late 1950s in the East End of London. She documents some of the hardship and suffering endured by families and comments on the seemingly very involved, close relationships that seem to develop particularly between mothers and sons who are ill. This observation is similar to some of those made by the American family therapists who drew strong conclusions.

Relationships with Care Agencies.

Mills (1962) also noted the often poor relationships between GPs and relatives, with relatives feeling bitter that illness was not recognised or treated properly. This finding is echoed in studies by Creer (1975), Shepherd et al. (1994) and Strong (1997) which all highlighted the often poor relationships that families seem to have with service agencies and professionals. As should be clear by now, given the policy ambivalence and some of the theories informing professionals' attitudes, this is not surprising.

Clare Creer (1975) has provided, certainly the best known, and probably most in depth look at the problems faced by relatives. She carried out a survey of informal carers who had been involved in the formation of the National Schizophrenia Fellowship (NSF). She interviewed 50 NSF members and also 30 non-NSF relatives in an attempt to counter-balance the self-selectivity of the NSF sample. Various data were collected on the characteristics of the patient. More data was collected on the feelings and difficulties faced by the relatives themselves. She uncovered a great deal

of distress. 47.5% of the sample described their health or well-being as being impaired to a 'Severe' or 'Very Severe' extent, only 18.8% described their health or well-being as not being impaired. A lot of stress was caused by the unpredictable behaviour of the cared for person. Depression and grief were commonly described as relatives felt the person that they used to know had gone away. Creer reported that this grief was exacerbated as relatives often felt that professionals made no attempt to understand this.

The causes of the distress can be described as fitting into a couple of categories:-

i) Dissatisfaction with Service Provision.

There was a lot of criticism levelled at the services that were available. Relatives also often felt that help had not been available until late in the day, when traumatic compulsory hospital admission would occur. Following discharge there would be little in the way of back-up.

ii) Emotional problems.

Creer describes anxiety and depression as being reactions to the difficult and traumatic circumstances faced by the relative. In addition, grief was experienced as relatives felt that the person they had once known had 'gone away'. This grief was exacerbated as relatives often felt that professionals made no attempt to understand this. Indeed it was felt that professional workers judged relatives as being 'over-anxious' or 'unstable', sometimes even explicitly blaming them for causing the illness.

A small study consisting of guided interviews with ten relatives of people on a Community Psychiatric Nursing case-load is reported by Simmons (1990). Simmons describes her work as illuminative research and indeed the study includes some very interesting quotes and discussions, which might well provide insight into the experiences of these ten people. However there is little attempt to interpret or place what the relatives are saying in a wider context. What they say tends to be taken

simply at face value. This is perhaps typical of the symbolic interactionist stance that is taken by the study (this point about symbolic interactionism is taken up in the Methodology chapter). In spite of some very rich material, the conclusion consists of essentially two points. Firstly that families need more information, and secondly that professionals should take more notice of what families say and that what is required of professionals is a more collaborative approach.

Conclusions.

To an extent nearly all the literature reviewed in this chapter, despite very different premises, points to one overwhelming conclusion: that families' relationships with mental illness and with members who are deemed mentally ill, are highly problematic. This review of the research literature has revealed particular lacunae which need to be addressed:-

Co-Residency.

There is little work on families who are not co-resident. Simmons (1990) is unusual in including non-co-residents in her study. In the light of moves towards a community orientated approach this seems to be a serious omission. This issue is relatively easy to address. This study will therefore aim to include family members who are not co-resident with the identified patient.

Relationships with Professionals.

There is increasing disquiet about the poor relationships that professionals have with families. This has been reflected to an extent in the research literature (Creer 1975, Simmons 1990, Shepherd et al. 1994, Strong 1997) and more clearly in statements from voluntary family groups (Hatfield 1984). It will therefore be important to develop insight into the understanding that relatives have of the psychiatric world.

What are points of agreement and disagreement between the lay beliefs and psychiatric beliefs, how do the relatives construe the institutions of the psy-complex?

Meaning and Subjectivity.

The most obvious hiatus has been the inadequate amount of work on how family members experienced and attributed meaning to the suffering of their ill relative, and how they attach meaning to their own difficulties which occurred as a result of this. As Terkelson (1988:129) notes in writing a chapter on the importance for professionals of reaching an understanding of what mental illness means for families: ". . .so few formal studies exist that this chapter could be a catalogue of required rather than completed research". Of particular importance is how could the attachment and commitment to the relative be characterised? Chapter 1 highlighted affective relationships as being at the heart of the contemporary family. Given the assumptions of community care policy, with its positive emphasis on the nurturance of informal social support (of which family support is arguably the most credible element) it would seem desirable to understand the commitment that families might have for a member suffering mental illness, and what the difficulties in maintaining that commitment might be.

Some researchers have highlighted the importance of the subjective difficulties or burden that relatives bear. Platt (1985) alludes to the difficulty of apprehending subjectivity. This difficulty is shared widely in traditional social science. A major project of this thesis will therefore be to consider the understanding of subjectivity within social research in the following methodology chapter.

Reflexivity of the Research Itself.

As this chapter has highlighted, a great deal of research work has been quite unself-consciously moulded by methodological strictures and social and political aims. Much of the work reflects the concerns and assumptions of the professionals and researchers, rather than the families. It can be argued, and this will be taken up in more detail in the next chapter, that what is required, is work that is more self-

consciously able to be aware of its own practice, and which is therefore better placed to fully engage with and appreciate the experiences of those who are studied.

CHAPTER 3.

Methodology.

Introduction.

This thesis requires an insight into the subjective experiences of relatives of people suffering from long-term mental illness. A quantitative approach would not be appropriate because of the positivistic assumptions underpinning such work. Briefly put, quantitative work would be problematic because:- 1) There are no established means to reach a consensus about the measurement of the subjective experience. 2) Any attempt to apply one's own a priori categories to people's experiences breaks up the very phenomena of interest, which are multi-faceted and relational.

To know what is not going to be helpful seems a relatively easy decision to make. It is more difficult to know how to proceed 'qualitatively'. There is a curious paradox in contemporary social science. In theory positivism has been convincingly discredited. Yet, in practice, positivism seems to dominate empirical research and debate about methodology, and certainly methods. This chapter will argue that an important reason for this is the failure to develop a coherent alternative to positivism within empirical social science. This seems to have resulted in a "panic and lack of confidence" (to use Rom Harré's 1986 term) and a retreat to positivism. When qualitative methods are discussed it is often within a positivist framework. Contemporary users of qualitative research often seem to play lip service to the philosophical underpinnings but have forgotten the implications of the philosophical concerns.

There is now increasing interest in the sociological significance of the emotions. Such an upsurge is connected to important theoretical movements within sociology. Borne on the back of post-structuralist thought comes the notion that the feelings we have for each other and for things may be considered to be important aspects of social structure. This case has been most notably put by Foucault (1980) through his discussion of *The History of Sexuality*. Despite prominent theoretical work (Giddens

1992, Luhmann 1986, Wouters 1992, Beck and Beck-Gernsheim 1995) sociologists have seemed reluctant to engage in much empirical research on the emotional worlds of their subjects (Kleinman and Copp 1993).

This chapter will consider the contribution to methodological debate which might be made by dialogue between sociologists interested in the empirical study of contemporary phenomena and psychoanalytic ideas on interviewing. Whilst sociologists have been interested in psychoanalysis for some time this interest has tended to be confined to the application of psychoanalytic ideas at the macro-level (notably the Frankfurt School). Psychoanalysts on the other hand, despite clearly being dependant upon on non-positivistic methods (Klauber 1981), have been reluctant to enter into wider debate.

The recent testy exchange between Craib (1995) and Duncombe and Marsden (1996) following Jackson's (1993) and Duncombe and Marsden's (1993) excursions into the sociology of the emotions bears witness to the treacherous and contested nature of the terrain. Craib, writing as a sociology lecturer who has a training in group therapy, is pessimistic about cross fertilisation in this area: "when sociologists comment on emotions, they do so with the same sensitivity and understanding that psychoanalysts display when commenting on society" (1995:151). Only therapists with years of training, working with someone in a long term therapeutic relationship (at least for a year), he implies, can be trusted to really understand the emotional world of another.

Given the theoretical significance of emotions it would be unfortunate if this impasse were to continue. It will be argued that psychoanalytic ideas can have important impact when considered in the context of sociological epistemological debates about qualitative empirical work. The concepts constructed by psychoanalysts which they use to make sense of the data that they accrue through clinical practice offer a means of structuring both the research interview itself and its analysis.

Such recourse to psychoanalysis is necessary, it will be argued, because of the failure to develop methodologies which truly rise to the challenge set by the radical and

convincing critiques of positivism which have arisen mainly within sociology. There seems to be a curious paradox in contemporary social science. In theory positivism has been convincingly discredited. Yet, in practice, positivism seems to dominate empirical research and debate about methodology, and certainly methods. It will be argued, perhaps unfashionably (Hammersley 1995, Bryman 1992), that there are fundamental philosophical differences between quantitative and qualitative approaches which seemed to have been submerged in recent debate.

There follows:-

1) A discussion of the crisis in qualitative work. There is confusion over whether qualitative methods are simply techniques of data collection or whether they occupy different philosophical positions. The terms of this particular debate are, however, informative since they assume the separation of data collection from the analysis of data which is truly a hallmark of a positivistic approach. It will be argued here that what is required is a sharpening of the debate on the conceptual issues surrounding the study of subjectivity.

2) A brief reconsideration of phenomenology and interpretative sociology and its implications. It will be argued that *methods* that have developed out of the critique of positivism (for example grounded theory, ethnomethodology, symbolic interactionism and discourse/conversation analysis) have avoided firstly, the problem of the double hermeneutic (reflexivity) and secondly, the issue of power.

3) A brief discussion of two disciplines which have developed alternatives to positivism: history and psychoanalysis. It is through discussion of the philosophy of history which both Gadamer and Habermas used as a platform for their debate about hermeneutics, and where Foucault elucidates his conceptualisation of power. Psychoanalysis has specific contributions to make in organising ideas about unconscious processes and in developing ideas about researcher subjectivity, in particular the clinical notion of "counter-transference". Ideas deriving from these two disciplines inform the fundamental principles of the post-structuralist critique.

4) A brief review of the post-structuralist critique itself which has provided a means of apprehending the relationship between power and knowledge. This theme has been explicated in terms of the relationship between gender and science (in feminist readings of object relations theory) and in basic human impulses (in readings of Kleinian psychoanalytic theory). This material is important not only for the contribution it makes in informing the empirical component of this thesis, but also to the insight into why the research on families has been so difficult (this debate is picked up in the 'Concluding Discussion' at the end of the thesis).

1) **The Crisis in the Qualitative World.**

The seeming crisis in qualitative research that is being considered here might be summed up by saying that after winning all the arguments it seems to have lost the war in social science. Perhaps it would be more apt to say that positivism has won the peace. There seems curiously little debate, when methods are discussed, within social science on substantial theoretical issues. As Coser warned in 1975, in discussing the "crisis and fatigue within the discipline" of sociology, we are facing:

years of normal science with a vengeance, in which not only the mediocre minds but even the minds of the best are hitched to quotidian endeavours and routine activities. This seems portended by the recent insistence among many sociologists on the primacy of precise measurement over substantive issues (p295)

It is worth reiterating the principles of positivism:-

- 1) Only direct sensorial experience can be considered as constituting scientific knowledge.
- 2) It is not the place of science to consider any deeper reality which might involve abstractions which go beyond direct sensory experience.

3) Facts can be separated from values.

In natural science the enunciation of these principles, particularly through Popper's formulation of falsifiability, is seen as successfully demarcating science. The principles remain far more controversial in social science. Any consideration of consciousness, intention, personality, or social structure is effectively ruled out of court by adherence to positivism. A wish held by only a few within social science. As Silverman (1985) points out, positivism has been profoundly critiqued, the problem is however, what has taken its place? The debate about methodology seems still to be couched in the language of positivism.

Indeed, Agar (1986) sees *the problem* as being one of language. That despite there being many different styles of research, there is really only one language in which to talk about research. This language, the 'received view' of social science, is couched in terms such as "What's your hypothesis? How do you measure that? How large is your sample?" What Agar suggests is that ethnographers develop a language to describe what they do.

It will be argued that the problem with language is a symptom of something deeper; that there is a crisis of confidence which has beset those working to develop an alternative paradigm. The powerful philosophical arguments which prompted the rejection of logical positivism have become submerged. The result is that there is now a tendency to try and make qualitative research fit in with the safe ground of mainstream quantitative research.

This submergence can be seen in recent debate about qualitative research. The very distinction between qualitative and quantitative work is being questioned. For example Bryman (1988) can argue that qualitative and quantitative methods are simply different techniques of data collection. Bulmer (1984) describes the drawing of distinctions between qualitative and quantitative as being dangerous in reifying the differences between methods so that they might appear to be quite separate and alternative methods of social enquiry. Bulmer's position is that methods ought to be chosen to fit the aspect of enquiry, and that different methods can be included within

one study as bolstering evidence (the triangulation of data). On the face of it such sentiments seem laudable, however some discussions about triangulation seem to suggest a revealing agenda. For example Fielding and Fielding (1986) discuss the use of triangulation to field researchers:- "The role of triangulation is to increase the researchers confidence so that findings may be better imparted to the audience and to lessen the recourse to privileged insight." (p23). Here triangulation is effectively being seen as a rhetorical device. Now clearly argument is a respectable occupation for any scientist, however what is more worrying is the way that the role of "insight" is being implicitly down-graded. This is an odd move for an interpretive sociology. Silverman (1985:143) argues that counting procedures can help vitiate the problem that qualitative accounts have to be taken "largely on trust" which raises the issue of morality in research. This assumption, that somehow qualitative data is less trustworthy is, perhaps a common one, but is nonetheless difficult to sustain in a post-Burt world.

It will be argued here that one reason for the retreat from interpretation is the uncomfortable conclusion of the critique of positivism. The philosophic roots of field research are in phenomenology, whose conclusions are not necessarily commensurate with current notions of science.

Bilton et al. (1987) describe the difficult political situation that sociologists find themselves in. Social science disciplines expanded rapidly through the sixties and early seventies, being attractive to government as seeming to offer a means of finding the answers to social problems. The critical attack on easy empiricist solutions from within sociology led to sociology being seen as less useful which resulted in cutbacks in government funding. Bilton et al. identify two overlapping responses: 1) to adopt methods which are highly quantified, usually involving computers to give a scientific 'feel' to the research. 2) to effectively ignore the debate and difficulties and 'get on with the job'. These two trends are very clear from popular methodology text books which adopt a basically positivist stance but include 'qualitative' research in a couple of chapters (effectively relegating them to different methods of data collection)¹⁰.

¹⁰ A good example is Judd et al. (1991).

2) **Phenomenology and Interpretive Sociology.**

Phenomenology's salience in sociology can be traced to Alfred Schutz's attempts to incorporate the philosophical writings of Husserl with his own critical developments of Max Weber's interpretative sociology (see Wolff 1978 for outline). Phenomenological sociology assumes that the social world, with all its categories, is created by social actors. To study society it is therefore necessary to study the rules that social actors utilise. Such rules are in a constant state of flux, being busily created and reshaped by the actors. These principles have driven the empirical work of the symbolic interactionists, ethnomethodologists and grounded theorists. The difficulty is that once the importance of studying the internal states of others is accepted, you have to also accept that you can only study others through your own subjectivity. This is implied clearly in Wolff's definition:- "Phenomenology asks us not to take received notions for granted. It asks us to question them- to question nothing less than our culture, that is our way of looking at and being in the world in which we have been brought up." (1978:500).

Social science is thus in double jeopardy. On the one hand many of its, arguably, central fields of study is not open to direct observation and measurement, but also the only access to those internal states of others is through our own interpretations of another - and our own interpretations are, of course, not open to objective scrutiny. This has been called the 'double hermeneutic' (eg Giddens 1976).

Schutz (1954) himself argued that such a formulation was wrong, he responded to Nagel's accusation of solipsism:

. . . he is right in stating that a method which would require that the individual scientific observer identify himself with the social agent observed in order to understand the motives of the latter, or a method which would refer the selection of the facts observed and their interpretation to the private value system of the particular observer, would merely lead to uncontrollable private and subjective image in this particular student of human affairs, but never to a scientific theory. But I do not know of any social scientist of stature who ever advocated such a concept of subjectivity . . . (1954:490).

However, as Wolff points out, Schutz is ignoring the difficulty here. Schutz does not resolve the contradiction "between the no more than asymptotic character of intersubjective understanding, on the one hand, and on the other, his conception of subjective meaning which implies the possibility of "genuine" more than asymptotic intersubjective understanding . . ." (1978:517).

This point has been the subject of a great deal of heavy weight philosophical debate. At its heart is the question most famously raised by Kant: Is 'pure reason' or absolute knowledge possible? This question is at the centre of the debate around hermeneutic sociology expounded by Gadamer, the debate being joined by Habermas.

Gadamer and Hermeneutics.

Gadamer (1975) argued that all forms of understanding, including those gained through the apparently scientific, objective methods of the natural sciences, are socially and historically situated.

However, rather than throwing up his hands and agreeing that 'anything goes', and that all knowledge is a matter of opinion, Gadamer tried to argue more constructively for a form of Socratic knowing, one that is worked out through dialogue. Gadamer proposed a particular form of dialogue, taking place in certain special conditions, which made it a non-adversarial form of exchange. Firstly, the participants must be able to assume that they do not know all there is to know themselves; they will thus have a willingness to listen seriously to what others say. Secondly, the participants must be genuinely concerned with understanding the others' point of view. The participants must not be concerned with trying to outwit the other with rhetorical devices in order to be seen to win the argument. In this way a form of consensus of meaning can be built, such that "all participants are led beyond their initial positions towards a consensus that is more differentiated and articulated than the separate views with which the conversation partners began." (Warnke 1987:169).

Habermas's criticism of Gadamer is relevant at this point. He argued that it would

be likely, certainly under contemporary conditions, that the communications of participants would be open to systematic distortions. Therefore whatever might result from the dialogue was also likely to be distorted. Habermas was particularly concerned with 'ideological' distortions, in a Marxist sense of ideology (ie, hidden and thereby all the more effective). Habermas argued that it was therefore necessary to have a reference system, a theory which can apprehend ideology itself. Gadamer countered this by asking who could judge the reference system, that any attempt to be the arbiter of 'communicative competence' was surely elitist (Warnke 1987 reviews this debate).

It can be argued that the failure to really engage with this problem, let alone resolve the conundrum set by the 'double hermeneutic' underlies the crisis in the confidence in the qualitative world. Sociologists who have attempted to develop methods that have taken the inadequacies of positivism seriously, have avoided the problem. Four salient sociological methods are reviewed briefly below. What seems to link them together is that in the face of an apparently damaging crumbling into solipsism, the response has been to retreat. So the subjectivity of the other is studied, but in a way that ignores (or avoids) that of the observer. This manoeuvre also sidelines the issue of power in research, since it is in the dynamic space between researcher and researched that the imbalance of power becomes most conspicuous. The dynamic is avoided in the attempt to remove the 'I' of the researcher to a position of observation rather than engagement.

Qualitative research does then become a matter of technique for 'objectively' studying the subjective states of others. For example, Kirk and Miller (1985) argue that qualitative researchers need to develop techniques to reassure the public of the reliability of the methods used:- "It is our argument that qualitative research can be performed as social science and can be evaluated in terms of objectivity" (p73). This can be done by adopting systematic methods. This approach is best exemplified by Glaser and Strauss's grounded theory.

i) Grounded Theory.

Glaser and Strauss's (1967) programme for the "discovery of theory from data systematically obtained from social research" seems close to Husserl's dictum to "go back to things". Glaser and Strauss argue that one should simply collect social data and then systematically convert this raw data into coded categories. Natural categories should emerge from the data which the researcher can fit to theories. There are problems with this formulation. As Bulmer (1984) notes Glaser and Strauss have never dealt with the "paradox of categorisation". It is simply logically (not to say psychologically) impossible to begin to collect data from the social world without having some sort of categories in mind at the outset- how would you begin to know what to collect? The subsequent coding of the data without prior assumptions is, although arguably laudable, equally implausible. Glaser and Strauss seem to try and get around this problem by suggesting that the categories should be 'natural'. By this they seem to mean that only the superficial meanings can be considered. For example Strauss (1987) argues that subjects' responses should not be interpreted; that 'psychological' issues like motivation should not be imputed. Though not explicitly spelt out, the objection seems to be that to introduce psychological issues is to bring too many of the researcher's presumptions to the data. The difficulty is that of course everyone is going to bring presumptions to the data, the decision to ignore 'deep' motivational issues is just as much a presumption as to not. Taken literally grounded theory seems to have no way of challenging the meaning of supposedly 'natural' surface phenomena. In sociology it is the ethnomethodologists who most clearly set out to challenge these natural assumptions.

ii) Ethnomethodology.

Those working under the label coined by Harold Garfinkel (1967) again seem close to the concerns of phenomenology. Their main area of study has been in uncovering the social rules that govern our lives. Such rules are exposed through "ingeniously and upsetting 'experiments'" (Gouldner 1970). An example of this comes from Garfinkel who instructed some of his students to go home to their parents and behave like boarders. Such behaviour typically resulted in distressed parents. Whilst

Gouldner's (1970:393) charge that Garfinkel achieves a mix of "objectivity and sadism" ought not be ignored ¹¹, there are further problems. Ethnomethodology never seems to really get to grips with the problem of studying the researcher's own assumptions. Ethnomethodologists are well aware of the difficulty of assuming that what they observe is anything more than a product of their own subjectivity, as Mehan (1975:167) writes "[t]hough they are rarely written this way every ethnomethodological study speaks to the spectre of the reflexivity of reflexivity". Like grounded theory the chief response to the problem is to stay on the surface of things. So their studies have in the main concentrated on the exposure of everyday social rules (Bilton et al. 1987). Rogers (1983) argues that "The hallmark of the phenomenological perspective is its insistence on the priority of consciousness and its concern with methodically demonstrating that priority" (1983:117). Ethnomethodologists, Rogers argues, ignore consciousness which is to ignore a vital strand of the phenomenological project. Whilst Garfinkel's methods can successfully expose the existence of social rules, they have trouble investigating where the rules come from, why they are important to people, and why people are distressed when they are broken.

iii) Symbolic Interactionism.

Researchers using symbolic interactionist principles are a less easily defined group, including diverse writers such as Blumer, Becker and Goffman. There is, consequently, a less clearly defined method, besides the promise to 'tell it like it is', 'to see things as they are seen by the actors themselves'. In doing this the symbolic interactionists have produced many valuable insights and their work is characterised by a respect for those that they study. It should still be noted, however, that there is a definite concentration on the rational, conscious direction of people's behaviour. There is little interpretation of hidden motives or consideration of social structure. Whilst Bilton et al. (1987) argue such a perspective is in keeping with an

¹¹ Wolff (1978) develops the point suggesting that ethnomethodology fails because of its pointed indifference to moral questions which Wolff implies ought to drive social research.

individualistic American approach to social science, it is of course also consistent with an essentially positivistic stance.

iv) Discourse Analysis/Conversation Analysis.

Whilst being a significantly emerging area, 'discourse analysis' seems to contain an extremely heterogeneous range of ideas (Silverman 1993:120). On the one wing is Conversation Analysis itself, coming directly from ethnomethodology, whilst there is also the Foucauldian 'archaeological' approach which examines the whole gamut of human discourse.

Whilst discourse analysis particularly incorporates the potential to engage with the hidden, subjective and emotional worlds, it most often seems to consist of a quite narrow analysis of the words, pauses and grammatical constructions favoured by Conversation Analysts (see the journal 'Discourse and Society', for many examples). Potter and Wetherell (1987) although discussing the use of discourse analysis in social psychology, include no mention of emotions. Whilst the issue of reflexivity is acknowledged they feel they have no technique for including it, so "the most practical way of dealing with this issue is to simply get on with it, and not get caught up in the infinite regresses possible" (1987:182)

The essence of Conversational Analysis is summed up by Emanuel Schegloff in the introduction to the collection of Harvey Sacks' lectures: "there [in Sacks early work] is the distinctive and utterly critical recognition here that the talk can be examined as an object in its own right, and not merely as a screen in which are projected other processes . . ." (Sacks 1992:xviii). To take, as Conversation Analysts do, as data the transcripts of conversations with the pauses (timed to tenths of seconds), syllabic emphases, in and out-takes of breath is, of course, highly positivistic, it even looks very 'scientific'.

Qualitative Positivism.

Phenomenology prioritises the study of human consciousness, which cannot be directly sensed but only imagined within the consciousness of the researcher. By ignoring the difficulties which are logically raised by taking phenomenology seriously, qualitative researchers have often tended to shift the debate onto ground where they are vulnerable to attack from positivism. In fact qualitative methods do then become simply a means of collecting data from others. The paradoxical subjectivity of the observer is ignored at great cost to the original arguments which so effectively critiqued positivism.

There seems to be a case for arguing that these users of qualitative research have taken on board a central tenet of positivism - only that which can be directly sensed can be the object of study. To attribute factors such as motivation, or consciousness is in fact *explicitly* ruled out by grounded theory and ethnomethodology.

Rogers argues that the promotion of phenomenological understanding of society will be through "a sociology practised through rigorous self-consciousness" (1983:139). In the next section it will be argued that work within history and psychoanalysis, has been concerned with developing and using this self-consciousness.

3) Alternatives to positivism: History and Psychoanalysis.

Several useful themes can be drawn from the disciplines of history and psychoanalysis which are both often considered rather marginal to the social sciences. These two disciplines have both developed methodologies which do not make recourse to positivist ideals.

3a) The Study of History.

The relationship of historical studies to sociology and other investigations of human society, is useful to consider. R.G. Collingwood (1946) sketches out the 'typical'

modern historian's view of how history ought to be: "history should be (a) a science, or an answering of questions; (b) concerned with human actions in the past; (c) pursued by interpretation of evidence; and (d) for the sake of human knowledge." (p10). Elsewhere Collingwood clarifies his use of the word science- "History . . is a science, but of a special kind. It is a science whose business is to study events not accessible to our observation . " (p251) The argument is that history is distinguished from studies of contemporary societies since it does not have the means to directly observe its object of study. However, it is clear from the above discussions of phenomenology, that investigators of contemporary human affairs often do not have direct access to that which they study. They, like the historian, have "to study these events inferentially, arguing to them from something else which is accessible to our observation . . ." (Collingwood 1946:251). Therefore, a brief consideration of historical methods will be worthwhile.

As Schaff (1976) notes, the philosophy of history has been dominated by debate between positivism and what he refers to as 'presentism'. Positivistic history, most forcefully represented by the historian Leopold Van Ranke (Schaff 1976:87), is couched in terms that will be familiar from the preceding discussions of positivism. Most crucially positivistic history assumes a separation between historian and the subject of study, that the facts of history can be studied objectively. Schaff characterises the chief rebellion against positivism as being presentism, where firstly subject and object constitute an organic whole and secondly, the cognitive relationship is never passive-contemplative but activistic.

Discussion of the form of historical study, which Schaff labels 'presentism', which grew up in opposition to positivistic history is instructive. Collingwood has been credited with lifting the banner of presentism in the English speaking world, through his interpretation of Croce (Schaff 1976:88). The distinguished historian EH Carr (1961) in raising the question "What is history?" refers to Croce's dictum that all history is contemporary: "meaning that history consists essentially in seeing the past through the eyes of the present and in the light of its problems." Paraphrasing Collingwood, Carr discusses three related aspects of the study of history:-

1) What might appear as facts in historical studies, are not pure facts but have already been processed by the mind of the writer. Whenever we read a work of history we should always concern ourselves firstly with the historian.

2) The historian needs the imaginative understanding of the minds of the people with whom he is dealing, this is referred to as re-duplication.

3) Collingwood sums up 'presentism' by arguing that " . . . we can view the past, and achieve our understanding of the past, only through the eyes of the present. . . "

So, to literally know the past is impossible. To study history is to offer an interpretation of the past.

An example of the re-interpretation of the past, in the light of our changing perceptions of ourselves, comes from the way that the story of the Roman occupation of this country was told. For a long time (at least since Gibbons' 18th century work on the Roman Empire) the Roman Empire was seen as a civilising influence. More recently, however, that interpretation is being seen as a reflection of earlier British historians' need to show British adventures abroad in a positive light. Now that British/European imperialism is being seen as more essentially destructive in its effects on large parts of the world, so the view that the Roman occupation did a lot of damage to ancient British culture, leading to the Dark ages and centuries of turmoil, becomes tenable.

What that example brings up is the question of values. What Carr importantly argues is that since absolute facts are not obtainable, the best we can do is interpret the past in the light of the future, or how we want things to be. With this emphasis on values it is not surprising that Jurgen Habermas began his effort to characterise critical sociology by appeal to the philosophy of history (McCarthy 1978:126).

In summary, there is a view that the study of history is not the study of the past as such, but the study of our knowledge, of our perception of the past. And secondly,

good history contains a vision of the future, it is immanently concerned with value.

Foucault and the Archaeology of Knowledge.

Foucault's discussion and development of the notion of archaeology (and genealogy) of knowledge seems to bear some interesting resemblance to the deliberations within the philosophy of history. This is in spite of the fact that he presents his archaeological method in opposition to conventional historical study. Foucault (1977) wonders of his own work on the criminal justice system: "Why am I writing this history of the prison? Simply because I am interested in the past? No, if one means by that writing a history of the past in terms of the present. Yes, if one means writing the history of the present." (1977: 31) Sheridan locates Foucault in the present: ". . . where all truly original minds begin, . . . His passion is to seek out the new, that which is coming to birth in the present." (1980:195) This seems not so far from Collingwood (1946:10):- "The value of history, then, is that it teaches us what man has done and thus what man is."

Foucault's interest is in the history of ideas. His archaeological method is an attempt to understand those ideas within the context of the era that produced them. He is disparaging of conventional historical thinking which uncritically views the past in terms of patterns which take as their template the structure of ideas in the present. From the very brief survey of history and the tradition of presentism it is clear that such thinking is hardly new. However, Foucault's application of these ideas has been original. His particular concentration on the human sciences - the study and treatment of mental illness, the criminal justice system and the insight he has contributed to these areas ¹² has brought these ideas to the attention of the wider social science public. What is revolutionary about Foucault is his application of the archaeological method to the contemporary period. He takes the questioning stance of the modern historian and applies it to the circumstances he sees around him. What he cultivates is a thorough questioning of the categories we use.

¹² Foucault's influence on thinking about psychiatric Asylums was mentioned in Chapter One.

Of course there is much that is paradoxical here. How ably can you stand aside from your own society? The questioning of the ground on which you stand can lead you to have no position at all. Foucault attracts the charge of nihilism, the danger Major-Poetzl points to in her summing up of *Foucault's Archaeology of Western Culture*:

Foucault's primary intention is to demolish our conventional categories of thought and to render unbelievable the science-myths that organise our perception of the past. He is likely to be more successful as a destroyer than as a creator. (1983:199)

Foucault himself can be unashamedly aggressive in his evocation of Nietzsche:-

. when it is a matter of determining the system of discourse on which we are still living, when we have to question the words that are still echoing in our ear, which become confused with those we are trying to formulate, the archaeologist, like the Nietzschean philosopher, is forced to take a hammer to it (quoted in Sheridan 1980:196).

Sedgwick (1982) sums up a discussion of Foucault's influence on ideas in the study of the history of psychiatry: "Foucault's work will be measured to the extent that it can aid in the formation of an informed political practice, the key which can both open and destroy the locks, bars and fetters of psychiatric and social confinement." (1982:148)

Near the end of *The Order of Things*, as he briefly introduces and heralds a period of transformation in the contemporary period Foucault celebrates the most challenging and questioning disciplines of ethnology¹³ and psychoanalysis:-

. . .not because they established the foundations of their position better than any other human science, and at last accomplished the old attempt to be truly scientific, but rather because, on the confines of all branches of knowledge investigating man, they form an undoubted and inexhaustible treasure-hoard of experiences and concepts, and above all a perpetual principle of dissatisfaction, of calling into question, of criticism and contestation of what may seem, in other

¹³ A separate discussion of anthropological methods might have been appropriate. However, there is clearly great overlap and most of the pertinent philosophical issues are covered through the ensuing discussion. The uniquely characteristic aspect of anthropological method, the "ethnographer participating overtly or covertly, in people's daily lives for an extended period of time" (Hammersley et al. 1983:1), was not adopted in this study.

respects to be established (1974:373).

As an empirical discipline which grew from therapeutic practice, but having found that "perpetual principle of dissatisfaction" , it may be that psychoanalytic theory can offer a means of inquiry which is ultimately more constructive.

3b) Psychoanalysis.

The interests of social scientists in psychoanalysis have traditionally focused on the theoretical implications (the Frankfurt School of Critical Theorists, for example) at a macro-social level. Perhaps, however, it is in discussions of issues of an apparently technical nature, at the micro-social level, that psychoanalysis may provide social science with a rich source of ideas.

It will be argued that within the discipline of psychoanalysis lie the tools that can help us to not only interrogate the structures on which we stand (that aspect of psychoanalysis which attracted Foucault), but also those to build a more constructive understanding of ourselves and of our world.

Foucault is surely correct in highlighting in psychoanalysis the questioning of its own ground. The problem of how the psychoanalyst can *know* about a patient's mental state has become increasingly central to psychoanalysis. Psychoanalysis has attempted to confront this difficulty by pushing the analyst's subjectivity to the centre of its project. This is symbolised by the requirement that the training of psychoanalysts consists, in substantial part, of their own analysis. There has also been growing interest in the clinical notion of counter-transference: that is the feelings engendered in the analyst by the patient, and the problem of how the analyst can separate out, from those feelings, what they bring to the relationship themselves. The increasing emphasis on counter-transference highlights the importance of reflective self-scrutiny in reaching an understanding of others. So, in large part, psychoanalysis seems to accept that the study of others fundamentally involves the study of the self.¹⁴

¹⁴ Andrew Samuels (1993:31) discusses the use of depth psychology to understanding of the political world:- "I want to suggest that it is not in metapsychology, nor in models of the psyche or the unconscious, nor in schemas of personality development, and not even in the analytic attitude itself, that our usefulness to the

Psychoanalysis in The Field.

Jennifer Hunt (1989) gives examples of using psychoanalytic principles in her studies of the police. Her approach is that of traditional sociological fieldwork; she goes out as a participant observer with the police as they do their job. Psychoanalytic theory is used to understand what she observes and experiences in the field. Hunt outlines three key distinguishing assumptions of psychoanalytic thought:-

- i) Much thought and activity takes place outside of conscious awareness. Any meaningful social theory must therefore take this into account.

- ii) Transferences are routine features of relations. That is, people bring (transfer) what they have learnt from past relationships (particularly those with parents) to new ones.

- iii) Intrapsychic conflict is an important aspect of individual functioning. In other words, people have conflicting motives and feelings.

These features on their own, if correct, make the consideration of psychoanalytic thought essential to any fuller understanding of the social world. What I am arguing is that psychoanalysis can offer, not only this theoretical perspective, but also specific techniques and insights which advance understanding through its insight into the dynamics of the in depth interview.

Psychoanalytic Contributions.

It can be argued that psychoanalysis can make two major contributions to a study of contemporary social phenomena. Firstly there is the notion of the unconscious. For the researcher this brings the important idea that many of the meanings which

political world may be found. Rather it may be the analytical and psychotherapeutic methods - modes and techniques of therapy - . . . In particular those aspects of clinical practice clustering around the concept of countertransference may be the most liminal with politics."

constrain and direct social acts are not necessarily open to the subject to report them to the researcher. If unconscious aspects of the social world are to be studied, methods must be used which do not depend upon people simply being able to verbalise their experience.

Secondly, there is the notion of counter-transference which refers to the thoughts and feelings of the therapist during therapy. It will be argued in Chapter 4 that the concept of counter-transference offers a means of structuring the study of reflexivity which has remained elusive in the other methods discussed earlier.

The details of how psychoanalytic concepts were used to make sense of the interviews and the interview transcripts is discussed in more detail in Chapter 4. Psychoanalysis has been heavily criticised for its non-adherence to scientific method and the difficulties of establishing reliability and validity (Eysenck and Wilson 1973, Gellner 1985). A discussion of the post-structuralist critique of science will help put these difficulties into context.

4) The Post-Structuralist Critique.

Consideration of history, and Foucault's archaeology of knowledge in particular, leaves us with the realisation of the necessity to study events and objects within their contexts.

Psychoanalysis questions the commonsense notion of the unified subject, drawing attention to the fragmented and often unconscious aspects of experience. This is a version of subjectivity that does not rely on an essentialist notion of the subjective self, but introduces a version of the subjective that is multi-faceted and heterogenous.

These two elements form two significant prongs of the post-structuralist critique. As Hollway writes (1989:31) : "Post-structuralism deconstructs the subject as agent and the unitary individual, that is it provides a critique which gets underneath what is

taken for granted by these terms." Hollway has put these insights into effect in her own research (as discussed in Hollway 1989) and these concerns have informed Mama's (1995) research on the experience of black women in Britain.

Knowledge and its Relationship to Power.

A major contribution of the post-structuralist critique has been to supply a radical analysis of knowledge itself, in particular the means of its production. As Foucault developed his work on the production of knowledge, he began to perceive the crucial relation between knowledge and power. The idea that knowledge is socially constituted is far from new. Certainly the idea that knowledge could endow its holder with power was clearly pronounced by Machiavelli back in the 15th century. It has been Foucault who has most saliently argued that such a view of knowledge, as being an object or a tool to be picked up and used as an instrument of power, is too simple. Through his work Foucault eventually conceived a system where the very distinction between knowledge and power becomes blurred:-

We should admit rather that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations. (1977:27)

Therefore any system of knowledge, in order to be understood, needs to be considered in its network of power relations. The edifice of Western science is just such a system. Western science has indeed been analysed in terms of its political manoeuvrings, its relationship to government, to the military and to industrial corporations. However, Foucault's characterisation of the immanence of power and knowledge implies we might look more closely - not only at the use of science, and the chosen subject matters of science, but into the finer detail of its practice and its methods to trace the outlines of power. There is a feminist analysis of science that strives for such illumination.

Gender, Sexuality and Science.

Brian Easlea (1980) examines a series of scientific debates stretching from the middle ages to the dawn of the industrial revolution, focusing particularly on the rise and fall of witch-hunting. The conventional story has been that witch-hunting in Europe was defeated by the triumph of reason. Simply, that as human thinking and knowledge advanced, the view that the world was controlled by divine and demonic forces became untenable. Easlea argues that the expansion of rationalism through the Enlightenment cannot be put down to the triumph of reason alone, but needs to be put into the context of class struggle. As the old order broke down the growing strength and confidence of the ruling classes enabled them, through the technical advances being made, to imagine a universe tamed for their own use. Their concerns turned from demonic forces which had apparently threatened social order to the direct regulation of the growing labouring classes. Paradigmatically Easlea points out that in England the crime of witch-craft was abolished from the statute books in 1736, just ten years after the government introduced the death penalty for 'frame-breaking' (that is the destruction of industrial machinery, which had been occurring with increasing regularity as a sign of industrial unrest, and was clearly a threat to the industrial revolution). So-

Instead of allowing the prosecution and execution of old women who cursed and railed against an oppressive rural and patriarchal system of control and who were thought to use diabolical means to contribute either to its malfunctioning or the distress of its members, now members of the ruling elite concentrated their attention on the real actions of those who opposed the new, oppressive system of incipient industrial capitalism . . . (p240)

However, more intriguingly, Easlea's book is full of examples of the prominence of sexual conquest as a metaphor throughout centuries of scientific endeavour. Easlea's book (see also Fox Keller 1985 and Jordonanva 1989) is loaded with examples of a highly sexualised language used to describe science, only a couple of which can be referred to here as examples.

To Aristotle the earth was female, the heaven and sun were male. Reason itself was male. Francis Bacon, whilst accepting the female metaphor of nature, however

scorned Aristotle for supposing that men were "on such familiar terms with nature that in response to a casual and perfunctory salutation she would condescend to unveil for us her mysteries and bestow on us her blessings." (Easley 1980: 246) To Bacon more effort was required, in the shape of experimental method- "I invite all such to join themselves as true sons of knowledge, with me, that passing by the outer courts of nature, which numbers have trodden, we may find a way at length into her inner chambers." Similarly Humphry Davy, in the early 1800s, in celebrating "the man of science" who investigating nature "has penetrated into her bosom . . . for the purpose of allaying the restlessness of his desires or of extending and increasing his power" (Easley 1980: 248), is clearly linking sex, desire and power. Easley uses a class based analysis to argue that the presence of sexual metaphor reflected the requirement of a patriarchal system for a justification of the domination of women. Men needed to be portrayed as the rational knowers; women the irrational and mysterious who could be known by study.

The prevalence of the sexual metaphor in science is given more significance by a feminist analysis of the scientific process itself (Fox Keller 1985, Jordonova 1989). The idea that science as it exists can be seen as an essentially masculine enterprise has been examined in detail by Evelyn Fox Keller (herself originally a mathematical biophysicist). She argues that the practice of science as it has evolved is a function of masculine insecurity. She uses an object relations psychoanalytic model to suggest:

a network of interactions between gender development, a belief system that equates objectivity with masculinity, and a set of cultural values that simultaneously (and conjointly) elevates what is defined as scientific and what is masculine. (P89).

Crucial to this analysis is the drawing into question of the way that modern science divides the world very sharply into the knower and the knowable, subject and object.

Fox Keller, using Chodorow's (1978) model, sketches the development of the infant and in particular uses psychoanalytic insights into the formation of a separate identity of self. The development of a sense of self occurs, by necessity, in parallel to an

awareness of 'the other'.

The external environment, for most children consisting primarily of the mother during this early period, is experienced as an extension of the child. It is only through the assimilation of cumulative experiences of pain and pleasure, of gratification and disappointment, that the child slowly learns to distinguish between self and other, between the image and the percept, between the subject and the object. (Fox Keller 1985:81)

This development of a sense of self crucially involves the taking on of a gender identity. Culturally speaking, successful male development involves the disentanglement from the mother followed by identification with the separate and autonomous father. Female development also involves disentanglement from the mother but is then followed by identification with the same mother. The wrench involved in masculine identity is therefore greater, the distinction between self identity and perception of 'the other' all the more extreme. Masculine identity depends upon autonomy from the mother who had provided the initial sense of unity and comfort. Feminine identity is more ambiguous, being based on initial loss followed by reconciliation with the mother. Masculinity contains an inherent aspect of vulnerability, comfort lies outside of itself, whereas feminine identity includes an incorporation of the mother. Hence, on Fox Keller's reading, it is masculinity which is motivated by the restless search for knowledge outside of itself; which is what has become understood as science. The world was dichotomised between subject and object. Man became the knower, the contents of nature became the knowable- an object of study. Feminine identity involves a partial incorporation of 'the other' (the mother) so the distinction between self and other, knower and knowable is not as great.

Fox Keller goes on to argue that such a masculine way of relating with the world is one that stunts our ability to relate to one another (if we can only view each other as objects to be controlled), stunts our creativity (if our understanding is limited to objective knowledge) and ultimately stunts the practice of science:-

In brief I argue that the adherence to an outmoded, dichotomous conception of

objectivity might be viewed as a defense against anxiety about autonomy of exactly the same kind that we find interfering with the capacity for love and creativity. When even physics reveals 'transitional phenomena' - phenomena, that is, about which it cannot be determined whether they belong to the observer or the observed- then it becomes essential to question the adequacy of traditional 'realist' modes for cognitive maturity as well as for reality. (p85)

According to Fox Keller's narration of the history of Western science, knowledge, power and sexuality are indeed inextricably linked as Foucault claimed. What is clearer from Keller's use of psychoanalysis is how such a mechanism operates and is maintained. The psychoanalytic drafting of unconscious desire is an important one that can help illuminate Foucault's formulation of power and knowledge and his picture of power and sexuality. There is a reading of psychoanalysis which can be taken as viewing unconscious desire itself as the will to knowledge. This is shown through an examination of that most prominent manifestation of the will to knowledge - the Western enterprise of science (Clough 1992).

Thus, the social scientific approach, modelling itself on the natural sciences, must become an object of study itself. As when research on studies of the family were reviewed in the last chapter (where concerns about gender roles were highly salient) the assumptions and orientations must be made explicit and understood within the context of the structures that produce them.

Instrumental Reason and the Paranoid-Schizoid Position.

Alford (1989) has used the work of the psychoanalyst Melanie Klein in order to provide a critique of 'instrumental' reason which goes back to a more primitive level than that dependent on the Oedipal story presented by Helen Fox Keller. It does, however, converge to a similar theme about anxiety about autonomy and separation.

Melanie Klein argued that the desire for knowledge derives from a young baby's need to appropriate the contents of their mother's body; to own what they have lost, and to destroy it as a potential threat (the producer of rivals). It is "an utterly selfish desire to own, control, and possess the mother's body without any regard for the

mother's welfare." (Alford 1989:146). According to Klein, the desire for knowledge is thus at root a highly aggressive impulse.

Alford takes this argument further and argues that instrumental rationalism is a symptom of so called 'paranoid schizoid' thinking. Klein portrayed the young infant as being in danger of being overwhelmed by anxiety: anxiety at separation and dependency; anxiety caused by its own fearfully aggressive feelings. The baby's response to this anxiety is to split the world up. It splits the world into good and bad objects, it projects its own unacceptable feelings on to the 'bad' objects in the outside world (hence 'the paranoid-schizoid position'). It does this as a means of control, in that it can maintain its own sense of coherence and omnipotence by denying reality (that objects in the world are both good and bad; that its mother is both the person who cares and nurtures and the person who, by not being there all the time, deprives and neglects; that it has feelings that seek to destroy that which it depends upon).

This paranoid-schizoid position, Alford argues, is at the root of instrumental, positivistic knowledge. Here is the desire to break up the world into manageable chunks, to categorise and to analyse, in order to neutralise the threat posed by a seemingly unknown and hostile world.

Methodological Implications.

The search for knowledge is, in part, a deeply personal process. It is not sufficient to recognise that researchers have biases- there was a vogue for the confession of bias at the beginning of a report (biases in terms of political beliefs for example). What the above suggests is a requirement for a much deeper self questioning, a questioning that accepts that, at root, the search for knowledge is a process fraught with ambivalence.

From Fox Keller's use of object-relations theory comes the view that a methodology which relies on a sharp distinction between object and subject, researcher and researched, is one that is not only already imbued with distortion in the service of

power relations, but that those relations remain hidden under a cloak of objectivity.

From Alford's use of Kleinian analysis comes the view that to attempt to break up and categorise is a primitive and fundamental impulse permeated with anxiety and aggression. On this view the search for knowledge is fundamentally and intrinsically aggressive. This is in keeping with a more gloomy Foucauldian view of power relations as being everywhere; their neutralisation is not possible. Such difficulties will not be overcome simply by the adoption of certain methodological techniques. Indeed they will arguably not be overcome at all, but the distortions that they produce might be better understood. However, this will only be through a deeper self reflective questioning of the research process and its meaning.

What is called for are methodologies which can comprehend those very relations which not only constitute the object of study but the practice of the study itself: a methodology that can incorporate an understanding of its own practice. As the previous chapter illustrated, conventional social scientific paradigms that have studied the family have been imbued with assumptions and power relations which could not be comprehended by those same paradigms.

There needs to be an acceptance that the subject matter of social science is truly deep and is concerned with meaning and values. The researchers' role is thus one of interpretation. To be sure of avoiding the descent into solipsism, that process of interpretation needs to be at the heart of the research endeavour.

It is a reflexivity which is thus called for in this radical pursuit:- To quote Rogers again: "Phenomenological sociology is sociology practised reflexively through rigorous self-consciousness" (Rogers 1983:139). It is here that the psychoanalysts' notion of counter-transference assumes salience. Psychoanalysts have been developing such a framework for such reflexivity, using the clinical concept of counter-transference to explore the hidden unconscious meanings and forces which tie us together. Social science would have much to gain by taking their endeavours seriously, despite that fact that no easy answers will be forthcoming.

What follows in Chapter 4 is a discussion of the interviewing and methodology adopted in this study.

CHAPTER 4.

METHOD: THE INTERVIEWS.

To summarise the conclusions of the last three chapters as they prescribe for the empirical requirements of this study:

Firstly, it is important to reach a greater understanding of the experiences of the families of people with long-term mental illness, particularly those who may be seen as falling into the category of 'new long-stay' (as discussed in Chapter 1).

Secondly, it is important that the method allows for an understanding of the meaning that events hold for the interviewees, and particularly the emotional meaning of those events, to develop.

Thirdly, in trying to reach this understanding a couple of pitfalls need to be avoided. Previous studies have approached families with specific ideological biases that have made understanding hard to achieve. They have tended to objectify family members (in accordance with the particular viewpoint of the study) which naturally makes an understanding of their subjective states problematic. As argued in the Methodology chapter, a more viable route to understanding the subjective states of others is through the self-reflective understanding of ourselves and our own ideological filters.

1) The In Depth Interview.

In depth, relatively¹⁵ unstructured, interviews were the chosen method of investigation. Since I was specifically interested in what thoughts and feelings people had about having a relative suffer from mental illness, choices of method seemed to be limited to those that addressed them directly as witnesses. As discussed in the

¹⁵ Although these interviews would perhaps be described in conventional terms as being "unstructured", I qualify this with the word relatively here as I am not sure what an 'unstructured' interview would be. All interviews, all encounters, conversations have their context, their implicit and explicit understandings which structure them.

Methodology chapter, the utilisation of ideas that have roots in psychodynamic therapeutic work seemed promising. I was interested in looking 'underneath' people's overt understandings and communications in order to reach a more profound understanding of people's experiences than is possible with more conventional social science interviewing.

Observational techniques would not have been appropriate since I was less interested in the actions and interactions in which people were currently involved, than in understanding the meaning of people's experiences which meant listening to the stories people had, their recollections, their experiences and their hopes. An interview of some kind seemed to be the most viable method. Group interviews, such as focus groups (Johnson 1996) would likely to be difficult given the personal and often confidential nature of the subject area.

Written techniques, perhaps involving projective tests, might have been suitable given the sensitive nature of the subject - the assumption being that people might have been more willing to put down in writing feelings that were painful to express. However, such methods were more likely to make people feel that they were being tested. Having done some interviewing in this area, I knew that people might be prone to feeling blame and guilt. With the in depth interview there is more scope to encourage people to express themselves and help make sense of what are perhaps confusing feelings. Given the sensitivity of the area, it seemed most important to make it clear at the outset that I was interested in their story, and that I was sympathetic to their experience (for example, I would say something along the lines "I think that relatives are often ignored by planners and professionals".)

A major weakness of the method of this study is that it provides only cross-sectional 'snap-shots' of situations where there are good reasons to believe that they have been evolving for many years. However, at least this inadequacy could be acknowledged and taken into account. Indeed, relevant periods for some people covered over 30 years, so longitudinal study would simply not have been practicable. Observational techniques could also have less easily coped with this historical aspect. Interviews have long been used to gather biographical data or 'life histories', where the

from transcript after
re - what profs told them
- their attitudes (ie profs)
re medication
re causation

assumption is that people can only be understood within the context of their histories (Bertaux 1981, for example).

Any research strategy that relies on interviews of any kind is open to the reproach that the interview is an artificial situation. This criticism comes from those who would advocate a more 'naturalistic' approach. This criticism, however, seems hitched to positivistic notions of research (i.e. that there is some real, objective data out there to be collected Silverman 1985).

The aim of the style of interviewing was to provide space for the relatives' story to be heard, and for their understanding of that story to emerge. The chief framework for the interviews was provided by the context of the research. I was a researcher, connected to the health authority who was trying to understand the interviewees experiences of what it was like to have a relative suffer from severe mental health difficulties, and how they coped. I highlighted through the introductory letter (see Appendix (A) and through what I said when we met that I was there to listen to their stories. This emphasis was reinforced by what I tried to communicate through the interview. I used a tape-recorder whenever possible, so I could concentrate on listening. I was not there to make notes, tick boxes, or fill in questionnaires. I was there to listen.¹⁶ I avoided asking questions that obviously steered the conversation away from what they were saying. I say "obviously" because when I was transcribing the interviews I was often painfully aware that I had missed the point of what they were saying and had commented or enquired about something rather off the point. There will be several examples of this throughout the rest of the thesis. There were also times when I was aware of not pursuing areas that would have perhaps been too upsetting to explore in the context of a one-off interview.

I provided further framework by having certain questions in my mind:-

What does this person understand about what has happened?

What does it mean to them?

¹⁶ The details of how the interviews were carried out is dealt with in the next section.

What sort of relationship do they have with the ill person?
What does the relationship mean?

What sort of relationship do they have with the health and social services? What do they think of the treatments that have been offered?

How does what has happened affect their lives?

Does what has happened affect their relationships with others?
Is there stigma involved?

Most of these questions were implied by the context of the interview and were therefore addressed spontaneously by the interviewees. I would find ways of asking those questions that did not arise naturally. Interestingly, the questions about stigma were ones that I most often had to raise (a point that is discussed in more detail in the Chapter 7, part ii). As has been made clear in the preceding chapters I was interested in using the interviews to explore the emotional aspects of the relatives' experiences.

Investigating The Emotional: The Use of the Personal.

Clearly, in many respects, this work is an ethnographic exercise. I am trying to understand the meaning that this 'group' of people apply to certain events of their lives. Within this overall purpose I am arguing that psychoanalytic ideas can make a significant contribution by supplying a framework for constructing an understanding through in depth interviews which are, albeit of a very particular style, the means of investigation at the heart of the psychoanalytic endeavour. Psychoanalysis offers help in clarifying what can be achieved in studying the subjectivity of another through an interview encounter. It offers a means of structuring consideration of what are regarded as being the crucial, yet highly problematic area of the researchers' own feelings. This structured reflexivity, it was argued in Chapter 3, is the route to understanding the emotional worlds of others.

The Problem of the Personal in Research.

The location of the researcher, as a person, in research has always been problematic. Without a meaningful framework for exploring personal issues a researcher may well stumble into trouble. In his book *Doing Field Research* John Johnson (1975) admirably wrestles with the problem of his own experience as an observer in a study of a social work department. Johnson observes the importance of emotions:

There is a vast range of human feelings, and most of us understand the importance of sexual desire, love, hate, resentment, infatuation, exhaustion, and all the others. They are often the prime movers of our daily actions. But the methodological literature contains very few references to the writers feelings. On the whole, it is impossible to review the literature about methods in the social sciences without reaching the conclusion that 'having feelings' is like an incest taboo in sociological research. (p.146-147)

Johnson notes that the mention of feelings in participant observation studies are usually anecdotal, as though they are put in for comic effect (see also Kleinman and Copp 1993). However, the role that Johnson assigns to his own affects is not clear. He finds it necessary to confess that he had an affair with one of his informants (who happened to be a friend of his wife). Yet, apparently, he does not reflect this back to any of his conclusions. So he can also state:

To observe sociologically means that one deliberately cedes experiencing the things in themselves to the members of the setting; observation entails seeing phenomena as 'exhibits' of the things in themselves. If one elects to do observation sociologically, there is and can be no other way. (1975:159)

Johnson concludes that you can only observe another's experiences, aligning himself with a symbolic interactionist approach. Johnson outlines further dilemmas such as the problem of 'getting involved' which is posed thus: a researcher needs to get close, and involved, with the subject in order to be trusted so that people will disclose information. However, Johnson wonders, (and this seems to be a central dilemma) does the sentiment so produced through the construction of a trusting relationship bias the research? In attempting to gain the trust of the social workers he was studying Johnson used various strategies including selective biographical reconstructions.

Depending on who he was talking to he would talk about his 'early boyhood on a farm' and to others, with an urban background, he would recount his 'early boyhood in the city'. When discussing politics, to some people he would present himself as a 'radical-liberal', to others as a 'conservative'. This strategy appeared to come unstuck when different workers noticed the discrepancies. On being challenged by one particular worker (who is described as an intimate), Johnson explained why he did it. This, he says, enhanced his reputation. He does not say what it did for his acquisition of trustworthiness. This is certainly a strategy other researchers might not feel comfortable with.

The Personal in the Research Interview.

Ann Oakley (1981:37) takes issue with what she sees as the 'proper' interview that is advocated in the methods text books. She outlines two typologies of the interviewer that emerge from the methodology literature. The first is as the simple recorder of information, the second she refers to as the "Interviewer as psychoanalyst". The latter Oakley characterises as follows:-

The interviewer's relationship to the interviewee is hierarchical and it is the body of expertise possessed by the interviewer that allows the interview to be successfully conducted. Most crucial in this exercise is the interviewers use of non-directive comments and probes to encourage a free-association of ideas which reveals whatever truth the research has been set up to uncover. Indeed, the term 'non-directive interview' is derived directly from the language of psychotherapy and carries the logic of interviewer-impersonality to its extreme . . . (p37).

Oakley identifies both styles of interviewing as belonging to the objectifying tendency of masculine social science. She argues that what she refers to as the poles of proper and improper interviewing are analogous to the masculine-feminine poles in our Western culture:

Women are characterised as sensitive, intuitive, incapable of objectivity and emotional detachment and as immersed in the business of making and sustaining personal relationships. Men are thought superior through their capacity for rationality and scientific objectivity and are thus seen to be possessed of an instrumental orientation in their relationships . . . (p38).

As will have been clear from the Methodology section, I have a great deal of sympathy with this latter analysis of conventional social science. However, I am less sure about her solution, which is to propose interviewer 'involvement' with the interviewees as being good practice in order to establish equality.

In her own work she aims to establish non-hierarchical relationships with her interviewees through three means: by establishing equality through helping them with such things as housework "if the interview clashed with the demands of house-work and motherhood" (p47); by reassuring interviewees about confidentiality; and answering questions as honestly as possible (about herself, about her research, or questions asking for her advice). She notes that all of this had the effect of improving rapport and co-operation in her research.

The latter two points seem uncontroversial, the first point relates to her having made friends with a number of her interviewees. In many ways what Oakley describes is something more akin to a technique of participant observation. Her solution is to steer her research relationships firmly towards, and beyond, the participative end of the Participant-Observation research spectrum so she can talk about the 'transition to friendship' (1981:44). The difficulty here is how ably can you expunge power from relationships, even friendship (or perhaps particularly friendship)?

To attempt to achieve the degree of mutual intimacy required to make friends with interviewees is to certainly throw in many more variables, including the needs of the researcher. The imprudent introduction of the emotional needs of the researcher into the interview encounter may well not be to the benefit of the interviewee. Johnson's confession of having an affair with one subject, mentioned above, might be a pertinent point. There may be something to be said for having relatively formal boundaries around the relationship, particularly when the interviews revolve around topics which stir up strong feelings. Such boundaries can be provided by the context and paraphernalia of an interview. This issue is addressed by Stacey (1991), as she describes her doubts about the ethics of her own ethnographic work, fearing that "the appearance of greater respect for and equality with research subjects in the

ethnographic approach masks a deeper, more dangerous form of exploitation." (p113). This exploitation might arise from the conflict between roles caused when researchers develop quite intimate relationships with subjects, but still have their own professional research agenda.

Besides the ethical difficulties of introducing 'friendship', there are perhaps other points which might interfere with the veracity of the findings. Hunt (1989) draws attention to the extremely complex transferences, and counter-transferences that are inevitably awakened within the research encounter in participant observation studies. It may be that a more formal interview encounter is more likely to facilitate a researcher being able to take account of these complexities. If the researcher is able to keep account of their own feelings within the interview this can allow for greater clarity about what is going on. Oakley is not convinced by this point of view and puts great store on sharing experiences with her interviewees. The problem with this is that if the researcher freely expresses their own opinions, how able will the interviewee be able to express their own views, which perhaps contradict those of the interviewer? Problems must also surely arise when you want to study in an area in which you have no experience, or when you might feel profoundly out of sympathy with the people that you are interviewing. This latter problem is powerfully raised by Scully (1990) through her research on men who have been convicted of rape, and O'Connell Davidson and Laydor (1994) who discuss interviewing the clients of prostitutes.

Covering Painful Material.

All of these difficulties are particularly salient in a study that encompasses potentially painful issues, and may involve feelings which might be mixed.

Charles Rycroft (1968) from a psychoanalytic perspective provides a strategy rather different from Oakley's. He examines the affective communications occurring within the 'interpretations' that he makes (that is, suggestions as to the meaning of the patient's communications), arguing that each interpretation:

In addition to enlightening the patient about, say, his fantasies or defences, it also indicates that the analyst is still present and awake, that he has been listening and had understood what the patient has been talking about, that he remembers what the patient has said during the present and previous sessions- and that he has been sufficiently interested to listen and remember and understand (p244, reproduced in Kohon 1986).

Hence Rycroft sees positive regard, and thus trust, being communicated through listening and understanding. Such positive regard could be communicated directly in words but it "would be both irrelevant and useless to do so" as many would feel that the analyst was "forced and contrived".¹⁷ In this way the experience of this analyst shows how an apparently disinterested stance can still foster a trusting relationship. Ethically, Rycroft's approach seems much the more comfortable.¹⁸

It is, therefore, important to facilitate communication by being interested and *demonstrating* interest in what people have to say. One way of doing this is to reflect back to people what they are saying. For example, if someone is angrily describing how upset they were by something somebody said, it might be a good idea to comment along the lines "This is something that makes you angry". This will have the effect of, firstly showing that you are listening and taking in what is being said and will perhaps help clarify what is being said. Reflecting in a more interpretative way will have a similar effect of "deepening rapport", to use Malan's (1979) phrase.

Patrick Casement (1985) recommends the use of 'trial identification' in psychotherapeutic practice. Casement suggests that the therapist empathise with the patient and ask themselves - How might it feel to be asked that question at this moment and in that way? In an interview situation this has the effect of helping the interviewer to understand and empathise with the interviewee, bringing the interviewer into the present of the interview.

However, good unstructured interviewing does depend on judgment on the tact and timing of comments and questions that perhaps comes about through experience.

¹⁷ Similarly David Malan argues that an accurate interpretation will 'deepen rapport' and uses such signals as confirmation of theories about a particular patient.

¹⁸ Some of the discussions of technique produced by psychoanalysts contain important and sophisticated insights for in depth interviewing (eg Malan 1979, Casement 1985, 1989).

Mistakes will certainly be made. I held in my head the thought that since this was a research interview, the people I was interviewing were doing me a favour and I did not have the right to upset, or make people's lives more difficult. I therefore erred on the side of caution in striving to avoid stirring up strong emotions in people who I felt would have difficulty with this.

Implications for This Study.

As Klauber (1968:196) wrote:

. . . it remains a great advance in philosophical insight to perceive that an act of intuition by identification with the thoughts and feelings of another human being is a creative act which deserves to be distinguished in type from an act of creative intuition which does not depend upon identification. In the first, the sources of knowledge are weighted towards the revival in the historian or the psychoanalyst of endopsychic experience; in the second, they are weighted towards testing reality in the external world.

What is required is conceptual clarity about what questions are being asked. Different questions require different styles of analysis. There are relatively few structural questions being asked in this study, such as "Who is involved? How many people have family around? How many people with mental illness live with a relative?". These might be answered through the traditional quantitative means involving categorisation and counting: "testing reality in the external world" (Klauber 1968).

The great majority of this thesis is concerned with questions that are substantially about meaning, which can be seen as How and Why questions (these distinctions are in line with those made by Yin 1989). They involve an attempt to understand the experiences of the interviewees. To have any hope of gathering this sort of data requires Klauber's "act of intuition by identification with the thoughts and feelings of another".

This study makes the presumption that unconscious processes are important. The analysis of the data will therefore involve an attempt to interpret not only the overt communications, but also the covert ones presented during the interview. The data

consequently involve, not merely the words spoken, but also the interpretation of the responses of the interviewer to the overt and covert communications. Interviewing is itself a process that requires constant interpretation and questioning of those interpretations. There can be no meaningful distinction between the collection and the interpretation of data.

Aspects of psychoanalytic thought can be seen as constituting an archaeological approach to the present, in that the interview material can be understood only within its specific context. The research interview cannot be considered to be simply the collection of information which can be slotted in to the categories of the research, but is an event which must be understood in its context, whose meaning is open to interpretation.

2) Interviewing, Interpretation and Analysis.

The Application of Psychoanalytic Methodological Contributions To Understanding The Research Interview.

Ideas from psychoanalysis can provide a framework for managing and understanding emotions occurring within an interview setting. That is understanding the emotions of both the interviewee and interviewer.

A) The Emotions of The Interviewee.

Unconscious meaning.

It is the idea of unconscious meaning which would perhaps alienate many social scientists with an interest in the hermeneutics of the social world. Central to psychoanalysis is the notion that many of the meanings which constrain and direct social acts are unconscious, they are not necessarily open to the subject to report them

to the researcher. So whilst symbolic interactionist researchers firmly believe that they must understand the meanings that actors give to the social world, they assume this understanding can be gathered at an entirely conscious level.

The idea of the unconscious is central to psychoanalysis, and is viewed as consisting of feelings and thoughts which are actively excluded from the conscious awareness of the individual through the process of repression. This may be because either: a) the thought or feeling is unpleasant or unacceptable, or b) the experience took place in infancy before it could be processed by adult consciousness. Unfortunately however, according to psychoanalytic theory, repressed materials often consist of the most fundamental and guiding aspects of an individual's psyche. It is one of the frustrating paradoxes of psychoanalysis (which presumably has helped it remain marginal within social science) that the most important things that motivate a person to behave in certain ways maybe those that they are least able to talk about.

i) Free-Association: Covert Meanings and Their Interpretation.

Freud's chosen method of understanding the unconscious of a patient was free-association. Freud claimed that people's unconscious, repressed motivations, thoughts, and feelings do leek out in various ways. If a person is willing to just talk about what comes to their mind the analyst will be able to discern unconscious processes operating in the topics chosen to talk about, and the language used (Sandler, Dare and Holder 1973).

Thus, the basic method of psychoanalysis is the unstructured interview par excellence. Ideally, the analyst will intrude and direct the patient's free association as little as possible; the analyst will only comment and interpret what is said.

A number of techniques can be employed in a research setting which are based on, to coin a phrase, *the assumption of association*, which draw out the essence of 'free association'. In other words the assumption is made that the language people use and the connections that people make between topics can be taken as indicating the unconscious (and pre-conscious) meaning that topics and events have for people. The

words people choose, the connections they make can be taken as being covert communications. This implies paying particular attention to what people bring spontaneously to an interview; what words and thoughts are associated together; or what tone, or what facial expression, or posture is used to describe things that may suggest an alternative to the overtly intended meaning.

The reasoning here is that what people produce spontaneously is of particular significance. The researcher will listen to what is produced, taking note of the context in which topics are talked about. The context may be provided by the question or comment made by the interviewer, what the interviewee is talking about, or the emotional tone of what has been said.

The point is that these techniques offer a way of gaining access to people's feelings without them having to directly tell us what they feel. There is good reason to believe that people will be reluctant, in many contexts, to discuss feelings such as aggression, desire or shame. All of which are potent and socially significant emotions (Heller 1985, Stearns and Stearns 1988, Scheff 1990, Giddens 1992). Psychoanalysis has offered two particular concepts, transference and counter-transference, which can serve to enhance the analysis of research interviews. Following the discussions in the previous chapter which highlighted the importance of reflexivity, it will be argued that counter-transference is particularly critical.

ii) Transference In The Context Of This Study.

Put simply transference is the ability or habit of transferring thoughts and feelings that have arisen in one situation to the analysis/interview. Paradigmatically within traditional psychoanalysis this refers to thoughts and feelings about parents which might be transferred to the analyst (Laplanche and Pontalis 1988, Sandler, Dare and Holder 1973, Raynor 1991).

A striking example of transference comes from this study. A number of people were quite hostile to me when I turned up on their doorstep to ask if they would take part in the research. Although I had written to explain what I was doing I think I was still

seen as someone representing officialdom. The people who were hostile had had particularly bad experiences of the health and social services. Rather than simply regarding their hostility as an impediment to the research, the hostility could in fact be regarded as data. It is important to note that when I recognised that their hostility, directed at me, could be understood as communication and I then gave people space to tell me how they felt, the hostility dissipated. They were able to tell me how and why they felt so angry. This was possible because I did not take the hostility personally, I knew it was coming from somewhere and tried to understand it.

B) The Emotions of the Interviewer.

Counter-Transference In the Context Of This Study.

The notion of 'counter-transference' has a complex history, having taken on several different meanings. Freud coined the expression to refer to "the awakening of the neurotic conflicts of the analyst through an unconscious reaction to the patient's influence on the analyst" (Kohon 1986:51). In other words it referred to some unresolved issue within the analyst which resulted in a failure to understand some aspect of the patient's unconscious. It was this model of 'counter-transference' which originally led to the belief that analysts must undergo their own analysis as part of their training.

Since Freud's original use in 1910, the concept has become considerably refined and developed, in particular by the British school of object relations (Kohon 1986, Rayner 1990). Counter-transference is now often broadly viewed as a felt reaction to the patient. This affective response, if carefully monitored by the analyst, can give vital clues to the patient's internal world. Paula Heimann's (1950) paper on counter-transference is considered seminal in introducing the idea of counter-transference as being communication: "the analyst's unconscious understands that of his patient. This rapport on the deep level comes to the surface in the form of feelings which the analyst notices in response to his patients, in his 'counter-transference'." (p83) Hence, now, the analyst's own understanding of his or her own unconscious is still

essential, not so that all flaws can be removed (a hope that is viewed with more humility), but so that it can be monitored and used as a tool in understanding the patient.

Counter-Transference As A Block to Communication.

Researchers' failures to hear what someone was telling them often emerge when the tape is listened to or the transcript read (Anderson and Jack (1991). How many researchers have noticed at this stage how they have missed the real point that someone was making and have changed the subject? I was aware sometimes of changing the subject slightly when I could see we were getting close to things that were very painful. There were also doubtless times when I did that unconsciously, perhaps protecting myself from something I did not wish to dwell on. I came across a particularly startling example of this when I was transcribing one interview with Mrs Christian:

DJ: This is still very stressful for you isn't it?

LC: Oh yes, I think that that's why I try and get something better for him while I'm around. Because what would happen, I know [family], . lots of them but they're not in London . . and somebody who would see to some needs of Peter or who would talk to somebody I had thought of asking DW [local NSF activist] to keep an eye on things. Because D. is really . do you know D.?

Somehow I managed to understand this to be about her thinking of moving from London, and not an allusion to her own death, hence I could ask a minute or so later:-

DJ: So you have been thinking that you might want to leave London?

LC: Not leave London, I won't leave London- when something would happen to me, but I'm not going to leave London.

Counter-transference As The Communication of Emotion.

The expansion of the notion of counter-transference to include the felt reactions of the analyst to the patient is important in that it widens greatly the scope for understanding the subjectivity of another beyond the linguistic limitation of 'free-association'. It also brings the reflexivity asked for by critics of sociological practice such as Rogers (1983) and Phillips (1973) into the very heart of exploration. Andrew Samuels (1993:31) discusses the use of depth psychology to understanding of the political world:

I want to suggest that it is not in metapsychology, nor in models of the psyche or the unconscious, nor in schemas of personality development, and not even in the analytic attitude itself, that our usefulness to the political world may be found. Rather it may be the analytical and psychotherapeutic methods - modes and techniques of therapy - . . . In particular those aspects of clinical practice clustering around the concept of countertransference may be the most liminal with politics.

He suggests that counter-transference could serve this role as it demarcates an area of experience where "there is uncertainty about whose 'stuff' it is - the analysts (the citizen's) , the patients (the political problem's), or a mixture of the two" (1993:33), since it is where the inner and outer, the objective and subjective meet. Kleinman and Copp (1993) argue that there has been great damage done through the inability of field researchers to integrate their own emotions with their observations and conclusions.

My Stuff/Their Stuff.

Broadly speaking, carrying out interviews with people who had a relative suffer from long term, severe mental health problems was an emotional exercise. Going around to people's homes, getting them to open up about their thoughts and feelings about events that were experienced by them as tragic, was often upsetting and draining. For me there were complicated feelings involved, I needed care to understand which was my stuff, and what was their stuff. To witness people's pain was upsetting. Yet there

was also a certain fascination in this; so I had to recognise my own voyeurism (see the Concluding Discussion for reflection on the role of aggression in research). There was also the more uncomfortable feeling that their sorrow was my triumph. Their suffering was giving me the substance for a Ph.D.. For me it was "good material", yet I felt I was giving nothing in return.

There can be no doubt that my analysis, my writing and my conclusions were coloured by the emotions of this experience. I think I have reconciled some of my more guilty feelings by trying to represent their experience as well as I can. If their experience can be understood a little better then I am giving them something back. This does mean that this cannot be considered to be a straightforwardly impartial account.

There were times when I was moved and touched, quite lost in admiration for the depth of love and humanity I was witness to. There were times that I was upset and frankly angry by the way that families had sometimes been treated by professionals. Yet, paradoxically, I think that in the end this is a relatively impartial account, precisely because I was able to acknowledge the emotions involved. These emotions I felt were part of the communication between me and the people I was interviewing. As Samuels puts it, drawing on clinical practice:- "countertransference focuses on what is happening in the analyst's subjectivity - the part of that subjectivity that is somehow connected to the patient." Had I not been able to empathise with the feelings (the anger and grief, the hopes and fears) of the people I was listening to, what hope would there be of reaching an understanding of their experience? Samuels argues that the analysis of personal feelings invoked by the social world has import for political analysis: "Bodily reactions, worked on and distilled in ways familiar to the clinical analyst, lead the political analyst to the heart of the culture and its political problems. The body of the political analyst leads in a spontaneous political analysis." (p32) The feelings evoked in me by the people I was interviewing represented a point of contact, between my subjectivity and theirs. They were not distortions that simply needed to be filtered out. In fact through the communication of distress, people were able to tell me what was important.

Thus through the development of counter-transference psychoanalysis has attempted to confront the related issues of reflexivity and the communication of emotion by pushing the analyst's subjectivity to the centre of its project. This is symbolised by the requirement that the training of psychoanalysts consists, in substantial part, of their own analysis.

Analysis and Interpretation.

The first 12 months or so of work on this study was spent on literature work. Specific areas of previous research were covered and decisions made about methodology. The interviewing was then carried out over the first nine months of the second year (some of the more in depth work carried on for a further 12 months). I then spent approximately 12 months analysing this interview material. That is I spent 12 months on a process which consisted of going through the interviews, writing about what I found in the interviews, reading literature that seemed to help and then going back again to the interviews. After 12 months of this I stopped going back to the original interviews, and decided I was going to write the thesis around what I had excavated from them at that point.

There have been two distinct processes of analysis:-

Systematic Analysis.

Chapters 5 and 6, were mainly produced through a systematic analysis of each interview. I firstly examined (with the help of the cut and paste functions of an ordinary word processor) the openings of each interview. I had asked very open questions so I was interested in what people first said, which was very often to refer to an event of illness (this is described in Chapter 5). From here the rest of the chapter flowed from the development of ideas about this illness model and the way that it was being applied. So for Chapter 5, part ii ("The Relationship to Psychiatry and Psychiatric Knowledge") I trawled through each interview looking for references to psychiatry (or allied professions) or the health and social service institutions. These comments were then all gathered together, read through and condensed down into a

coherent story. What I am calling the "systematic analysis" did not take place in isolation from the "integrative analysis" which is described below.

Integrative Analysis.

The other sections where interview material is being presented (that is Chapters 7, 8, and 9) evolved in a very different way. Here, no meaningful distinction can be made between the process of data collection and data analysis. Furthermore, I cannot make any distinction between those processes and the reading and writing I was doing during this time. Or indeed between all of these things and what other living and experiencing was done in this period.

Certainly, it is important to acknowledge that the literature work (and feeling and thinking) continued throughout the data collection period. In fact, what now form quite significant theoretical elements were developed during the period of data collection. Individual interviews themselves have stimulated feelings and ideas which have fed into my thinking, my reading and my writing. This has then, fed back into what I was listening for in subsequent interviews. In other words, the process has been a very interactive one.

3) Sampling.

As discussed in Chapter 1, there are particular reasons to be concerned with the welfare and anchorage in the community of the group of people who might be called the 'new long-stay'. It was decided therefore to talk to relatives of this group. The first task was to identify a sample of people who would be seen as fitting into this category. In order to reflect the convoluted nature of the status of a so-called 'new long-stay' group within a service in transition, two slightly different means of identifying people were set up-

i) People who had been admitted to one of the acute wards at the local District General Hospital or at Friern Hospital for a continuous period of at least six months according to the database kept by the Mental Health Service (going back approximately two years).

ii) In recognition of the fact that attempts were being made to transfer long term care away from hospital wards, another group of patients were included from a random¹⁹ sample of people referred to the Community Psychiatrist. The grounds for including this group were that a decision had been made somewhere that these were people who would be requiring long-term support.

From both groups only people who, according to the notes, had at some time received a diagnosis of schizophrenia, or manic depressive psychosis²⁰, who were below the age of 55, and were not being resettled as part of the reprovision programme were included. There was some scope for bias here in that to enter this procedure people could only be included if their case-notes became available. Some people's notes did not become available over the period of study, as they were somewhere in the hospital system, but could not be tracked down. There is no reason to believe that systematic bias would have resulted at this point. The notes that were found were then

¹⁹ Numbers were assigned to each case on the case-list. Computer generated random numbers were then used to select the sample.

²⁰ Or "bi-polar affective disorder".

searched for names and addresses of relatives. I then contacted relatives myself.

A total of 59 people reached this last stage of the search for relatives' addresses. For a variety of reasons, I was not able to do interviews with relatives of 23 of these.

Those Not Interviewed.

One of the important questions that underlies this study is how feasible it might be to assume that families will supply any measure of support. The size of the group whose relatives were not interviewed is therefore important, as it may be that they have no family to speak of. Clearly a larger scale, more quantitative approach would be better suited to addressing this issue.

The different reasons for not making contact with relatives are presented in Appendix (B). They are difficult to summarise, but it would seem that only 2 people definitely did not have any family.

It must be stressed that if the address was not in the notes, or if that address did not seem correct, I did not feel that I had time to indulge in detective work in tracking down relatives. There was simply not the time nor the resources to do this. Particularly in the light of this point, the number of people with families being involved seemed surprisingly high, given the nature of the area: an urban London district which might be expected to have a relatively transient population. As will be shown, those relatives who were interviewed were often very involved.

In terms of the crude demographics of this group there were 17 men and 6 women, their average age was 35. In terms of age they are similar to the group whose relatives were interviewed (details summarised in Appendix C). There are a slightly higher proportion of men in the not contacted group. This might reflect men's lesser involvement in, or marginalisation from, family life (Robertson Elliot 1996).

4) Introduction to the Interview Material.

The Interviews.

The core of the empirical material consists of the records of 38 in depth open ended interviews (with 47 individuals), concerning 34 'identified patients'. Eight of these interviews were not recorded due either to refusal to be recorded or when conditions were not appropriate for recording. The rest were transcribed verbatim by myself. It is these transcripts which form the central material for analysis. The transcripts themselves, however, would mean little if analysed on their own, as they really represent a quite pale reflection of the actual conversations. Anderson and Jack (1991) comment on the dismay in finding "discrepancies between our memories of the interviews and the transcripts because the meaning we remembered hearing had been expressed through intense vocal quality and body language, not through words alone." (p12). Hence the interview material that is presented in the following sections is annotated. All the presented interview material is preceded by text which contains numbered points referring to places within the transcript. Here I present my interpretations on what is being said. This is an attempt to expose the process of analysis as much as possible. In addition, a small number of people (one father, one mother, and one wife) were seen more often²¹. This simply provided for a deeper impression of the impact of events to be gained. The majority of the data and ideas for subsequent discussions, however, come from the more circumscribed recorded interviews. Most interviews took place during one meeting and the average length of interview was around one and a half to two hours. Several people were seen more than once (one mother, Mrs Christian and a wife, Mrs Sutherland were both followed up almost two years after the initial interview). At the very outset it had been assumed that more in depth explorations with a smaller group would form a larger part of the study than they did. In part the more in depth explorations were not necessary because of the richness of the material produced during the single interviews. Also seeing people more often did not necessarily produce much greater

²¹ A father, Mr Sole was seen on a weekly basis for around six months and then numerous occasions after that. A wife, Mrs Mansell was seen on six different occasions. Mrs Mason, a mother, was seen on a fortnightly basis for around nine months.

insight, perhaps because to have explored in greater depth would have involved a blurring of the boundaries between research and therapy. This issue and the ethics of such research is returned to in the Concluding Discussion (p318).

Characteristics of sample group.

Information on the group whose relatives were contacted and interviewed as well as their relationship to the interviewee is summarised in Appendix C. The average age was 33, there were 23 men and 11 women. This proportion reflects that found amongst the local "new long-stay" population and within the long-stay population of Friern and Claybury Hospitals (Jones and Margolius 1989).

The living arrangements of the people whose relatives were contacted can be broken down into four categories. One person (Gouella) had left the country and is not included here (although his aunt was interviewed):-

1) At home with family=5

2) Hospital at time of interview=7

Long-stay ward = 1

Usually at home with family = 4

Previously homeless = 1

Usually in hostel accommodation = 1

3) Hostel/supported accommodation=14

4) Independent Accommodation=8

Council flat/housing association=7

DSS Funded Bread and Breakfast accommodation=1

The first striking point is how few people actually lived at home with relatives. Only five people in fact. This reinforces Rogers et al.'s (1993) finding from a survey of British users of mental health services that they did not live with relatives. Interestingly another four people were in hospital who had been living at home with family (two of whom were perhaps unlikely to return there). Of the seven people in hospital, at the time the relatives were interviewed, none had been admitted from

independent accommodation (council or housing association). This has been a consistent finding of British psychiatry (see Brown et al. 1966 for example) which gave the impetus to the expressed emotion research. Two hypotheses are raised by the finding, firstly that living with other people may cause such stress that 'relapse' is more likely (the premise of EE research) or secondly that the behaviour so disrupts the lives of the people living with them that they seek their admission or that those living with them become aware of their distress and so seek help for them.

The relatively large group of people living in subsidised independent (local authority, or housing association) accommodation should be noted. This supports the suggestion made in Chapter 1 (p44/45) that the availability of alternative accommodation has been significant in reducing the populations of the Asylums.

It is also important to note the marital status of the original group (Appendix C). Although I did not investigate people's circumstances in detail, the fact that only one person seemed to be in a long-term relationship is noteworthy. None were currently married. Therefore in talking about people's families, it is important to note that these are very largely the families of origin.

So far as the interviewees are concerned, there is an over-representation of mothers (15) compared to fathers (8). This might reflect consistently found gendered differences in caring (Finch and Groves 1989). However there are an equal number (8) of brothers and sisters interviewed.

Descriptions of some of the situations that I found are described in appendix (D). All names used in this thesis have been changed, as have certain incidental and biographical details which might identify people too closely.

Demographics : The Difficulty of Categorisation.

Clearly, when doing interviews I was aware of class, ethnicity and gender. However, for the purposes of the analysis I have not systematically broken down the data along these traditional lines. This is due to the substantial problems with doing a priori

categorisation. Certainly, ethnicity and social class are highly complex and multi-faceted phenomena. To have allotted people to rigid groupings would have been quite at odds to the approach I have taken: which is, in significant part, an attempt to analyse what lies underneath commonsense categories. I have no doubt that to have interviewed people about these issues would have been both informative and interesting. The numbers involved were also too small to justify generalisation across groups. The social class of the interviewees reflected the heterogenous nature of the urban London borough. I carried out interviews in neglected local authority estates and leafy suburban avenues.

A systematic analysis of gender differences is perhaps the most surprising omission. A great deal of literature on caring has emphasised the disproportionate amount of caring that is carried out by women. The distinction that has been made between 'caring for' and 'caring about someone' (Mason 1994) is perhaps relevant here. This thesis is less concerned with the labour of caring than with the feelings involved. It was true that there was some evidence of slightly different burdens falling between genders. Women were more likely to mention going around to clean, or cook for people. Men were more likely to be doing things like repair work, or sorting out things like the payment of bills, or difficulties with social security payments. This difference was not very striking. The fact that I was generally interviewing people who were not living together meant that the notion of caring was not merely confined to the domestic. Of interest in demonstrating how difficult it is to define what 'caring' is, is the case of one relative who lived in Ireland. I contacted her by letter and she wrote back with a few comments and quite spontaneously referred to herself as "a carer" of her sister (living in London), even though she herself lived in Ireland. She actually described being available on the telephone to her sister, sorting out problems with bills and housing. The fact that I interviewed more women than men is probably the most significant point about gender.

In order to illustrate some important points about methodology I will firstly discuss the interviewing context. A relatively long extract of an interview is presented in Appendix (E) in order to give an impression of what an interview was like and to illustrate certain points about the manner of analysis. In analysing this interview I am

clearly focusing on quite fine detail. Examining the individual words that are used, noting what topics are associated together.

The Interview Context.

I am male, white and I was studying these people in order to gain a Ph.D. I had my 28th birthday during these interviews. Many of my interviewees were considerably older than this, many (around half) were black and many working class. Such differences were perhaps unfortunate. How easily would people communicate with me? How easily would I comprehend, be able to interpret what was being communicated? One point in my favour was that I was aware of this. Ultimately I can not judge how well, or badly, I did facilitate communication. I felt that I did the poorest interviews with older black people. Although there were exceptions, these interviews were the ones that were more likely to be more superficial and guarded than others. I did not feel the same way about the interviews with younger black people. I felt that generally class similarity, most particularly education (regardless of ethnicity or age), facilitated communication. People that understood what I was doing most clearly, were less suspicious and seemed to grasp the interview as an opportunity to get their point of view across.

For example Jason Manula, a black South African, was studying for an MSc. in the University of London is clear about his motivation for agreeing to be interviewed (although he also expresses his cynicism):-

JM: .. But this is interesting you know, this is the first time I'm talking about it to someone who's working for the Health Service so, and I'm finding this helpful but at the same time I'm not sure, I'm so cynical now that I'm not sure what it's worth. Because frankly I . . .I agreed to talk to you simply because I wanted the study partly to convey what we feel as a family. But at the same time I'm so used to a negative response that I don't expect anything of this. Because at a time when severe cuts are being made everywhere, privatisation and talk of privatisation is in the air, you expect even less and less. Especially in the past when these so-called support structures were there, people were not listening that

closely to what families had to say . .

Whilst Jason's self-consciousness about the interview was perhaps unusual, his motivation in wanting to get his story over was not.

Dress.

I thought carefully about what to wear when going out to meet people. I wore a collar and tie and casual trousers. I wanted to strike a balance between not appearing too formal and official and appearing as a responsible person who could be trusted with delicate information. To have worn jeans and a tee-shirt may have made certain interviewees feel more comfortable but others would have, I felt, been put off. Perhaps they would have felt uncomfortable about trusting someone dressed like that, who seemed outside the boundaries of the sort of person that they trust with confidential information. On the other hand to have appeared too formal may have inhibited people. This reasoning might sound manipulative - I don't think it was - I was not pretending to be what I was not. I felt comfortable with this role, it was appropriate. I did regard myself as someone who could be trusted with confidential information.

The Introduction.

People had already received a letter (Appendix A), which clearly sets the context in terms of mental-health problems. The letter was written under the letterhead of the 'Team for the Assessment of Psychiatric Services'. This might have identified me too closely with the psychiatric services and so may have inhibited people from criticising those services if I was identified as being a part of them. However, as will be seen, this is doubtful as most people did not seem inhibited in this way. I have no doubt that in the vast majority of interviews I was seen as someone impartial (as regards service provision) who did want to hear what people had to say.

If people were in when I arrived at the address, I would re-iterate the main points of

the letter:

I would explain that I was attached to a group based at Friern Hospital who were studying various aspects of psychiatric hospital closure.

That my interest was in the families of people who used those services as I felt that the involvement and responsibility taken by families was not always recognised by professionals and service planners.

That I was listening to what family members had to say about their experience of caring for someone, and what they thought of the services they had had contact with.

I then reassured people that if they did agree to take part, anything they said would be regarded as confidential; that if I used something they said to illustrate a point I would not use their real name, and that identities would be disguised. If people agreed to take part, I then asked if they would mind being tape recorded.

Most people had no objections to being recorded. On two occasions I did not seek to use a tape-recorder due to very strong accents (and a felt uncertainty or awkwardness about the interview) and on two occasions when there was a lot of background noise. I knew from experience that transcribing is far more difficult than understanding someone sufficiently to converse. Transcription depends on the un-aided full comprehension of individual words that are picked up by the tape recorder. In conversation we can get by on the 'gist' of what someone is saying, aided by visual cues.

Class and educational background again facilitated acceptance of the tape-recorder. People would make comments like, "good, a very sensible way of keeping a record of a meeting".

On five occasions people refused to be recorded. Mrs Teague had not seen her son for six months, things had become too upsetting and traumatic. As she relaxed and

talked to me it became clear that her only contact with professionals had been when they had been trying to persuade her to have her son back to live with her. It seemed that she has assumed I was also there to do that. Mrs Lord was hostile to professionals, blaming them in part for her son's difficulties. I was on the receiving end of that hostility. When it was clear that I was simply there to listen, things became easier. The Cook family were initially hostile and suspicious of my presence. The parents were going to refuse to talk to me, but first got their son to hear what I had to say. He decided it would be alright to talk to me. He and his mother were happy to be recorded, but the father was not. They, as a family, had a great deal of anger for the way that their son/brother had been treated, and for the way that they had been regarded and excluded. Again the refusal to be recorded seemed to reflect hostility towards the health and social services. I actually spent about three hours with them and parted on good terms. These three cases of refusal seemed to be specifically about hostility towards the health and social services with whom I was, in the interviewees' minds, associated.

Mrs Murray was reluctant to be interviewed about her daughter, and only agreed to talk if I just took notes. In her case she seemed to feel a quite strong degree of shame, and even guilt for what had happened (this is discussed in Chapter 6 p187). Whilst we parted on good terms, this was the most difficult interview, with her remaining prickly throughout.

These four refusals have all involved black families. The fifth refusal was with a Greek Cypriot family (about George Christodoulou). I interviewed the brother who did not wish to be recorded. He was initially hostile saying he did not think he had anything to say. I ended up listening to him for about two and a half hours; about his sorrow about the way his brother was now; about his anger on how little help there had been. He told me that he spoke to no-one outside the family about his brother's difficulties. This suggests it may have been something about the shame he felt that made him reluctant to be recorded. This might therefore be regarded as data - shame is discussed in detail in the following chapters.

The ethnicity of this refusal group is likely to be relevant. It may well be that these

families were more likely to feel alienated from services and from me as a white researcher. Certainly the Cook family and Mrs Lord felt that they had been treated differently because they were black. It is worth noting that in all cases I parted on good terms. A bit of sensitivity and a willingness to listen seemed to overcome a good deal of hostility.

The Presentation of Data.

In the sections that follow, a great deal of verbatim interview material is presented. I am trying to achieve two things in this presentation. Firstly, in common with an 'oral history' tradition (see Berger Gluck and Patai 1991 for example) I do want the voices, the stories of these people to be heard. However, I also want to expose the process of analysis to scrutiny as much as possible. Hence quite lengthy quotes are included, preceded by my own comments which refer to numbered points in the text. This is a compromise between the, perhaps paradoxical, wishes to have their stories heard and to expose the analysis as much as possible. I am anxious to reinforce the points made in the Methodology chapter that data cannot be considered to exist on its own. I would not like to pretend that the excerpts from transcripts that I am presenting here can be considered as 'raw data'. They are by no means raw but have been distilled (by myself) from interviews, which were initiated by me, and to large extent controlled by me. Through including questions and comments made by myself in the interviews and the system of annotation I hope to unmask to an extent the power I have exerted over the stories that people have told me.

The interview extracts are presented largely verbatim. Pauses occurring within people's speech are represented by full-stops and spaces: ' '. If words have been removed this is shown: [edit]. This occurs either where I have removed unnecessary personal detail that might lead people to be identifiable or in the interests of clarity. Explanatory comments, from myself are also included in these brackets. As all interviewees were reassured at the time: all names have been altered and personal details have been changed in order to protect people's identities.

Exposing The Analysis.

The system of annotation should give some insight into how I have been analysing material from the interviews, whether this has been through what I have called the 'systematic' or 'integrative' manner.

The intended style of interviewing was to be non-intrusive. As much as possible my intention was to encourage people to talk in their own terms. The interview, with Mike Harris, is presented in Appendix (E) in quite considerable detail because it illustrates some important points about methodology (the interviewing and the analysis). The focus of the interview was to be the family members themselves. For example, throughout the interview with Mike Harris, of about one and a half hours, I made a total of 37 interventions. 26 interventions contained the word "you", as in "You felt . . .", or ". what did you think?" , or ". . Was that something you ever felt?" " or . "Have you had much contact with the hospital . . . ". This reflects how relentlessly I tried to maintain the focus on them and their experiences (there would have been a great temptation to have talked about the identified patient, rather the their own experiences).The other interventions were:-

5 answers to questions.

3 clarifications.

1 follow-up explanation to a question.

1 exclamation.

1 reminder of what he had been saying before being interrupted by a phone call.

I always began interviews with a very open question such as "When did things start to go wrong?" This was an attempt to leave the interviewees to introduce their terms. People's responses to this opening are discussed in more detail in the next chapter. Despite that fact that I was interested in hearing about what interviewees thought important, there were certain things I did want to know (described on p102-103). So for example, if people did not tell me what they thought of the medication I would ask explicitly. There was a compromise to be made between simply encouraging their agenda and my own. There is also, I think an ethical point to be raised here.

Interviewing which simply encouraged people to talk, to go to greater depth could lead people to over-expose themselves. I was aware sometimes of changing the subject slightly when I could see we were getting close to things that were very painful. There were also doubtless times when I did that unconsciously, perhaps protecting myself from something I did not wish to dwell on.

The depth analysis of the interview with Mike Harris (Appendix E) illustrates how I was in some ways less concerned with the manifest content of what was said than in the more covert communications that are being made. I am assuming that what is spontaneously brought by the interviewee to the interview can be regarded as of being of particular interest. I think that the fact that Mike seemed unhesitatingly to see his sister's difficulties as being a medical problem is very powerful as data. More powerful than if I had, for example, asked him his opinion of the significance of the medical model. Indeed, in the interviews generally, the more open approach allowed for the medical view of illness to emerge alongside clear scepticism about specific psychiatric models of illness and treatment and theories about cause which were far from the organic model of illness. Such a finding of lay eclecticism would not have been possible in a less open approach which regarded such views as contradictory - a priori.

CHAPTER 5.

The Relatives' Construction of Events.

This chapter is in three parts. Part (i) begins the exploration of how family members have construed what has happened by examining how they began to tell their stories at the start of the interview. What emerges is a very distinct picture of discontinuity in the behaviour and manner of their ill relative which is apparently straightforwardly seen as being due to the intervention of an illness.

Parts (ii) and (iii) investigate the relationship that this seemingly unproblematical construal of illness has to psychiatric notions of illness. It will be shown that it seems that these family members have not directly been taught this medicalised version of events. In fact relatives often report very poor communication with psychiatry and considerable scepticism towards psychiatric treatments and definitions.

(i) The Rupture with the Past.

Having explained the purposes of the research, assured people of confidentiality and checked whether it was acceptable to record the interviews, I would usually start the interview with a fairly open question, along the lines of "When did things first start to go wrong?". Clearly I am making an assumption that things are seen as having gone wrong. However, I am leaving the terms of the difficulties to be laid out by the interviewee. I would try to avoid imposing language on them, but would follow along with their construction of events. I would refrain from using a word like 'illness' unless it had already been used by them. It is worthwhile to take some time to consider the responses to this opening gambit, as it is likely that what is volunteered initially will be of some significance in revealing how the situation is construed by the relative. Although in using the word "when" I am suggesting that there will be a beginning with a temporal location, it is very plain that most people construe their relatives as being altered in some way by the intervention of some entity.

The point to be noted throughout this section is the way that change has been construed. Most interviewees see that there has been a rupture in the desired continuity of their relative's behaviour. This rupture is most often seen as having a very specific temporal location.

Sudden Realisation Of Change.

Elly Blacksmith, now in her seventies, was herself born in Jamaica but has brought up her family in this country. Her son Terry has had a diagnosis of schizophrenia and lives nearby in a council flat. He comes around most days and helps his mother with routine household chores. This seemed to be about the most 'reconciled' situation I came across (discussed further in Chapter 9, p. 280).

In response to my opening question, Mrs Blacksmith refers back to an event occurring at a specific time, indeed a certain date has stuck in Mrs Blacksmith's memory (1). The time is associated with an exam, which perhaps marks a point of development and achievement (which it was felt was not maintained). There is also a hypothesis of cause hinted at: "studying a bit too hard" (3). These issues will be returned to in later sections.

Previously, Mrs Blacksmith has noticed that he has been a bit funny: "speaking a lot of different stupidity" (2). However, it is a very public display of remarkable behaviour (a crowd gathers, as he takes his clothes off (4)) alongside a violent incident (he threatens to harm himself with a meat cleaver) which brings things to full recognition.

Mrs Blacksmith's response to this crisis is to call the doctor (5). Apparently, very straightforwardly, the aberrant behaviour is construed as a medical problem.

Then, I am presented with Mrs Blacksmith's perception of a pattern of events (6). The pattern is seen as being a course of illness (the word 'ill' is used (7)) described in terms that could be considered as compatible with a psychiatric construction

("From there every year or every two year probably he gets a breakdown"). The breakdown follows a pattern of "depression" followed by "withdrawal" and then him doing "stupid things".

EB: Well you ask the questions . .

DJ: When did you first notice things going wrong?

EB: It was in 1980 (1) when he was supposed to take his exams he was supposed to sit for his City and Guilds . . and then it was on the 8th, he was supposed to take his exams on the 13th and then on the 8th he started to go a bit funny, speaking a lot of different stupidity, (2) . he was studying a bit hard really (3) to sit for his exams and then . . I was living in Cornell Road and then once a crowd gathered, I had a friend living in this area she saw the crowd and when she went up she saw that it was my son taking off all his clothes (4). She put him in a taxi and fetch him home . and then first he went into a butcher shop and took out the meat thing- cleaver or whatever it is to . . you know chop up himself and she brought him home. I called the private doctor (5) the doctor came and recommend him to the hospital. From there every year, or every two year probably, he gets a breakdown. But you notice what he does- he goes into a right depression state first and kind of withdrawal after that, you can see, because you see the stupid things sometimes (6). When he smoke his cigarettes, he buy a packet of ten he would put all in the fingers and then smoke them one after the other [demonstrates putting a cigarette in between all fingers.] from that you get to know each time he's taking ill (7).

Mr Reece, a 63 year old man, born in Jamaica talks about his son. Again I am referred to a specific point in time (1), when he was staying in his room (2) and being a bit aggressive (3). The word 'ill' is used (1,4)¹, and the doctor is called in (5):

DJ: When did you first notice things going wrong with Eric?

¹ This is an event which Mr Reece's daughter also refers to at the beginning of a separate interview. The same temporal location is referred to, and similar behaviour.

MR: Well that's a bit of a problem for to tell you what year. Um remember but . where to start from . Well he was ill (1) when we was living at Cranly Road. And he was in his room (2), small room and um he was a bit . what you call a bit aggressive (3), like you know? Nobody seems to take much notice of him with what he's getting on with, because if you're in the house and you just want to be left on your own - alright, leave on own. But his mother always use to try . so one day his mother, he didn't come out for nothing, . so she went in there to see what was going on . And when she went in there, she seen the position of him, he was well ill (4). So she get the doctor to check him out, so the doctor come and check him out (5). .

I feel uncertain about the significance of his use of the word 'illness', so I ask for clarification, and in fact I do seem to encounter some ambiguity. First of all physical symptoms and "a cold" are mentioned (1). However, following contact with the hospital there is mention of his son's lack of communication. The lack of communication is firmly associated with the illness (2). In hospital he wouldn't eat or talk to anyone. He was then brought home which still did not help. Like Mrs Blacksmith above, Mr Reece tries to get private medical help (3). Neither Mr Reece nor Mrs Blacksmith were by any means well off. Perhaps as they both moved from the Caribbean in the 1950s, they may be more used to a private system. Presumably there is also the hope of what special medical knowledge may provide.

DJ: How did he seem ill? You said he seemed ill?

MR: Yeah well, he got like um . . a cold or something like that (1), I think he was shaking and something like that. All these doctors they know more than I do, . he go by [hospital A], not [hospital A]- [hospital B] and from [hospital B] they send him to um . . [hospital A]. Well, they send him to [hospital A] and . they went to see him at once . because he always want to be a homely boy, like you know. Well, everyone in the family sorry for him because he never used to be communicating, talk to nobody and so on.

DJ: Even when he was younger?

MR: No, no in his illness (2) . So he was there, and he wouldn't eat nor talk to no-

one and so my wife and my eldest daughter Vicky you went to, they went around there and they feel was the best thing they was to do was to bring him back home. But that was the worst thing because . well I bring him back home, I carry him by a private doctor at Harley Street (3). Paid a hell of a lot some money, and then a lot . there again I still had to bring him back and carry him by [hospital A] Because Harley Street doctor couldn't do nothing for him, he needs a hospital . .

To give just one more example of the report of as sudden realisation, Mary Galton remembers her sister "started to get nervy" (2) within the space of a month of significant emotional trauma; breaking up with her boyfriend (1). It is the advent of aggressive behaviour which is remembered as being the prompt, for the family, to seek help (3). Again the help that was sought, with little apparent hesitation, was medical/psychiatric (4):

DJ: When did you first notice things going wrong with Rachael?

MG: After the break-up with her boyfriend (1), because it was really strange at first because it seemed that she wanted to get rid of him, I couldn't for the life of me fathom out how on earth she could have had a breakdown when she wanted to get rid of him . She said she'd do much better without him . .well, who was I to really say well, you can't because I hadn't really seen that side of Rachael but within the space of a month of her and her boyfriend splitting up, you know, she started to get nervy (2). We brought her to mum's, from there it was steady downhill where she would become violent (3) - everybody was against her. We tried to get her psychiatric help at [hospital A] (4) it was . . I can't really explain it, we couldn't get her admitted, she wouldn't admit herself and we used to bring her to hospital saying that she was beating up my mum, abused her, but we just couldn't get her admitted.

There are three significant themes that emerge from these interview openings. Firstly, these examples demonstrate how strongly and vividly people recalled there being an important discontinuity in the behaviour of their relative. Secondly, this discontinuity, this rupture with the past is marked by quite specific events involving various displays of unusual or alarming behaviour. Thirdly, the behaviour and the rupture are interpreted as being a medical problem.

Gradual Realisation Of Change.

Other interviewees reported a less clear perception of a specific rupture. In Mrs Dear's description of her son's difficulties (illness has already been mentioned before recording begins) there is an impression of change becoming gradually discernible. Certainly with hindsight, Mrs Dear sees an accumulation of events, of behaviour which it became less and less possible to explain in everyday terms: "I didn't know quite what was going on, I just thought that maybe he was trying to be funny or something." (1) This is similar to that described as being typical by Yarrow et al. (1954) in their study of how wives would struggle to construe their husbands increasingly aberrant behaviour in everyday terms (and not as mental illness).

DJ: Ok so you were living with Bruce when he became ill .

MrsD: Yes Bruce lived with me then when he first became ill, because then he was working . . and then. . I don't know quite how to put it, he started behaving strange . .

DJ: What did you notice?

MrsD: Things like he'll come in and . I'll just give you one instance one evening he came in and moved my bedroom around, that wasn't even his, it was my bedroom . and he came in said- 'Why did you do that, you're just doing these things to annoy me?', I said 'What? what did I do to annoy you?' And he said it was because I moved the bedroom around . . .I thought 'what has him moving my bedroom around got to do with him getting annoyed because it is not even his bedroom?' . . That was one of the things and then like if we were watching television, there might be something like the coffee table in the middle and he'll go on about that we've put that there to disturb him . . oh a bit of paper might be lying on the floor anything like that and he'll fly off the handle . I didn't know quite what was going on, I just thought maybe he was trying to be funny or something, (1) I don't know and then it went from there, . .

DJ: Things got worse after that?

MrsD: Yes . then he lost his job, and then just sort of stayed in bed most of the time, things like that. And then he started accusing us of putting things in his food . . all sorts . . .

Nevertheless despite there not be any particular outstanding sequence of events it is still clear to Mrs Dear that a definite rupture with the past has occurred.

Always Been Different?

Mrs Karajac responds to the opening question by going right back to when her daughter was four or five years of age (1,2). She was seen as being overly shy, but still normal; not significantly different from her brothers (3). Although she was also seen as capable of saying and doing odd things (4). Even so, Mrs Karajac eventually describes an "it" starting at sixteen years old (6), associated with doing O'levels and pressure from her husband (5):

DJ: When did things start becoming difficult with Janice?

MrsK: In the beginning you mean? . From a child she was very shy, maybe that was a starting point (1) I don't know. . and she likes all the time to fuss about . For example, when my sister came to visit I remember she went to France and she was coming back from France she was giving everybody presents, why she didn't . . she started screaming . wasn't made a fuss of, we didn't take any notice, we didn't realise it . .

DJ: What sort of age was she then?

MK: Four or five (2). Then when she went to school all the teachers used to say that she was very shy, she would never talk, she would never mix with the other children . . But we said "My other son is very shy, but otherwise he's ok . a lot of people are very shy, that's nothing to do with it" (3). She used to tell me all the time when she started . the last year of primary school, she used to tell me "Don't meet me at school you are too old you don't look nice, other children have got beautiful mummies and very young so I don't want you to come any more" (4), so I didn't take any notice of it, so I didn't go and that is it, and then . she had her

first communion, she went to the second part of the school . the junior . .
Sometimes she used to come with friends here, but my husband was very strange,
everything with him was just study, study, study .no messing about no friends
nothing . . he went to University, his first two sons went to University so they all
have to go to University . So the two boys didn't mind it very much, but she didn't
want it she wanted to go out, sometimes her friends used to come and say 'we go
skating', but he would say oh no they couldn't, and all the time, work, work, work.
No playing, no nothing. (5) . .[edit] . . The poor thing, she did quite well at school,
but not that great, because he went to University, the first two sons went to
University so they all have to go to university, but I was against it, but it was no
use. And she went on . she had a sort of thing about him he [was injured] in the
war, she put him on a sort of pedestal, how great he was he used to boast about
how he used to quarrel with people at work tell them what they had to do. Then
he was made redundant, she was starting her O'level exams, that's when it
started, sixteen years old . . (6). When he came and said that he had been made
redundant he got so upset that he had a heart-attack and he had to go to hospital

..

At this point I ask for more detail. What becomes clearer is that, in spite of the fact that Mrs Karajac responds initially by showing me evidence of Janice having been unusual since the age of four or five, something is still perceived to have happened to her at age 16. This change is again firmly associated with her father's redundancy and suffering a heart-attack and the stress of her sitting O'levels (1). Odd behaviour, such as excess washing, is remembered as emerging at this time (2). This behaviour is given meaning ("nervous trouble") through a friend who was studying medicine (3).

The fine detail presented (ten years after the events) is noteworthy. I am told that Janice had sat the first part of an O'level examination in one subject, but had difficulties when sitting for the next subject (4). The implication of the presentation of such detail is that events often occurring many years ago were very much alive and had meaning in the present. It will be argued in the section on "The Grief" (Chapter 7, part i) that this is indicative of the difficult and protracted nature of the process of bereavement that these relatives are involved in.

Further difficulties, such as her daughter seeing things in her room (5), are firmly linked to the stress of exams and also to the return of her husband from hospital (6). The ambivalent feelings towards the late husband are something that would have perhaps been interesting to take up, however this is an example of something that I did not feel able to take up in the context of a one-off interview like this.

DJ: What happened?

MK: He wanted to go on 'till 75 years old to make a lot of money, but he was 64 when they made him redundant, they gave him money, £5000 . . they had to sack a lot of people, so he was no use to them. He got so upset about it he got the heart-attack and he, . . Meantime she was doing her O'levels (1) it must have harmed her, she used to do come every day and spend the time washing herself, wash, wash, wash (2). I'd say: how can you wash like that, you are clean, you'll get pimples or get inflammation of the skin. Then somebody told me that it was nerves. That she was getting nervous.

DJ: Was that a friend of yours?

MK: Yes, she was studying medicine (3) . . . when she was at home . that is the first sign of nerves that means that she has got nervous trouble. But whatever you used to tell him [gesture to place on settee where presumably he used to sit] 'oh no, no, no, ' he knows everything better I don't want . She did the first part of the one subject, come the second subject, I think it was maths (4) . they phoned said she was behaving very strangely - she is leaving the examination room she is going to the toilet on, off, on off. In the end they had to send her back home, she is not well. So when she came back I said "What's the matter?", she said: "I'm not taking any more exams". Fair enough we went to the GP. . . Then she started seeing things in her room, she used to collect furry animals . . the room was completely full of it . then one night, she said to "Oh the rabbit is looking, look my little bear is moving its feet' she started seeing things moving (5) and she said she heard noise. So I took her again to the GP, it was a very good, good GP. He said 'I don't know maybe we'll have to take her to see somebody of the mind because I don't understand'. In the meantime he [husband] came back from hospital (6) . . it was then that she started to become really ugly, she used to . she refused categorically to go to school . all the others took their exams and she stayed at home. Then she

used to do all kinds of things, she used to take plastic bag and put it on her head at night, with an elastic band all around . . then she broke all the photographs and got the glass and cut her wrists, . But never a lot just to see the blood . Then the GP said "Look we have to take her . make an appointment to see" . you know in London here.²

Although Jacob Doors sees in his daughter the first clear signs of 'instability' at age 14 or 15 (1), he also, in a similar way to Mrs Karajac, sees his daughter as having a 'different' personality from a much younger age (2). Mr Doors is unusual in spontaneously raising a formal psychiatric diagnosis (3). Whilst it is clear from other interviews that disturbed, and disturbing, behaviour has apparently been unproblematically interpreted as a medical problem, the infrequency with which psychiatric terms and diagnoses were spontaneously invoked in these interviews is remarkable. The relationship between the relatives' view of 'illness' and the way they do not seem reliant on formal psychiatric categories will be taken up in detail in part (ii) of this chapter. Jacob Doors sees his daughter now as having been different from a very early age (4), but it is only with hindsight that this is seen as of any significance (5).:-

JD: Something that puzzles straight away, April first showed signs of instability from the age of 14 - 15 (1), although looking back on her life it's quite obvious that she was, she had a different personality from other children from school (2) in that she was . You know we thought for years that she was manic-depressive, in fact turns out to be schizophrenic (3), the symptoms are apparently very difficult. It took the authorities about ten years to find out the difference which I think is a bit puzzling . .

DJ: What started happening at age 14?

JD: Uh . well even before that at school she wasn't like her brother who was a sort of quite straightforward, steady sort of a person but er, she was extremely self centred she would er . .she wasn't academic, although she would notice tiny little

² Mrs Karajac's son in a separate interview also referred to this time, clearly perceiving an event occurring at that same time.

details rather strange. Like when she was two years old (4) I was driving down Oxford Street to show her the lights, Regent Street . and she wasn't particularly interested in the lights, which were quite magnificent, she noticed a little ice-cream sign inside a shop- you're talking about something that is about as big as a ten inches high sign when you're next to it, and this was a sign you could see from the car and 'Look daddy ice-cream!' so she noticed tiny little things pertaining to food, she'd notice all over the place so she was an extremely observant person, but only within a very limited 'April world' as it were. So it was quite marked in fact she would tend just to think of food. At the age of five on one occasion she appeared from her pictures, you haven't met April, no? . . from her pictures a very delicate, fine boned person and everybody noticed she was thin. . and a little boy from the local school offered her some sweets in a jar, . he didn't want to but his mother said "go on offer the little girl", and April daintily puts her hand in the bowl and grabs every single one of them and then when she tries to get her hand out, her hand wouldn't move because she'd taken too many and finally she forced her hand through and 3 or 4 had dropped back into the bowl and she was very annoyed about it . so she was quite a character in a way.

DJ: Were you worried about her?

JD: No, no (5). she definitely seemed different. She was an entirely self-centred person, she wasn't nasty, she was kind-hearted person, she was very self-centred though and she had some rather, strange ideas about the world and she was very attached to me. Her mother died as you possibly know, you know the background, her mother died when she was three. She didn't show any emotion at the time although her younger brother sixteen months younger actually did, she didn't show any feelings, she even made fun of him- 'Cor look at him crying like a baby' she thought it was rather odd. She had quite a strong streak in her .

Similarly, with hindsight, although Molly Quinn perceives her sister Christine's difficulties as having much earlier roots (2), it was later at age 18 (1), when "it manifested itself" (3):

DJ: So . when did things start going wrong with Christine?

MQ: In her late teens. When she was about 18 (1), but she was a twin and they were a boy and a girl and she was the . .they were total opposites, her brother,

my brother was very extrovert, very outgoing and she was very introverted. And there was always something, we felt, amiss with her (2) - couldn't quite put your finger on it but she was always a very tense child, very withdrawn. And then it manifested (3) itself in her late teens when my parents divorced, and she had to go and live on her own and that was really very sad for her but then it was . . then she started doing nursing at the [teaching hospital] then she had her first breakdown there. That was the start of it all really. What really happened 'though before that . . you're so far down the line thinking - she's a difficult child, she's this, she's that . A lot of relationships have broken down by the time you realise that she is ill, mentally ill. You don't really realise at the beginning, you just think that she is a difficult person.

Molly can reflect on the difficulty of telling apart what is a manifestation of illness from what is really the (difficult) person. It is still clear, however, that a distinction is being made between her sister and the illness that is seen as having affected her.

Perception Of Gradual Deterioration.

Penny O'Reilly is more equivocal about remembering abrupt change. It is a gradual deterioration she remembers in her brother (1). She describes having had difficulty in distinguishing her brother's personality from manifestations of illness (which is associated with psychiatric diagnosis). This process is complicated by knowledge of another brother's psychiatric diagnosis. However it still plain that a distinction is being made between her brothers' selves, what they are as people, and the illnesses that have been imposed upon them. Like everyone else interviewed, Penny saw what had occurred as distinctive change (although not precisely located in time), which represents a discontinuity which could only be understood as an illness (2):

DJ: Were you around when things began to go wrong?

PO: Um . yes it wasn't something that you could actually put a definite- one minute he was well and then he was ill- it was a gradual deterioration (1) and if you had known Andrew it would be hard to distinguish that he was actually becoming mentally ill. Because he'd always travelled a bit and was always a bit wild, adventurous, whatever, so when he started to talk about certain incidents . I don't

know how I felt, you know, you took them with a pinch of salt or I felt . I tried to just . What I must also add is that I have an older brother older than Andrew who's schizophrenic . I have an older brother. I have two schizophrenic brothers. It wasn't quite the same, so when Andrew started saying particular things you wanted to say to yourself "Oh Christ this is not possible, he's not going to be ill as well". But it was a different type of illness although they are both schizophrenic. . With Andrew it was much more gradual, [edit]. And things became so apparent- you know- walking around in the middle of the night, knocking on the door saying he was hearing voices and people are coming, voices are coming into the flat and things obviously at that stage you knew that he was ill (2), but prior to that even though his behaviour was a little erratic. I suppose I made allowances because I knew what his personality was like- he was a really happy-go-lucky sort of a person- off visiting all over the world etc. You couldn't tie him down I thought 'Well this is just part of his personality'. But as his illness deteriorated it became more obvious . you know the walking about and the nonsensical conversations, things that he was hearing and that happened to him. Whereas my elder brother never had those type of symptoms . .

Mrs Land began her story later on in her son's life. The starting point is his indulgence in drug taking. However, Mrs Land's narrative was not one involving specific significant events, but was a more protracted account of gradual deterioration. Nevertheless, the difficulties seem to be unproblematically seen in medical terms. So even when the process is seen as being a gradual one there is still a clear distinction being made between the person and "the sickness".

SUMMARY.

Illness Objectified.

An analysis of the interview openings reveals a definite consensus that some thing had happened to their relative. There is perceived to be a very definite rupture with past behaviour. There is some variance in the reported abruptness of this rupture. To some it was a very specific event marked by some overt change in behaviour such as aggression, or a very public display of peculiar behaviour. Other interviewees report

a more gradual realisation that things were changing, or perception of gradual deterioration. Although some interviewees did say that they thought that the person who had become ill had always been different, perhaps a little odd, there was still a perception that there was an alteration that was temporally well located.

An essential component of these interviewee's constructions is that there has been an event of illness, it is an 'it' - an object. It has either emerged from within them, or has been inflicted on them from the outside world. The details of how this has come about will be discussed in the following chapters. The important point to note is that the "it" is seen as being separate from the true self of the relative. It may be covering up, or it may have usurped this true self.

Medical Model.

Examination of these retrospective reports clearly shows that alongside the perception of something happening to change their relative there was an apparently automatic and easy decision that this was a medical problem.

In many ways the relatives' construction of what has happened is consistent with the professional/psychiatric picture of illness. An important question that this finding raises is therefore: can the constructions that these relatives apply to these events be argued to be supplied by psychiatry?

It is not possible to answer this question with great certainty. Clearly it can be argued that common folklore has been influenced by psychiatric folklore. Perelberg (1983) observed the families she studied as taking a medical model, and talked of the introjection of the medical view. However it is noteworthy, as the extracts above reveal, how rarely actual diagnoses were spontaneously referred to. I would often specifically prompt later on in the interviews about knowledge about diagnosis. It is the reactions to these specific prompts, and to other reflections on the categories of official psychiatry, that will be examined next. I will be arguing that there is something very important being revealed by these interviewees' comments about their

relationship to psychiatry.

Diminishment.

Not surprisingly, though still worth mentioning because it has great implications for the emotional impact on relatives, is the fact that the change that had occurred was always seen in negative terms, as a diminishment. Where positive aspects of people's personalities were seen to exist, this was *in spite* of illness. There were two partial exceptions. Mr Doors did see within his daughter a certain heightened awareness of the 'spiritual' nature of life that was associated with her illness. Jean Karajac also associated his sister's illness with her being very perceptive. However, instances of positive elements being associated with the illness were very rare.

Through the 'it' some people are seen as having become different people. Others are seen as being afflicted by an illness on top of what they are, others as having times when they are ill and times when they are not. A great deal of the rest of this thesis will be examining how relatives cope with this discontinuity.

ii) The Relationship To Psychiatry And Psychiatric Knowledge.

Critics working in the tradition of 'anti-psychiatry' (most famously Szasz in America, Laing in Britain) would suggest that the meaning (the use of the illness model) that these relatives apply springs from psychiatric hegemony. However, is it possible to characterise the relationship that these relatives have with psychiatry and psychiatric knowledge? Was there evidence that these relatives were importing meaning from psychiatry? I became particularly interested in whether people did have explicit psychiatric knowledge: in terms of diagnosis, or aetiological theories.

The first noteworthy point of evidence is that diagnoses were rarely spontaneously mentioned. It did not seem as though the formal diagnosis was considered to be

particularly meaningful.

Mr and Mrs Rivers were an example of people who seemed to have extremely little formal knowledge. Their daughter was diagnosed as suffering from schizophrenia, and was clearly quite 'disturbed', when I met her. They were apparently not getting much information from professionals. They were not aware that their daughter has been diagnosed as suffering from schizophrenia, certainly the word was not mentioned. During the interview, when I asked them what they thought was wrong, they focused on her unusual hand-washing, linking this to sickness, having seen something on television about this (presumably about obsessional hand-washing). Despite having very little psychiatric knowledge, they did not doubt that their daughter was 'sick'.

Words Without Meaning.

It was more usual for people to have been informed of a diagnosis, at some point. This did not, however, usually seem to carry very much meaning. For example, during the interview with Liz Regan and her husband, concerning their views on her sister's illness, no mention was made about any diagnosis until I asked them. It seemed that they had been asking professionals for information, and eventually they have been told it was 'schizophrenia'. However, this does not seem to mean a great deal. I asked what the diagnosis of schizophrenia meant to them, there is a hint that they hold the popular view of schizophrenia as meaning 'split personality' (1), even though their observations of what signalled difficulties were entirely commensurate with psychiatric models: voices from the television and paranoia (2):

LR: It was the first time I'd experienced anything like that. Alright one minute, and then (1) . . .

MR: She'd sit there talking to you, this is where it started from and you'd have the television as it is now she would say "Liz, they're talking about me, they're coming to get me", and that's where it started building up from there. And then you'd go round and see her "Liz the man on the television is after me, they're upstairs" (2)

. . things started coming out.

Some interviewees were very aware and knowledgeable about the psychiatric term that was being employed but still did not actually accord it with a great deal of significance (although not doubting the presence of illness). For example, right at the end of this interview with Fred Bryant I get myself into difficulty bringing up the subject of illness. John had been involved in prostitution a couple of years before. My bringing up of the word 'illness' raises fears about AIDS. This accent on the word illness is striking because otherwise Mr Bryant had quite a medical view of his son's difficulties. To diffuse any problems I introduce the word 'schizophrenia' (which I usually avoid) and what is noticeable is that Mr Bryant is very familiar with it, even quite knowledgeable about the term. The reason for him not mentioning it before appears to be that it is simply a term which he accords with little meaning; it is just a name, a handle (1) for which he had little use. He also seemed to question the categorical nature of the diagnosis in defining madness (2):

DJ: Have they talked about John having an illness?

FB: Who?

DJ: People at the hospital . .

FB: Talked about John having an illness? What do you mean by an illness?

DJ: Well, have they named any illness?

FB: No . I've asked them . Do they think he's got AIDS?

DJ: No an illness like schizophrenia, or . .

FB: Yeah they say he's got schizophrenia. I thought you meant he's got AIDS, I don't know, that would be possible. But I think they have blood tests there . . . But if there's anything they should tell me if there's anything wrong with him But I mean this schizophrenia, I read loads of books, it's just a name in't it? All different psychiatrists have got different opinions about it. What is it? It's just a name, just a handle isn't it (1)? . I mean you think about normal behaviour but most murders are committed by people who are supposed to be alright, aren't they? Not by mental patients, so who's . who's nuts? (2) You look at this bloomin' government, and gor' blimey and the people that elected them again I mean they are all nuts to have voted them in again. It's absolutely diabolical. Unbelievable that they got in again. If I'd have been Kinnock I'd have hung myself. . . But there we are.

Popular Understandings.

Some interviewees, whilst apparently accepting the psychiatric label, actually seem to have accepted the popular definition of schizophrenia as 'split personality' (1). The Cook family seem to hold this popular view but they are puzzled and express dissatisfaction with the level of communication (2) and the degree of understanding which professionals have of them (3):

JC: I think the diagnosis is . er schizophrenia .

MrsC: We got this letter from the social worker with his life story.

JohnC: That must have been sparse, they don't know much.

MrsC: Well a history .

JohnC: They said 'schizophrenia' but there was no explanation of what schizophrenia meant in his individual case . . . I know it's supposed to be split personality (1), a sort of Jekyll and Hyde thing, but what does that mean (2), what are the personalities he has? They [professionals] have no comprehension of what it is like to be in a family with someone with mental illness (3).

Vicky Reece also sees schizophrenia as meaning 'split-personality', but is equally unsure what that means in her sister's case (2). She has done her own reading (3) and has understood that there is some connection with hereditary (4), this does not, however, make that much sense (5), she also appears to have picked up something about childhood deprivation, but that makes little sense to her either (6):-

DJ: Did they talk about what sort of illness that Eric or your sister may have?

VR: No they just said Eric might be schizophrenic and Selena was just depression . . [Edit]

DJ: What about with Eric, what did schizophrenia mean to you?

VR: Split personality (1).

DJ: Does that seem to make sense?

VR: Erm . . No not really (2) but when I read up about it (3), lot of people inherit it (4), but er . . I've never seen my mum and dad have a split personality, everyone gets annoyed sometimes (5) . . and I didn't see what caused him to go to that, 'cos he was very spoilt (6), got away with murder. And he was a love child. But with Selena, being the youngest and twins they probably felt a bit left out.

Diane Mason, despite being a qualified nurse working in the health service, also seemed to have the popular understanding of schizophrenia:

DJ: Being medically qualified, what does schizophrenia mean to you?

DM: Well . . . split personality, I mean that would be my one or two word, split personality . . .

The Relationship With Professionals: Poor Communication.

Mary Galton, a woman in her late 20s, seems to get little information from professionals. The word 'schizophrenic' has been mentioned (1), which she seems to associate with a state of being- it "means a person that changes" (2), rather than an illness. This actually appears to contrast with the perception which emerged earlier in the interview, revealed in the previous section (p136), of her sister as having suffered emotional trauma affecting her nerves. The idea of 'schizophrenia', being expressed, here does not seem to necessarily fit with the idea of illness:

MG: What I can't understand is what . . . why does it happen to some people? I can't understand. Like the two of them [both her sisters have been diagnosed as suffering from schizophrenia] had so much going for them.

DJ: Did people talk to you about that?

MG: No . . .

DJ: Not at all?

MG: No.

DJ: Did anyone ever give a name to an illness?

MG: Um . . . not really, they said, I think schizophrenic (1)?

DJ: Mmm, what did that mean to you?

MG: That means a person that changes just like that, but I mean to me, I don't think that they can function in society, as a person, really (2).

DJ: Do you think that fits with Rachael, that she changes?

MG: Yes sometimes, she's very um . . . yes she does, even now she does. . . Cos things that get her down, I think to myself, "For god's sake!", you know . . . why?! How?! I can't understand it, . . .

A little later I probe more about her relationship with professionals; it seems as though she gets barely any information from them. Her knowledge of the meaning of 'schizophrenic' that has emerged might be termed the 'popular' one (split personality: "a person that changes just like that"). She also seems very aware of there being a power differential operating in her relationship with professionals (1). There is not only a paucity of information, but she feels that she is not valued by them (4). Mary Galton's experience suggests that there seems to be no grounds for constructive communication between herself and professionals. Mary feels that she does not use the right terminology, does not know the right questions to ask (2). There might seem to be an issue of class and race here (in that Mary Galton is a young black woman from a working class background) since she was demonstrably thoughtful and obviously capable of understanding psychiatric concepts.

Mary Galton also expresses clear scepticism about the efficacy of the treatment that is offered to her sister (an issue that will be returned to in the next section) (3):

DJ: How did they [professionals] respond to you, how did they treat you?

MG: Well when I did ask questions they just sort of looked at me as if to say- Who the hell am I, to be asking these questions? (1) They tried to be helpful by fobbing me off. That was their way of being helpful. I didn't know the terminology, I don't know it up to this day; you know what to ask, what not to ask (2). I can only ask what I see and they wasn't very helpful. "Come back and speak to the doctor", 'When would the doctor be available?' well such and such, you get there and the doctor's not available. It just seems to be drugs, drugs, drugs all the time (3).

DJ: Do you think they were interested in what you had to say . . as someone who knows Rachael?

MG: No they didn't seem to be. . . No they didn't seem to be interested . (4)

Other people, such as the Peters family and Jean Karajac, with more middle class backgrounds, were equally dissatisfied about how difficult it was to get information from mental health professionals. However, they did have access to other sources of

information. In these cases it was the NSF and SANE respectively.

Mrs Peters and her daughter Carol were interviewed together. Carol describes her brother's sudden admittance to psychiatric hospital from his workplace. In trying to find out what had happened the trauma seemed, certainly with hindsight, to have been exacerbated by professionals who seemed particularly unforthcoming. The anger about this is still there. This extract also portrays their sense of bewilderment and horror:

Carol P: . . . my sister and I were phoning up trying to find out what happened, and they had all been instructed at the company not to tell me and eventually after about 24 hours I got hold of a personnel lady there who I knew, and I said "You have got to tell me, something has happened, I know he's not been well but something has happened I feel it, you've got to tell me". She said look "I'll give you this telephone number and you phone the doctor direct". And what I couldn't believe was his attitude. He . he just . I got on the phone and I said "I'm Donald Peters' sister and I'm ringing on behalf of my family to find out about Donald Peters" and he said "What do you want to find out?". So I said "Well one, where he . . I gather he came to see you, can you tell me what was wrong?" "What do you think was wrong?". So I said "Well I don't know, that's why I'm asking you". So he said "Go on you're a clever girl you tell me what do you think was wrong?" I couldn't believe . I said "Look I'm sorry I really don't know, I suppose maybe he might have had a nervous breakdown or something". He said "That's it, he's loony".

MrsP: No "He's schizophrenic". at least that's what he said to me .

CP : No he didn't, he said to me "He's completely and utterly loony". And I said . he said "Why don't you think you've been told?". I said "I really don't know", he said "Go on tell me",- "Well I suppose the stigma attached to people that are mentally ill" . . I was just flabbergasted sitting on the end of this phone. He said "Yes I sent him down to [general hospital] yesterday morning and that's where he is, under observation, and the family are not allowed to see him until the observation has been done and they've determined what they will do to Donald". I couldn't believe it.

Mrs Peters has now acquired a great deal of knowledge about psychiatric matters (sometimes quoting figures to me on suicide rates, or mentioning innovative schemes that she has heard about, for example). She gets her information from the National Schizophrenia Fellowship (NSF). Her initial contact with the NSF was purely fortuitous (through a friend of a friend), as was Jean Karajac's contact with SANE (Schizophrenia: A National Emergency), described below.

The Peters' efforts to get information from professionals seemed to be fruitless. These people were white, they could probably be described as upper middle class, and they were certainly articulate. In their relations with professionals, however, they clearly felt utterly powerless and frustrated.

When I ask Jean Karajac about his relationship to professionals it becomes clear that it is not they who are the source of the knowledge that he has. Indeed to Jean, professionals far from forcing their view onto him, appear to actively withhold information. This he suggests is an exercise of power (1). Most of his information has come from contacts he made with the organisation SANE (2). His contact with SANE was through informal means³.

DJ: In your contact with professionals, psychiatrists, nurses . how have you felt that they have treated you? What's their attitude been towards you?

JK: . Urm I'd say helpful, not in a practical sense, but they do listen and they do register what you're saying. But as soon as you try and make suggestions or move into their field I come across the feeling that they feel threatened. "There, there just sit there and be a good person and we'll look after the person for you", you know maybe a little bit patronising (1). Because I suppose I understand more of it than quite a few people do . so . . Like I did a psychology course on the Environmental Science degree, so I can pick up things like quite easily. I think maybe it's unintentional but it does come across a little bit that way. Surprisingly SANE, without doubt have been about the most useful, frank source of information . without doubt, by a mile, I've learnt everything I know from SANE (2).

³ There is discussion in Chapter 7 (part iii) of the importance of "Group Solidarity".

Not only is there information available through SANE (1), but there is a sense of him being able to relate to others, finding that he is not alone (2). It is important to note that he still values these communications even when they are being far from optimistic (3, 4):

I just phoned up and said "Can you give us some information", they basically sent loads of literature down, which was very helpful and very supportive (1) . You realise that you're not isolated, you know there are a lot of people going through exactly the same crisis as yourself (2). And you can talk frankly, they basically said "Well the medication that she is on is all there is, but it's not perfect" (3). You know like all the doctors come across saying 'Oh this is the cure, this is it!' That's why they've set up this research centre the first in the world of its kind to research into new drugs, because they realise what they've got now is far from perfect . . . the whole point that annoys me is the medical profession won't recognise that, won't admit that they haven't got any answers (4).

The Use of Knowledge.

Sam Mason from his experiences of considerable contact with professionals concerning his brother has become particularly sceptical about what formal diagnoses are used for. Sam draws attention to the machinations of power that can underlie the use of certain diagnoses. Disputes over diagnosis are construed by him as revolving around the provision of resources (1), in that for the health service to give a diagnosis of schizophrenia would entail accepting medical responsibility. Again there is the strong awareness of a power differential in terms of whose perspective can be accepted. There is no sense of shared understanding being reached with the professionals. He certainly did not feel listened to (2). However humorously he presents some of his frustration in the following extract, there is clearly deep frustration and distress; "torment" (3) is the word he uses. At the end of this passage Sam makes the point that in these circumstances his own resources are being severely stretched (4).

. . . But you don't feel that the society, that the system will really provide anything. Because I don't think they understand it to be honest, to be honest I

don't think they really understand mental illness, because when I'm talking to some of the psychiatrists . they are mad, really! [laughing]. They really are, they are crazy. Because you'll be telling them, you'll be . you'll be the member of the family and you'll be saying "This person is doing this and this person is not doing this, they're not thinking in this way", and they'll be saying- "There's nothing wrong, they've just got a slight behavioural problem!" .or . [laughing] . ..

DJ: Why do you think they said that?

SM: Because they are mad! [laughing] . . . No, I don't know how much society really wants to care for these people, and sometimes I think that they . "Yeh fob them off to the family, let the family deal with them". If they do say there is something wrong then they may feel that they have to do something about it and that may cost time and money, or whatever (1). And the system is not geared for that, the system is not really geared for that, so the professional people do say . . his doctor, his doctor said he had "a slight behavioral problem" and this is after years of going in and out of hospital, after years of that doctor seeing him and giving that diagnosis that he was schizophrenic . . he's going it wasn't a behavioural problem then he said something like "he's extrovert" [laughing], this is before the last admission into hospital! So I'm led to the conclusion that they are crazy, they're absolutely crazy!

DJ: But other times they talk about schizophrenia, at other times?

SM: Yeah, but what happens is then we're sort of saying "He's at the stage, you must see him, you must do something". And they'll see him and they'll say "Oh he's an extrovert, just showing extrovert behaviour", but that's it. "I don't think we've got enough grounds to put him into the hospital, because he hasn't done anything". He has to do something, you know, or there has to be the potential for him to do something before they say: "This is the time". He's got to be abusive to my mother, threatening or hit . . or something like that, or if he's abusive to one of the workers at the centre, well, that might be alright because they're in the system they can get something done quicker. But we can be saying for months that something is going to happen (2), you know he's on a knife's edge; something's going to happen. But then he'll be at the doctor and the doctor will say "Oh he's alright . . not quite alright but almost alright . ." . It's sad it really is, cos I'd say for the family it is a lot of torment (3), you know to see someone of your family in a

position with him, him going down . you can't talk to him there's no logical conversation to be had and you are at your wits end to find a way 'round the problem the professionals aren't helping they're like saying "Can't see the urgency of it", you don't know what to do, .. OK you talk to him you try and encourage him, you go off and you'll do things for him . you'll say "Give us that . er amount of money and I'll pay that bill for you", or whatever. Or you'll get in touch, like I say, I've been in touch with this housing association and I say "Look that's leaking or this needs doing", all this sort of thing. But there is only a limited amount that you can do, because if you've done eight hours work you've got your bills, you've got your mortgage you can't then go and spend four hours of your spare time monitoring someone else (4).

Sam's sister, in an earlier interview, had raised the issue of ethnicity and alluded to her feeling of estrangement from professionals. From her observations, made whilst working in a general hospital with an attached psychiatric unit, she comments on the unrepresentatively high proportion of young black men in psychiatric wards. She wondered if this was something to do with professionals' tendency to too easily dismiss apparently aberrant behaviour from young black people as 'cultural'. They were therefore less likely to get help. This prompted me to raise the issue with Sam. I wondered if he too perhaps felt that ethnicity contributed to his feeling of alienation. Sam felt that the most salient problem is society's attitudes towards mental illness. He is aware of there being a class issue as well, with MIND being perceived as being for middle class white people.

Ultimately, however, it is important to note that despite his reservations about professionals and their diagnostic categories, Sam sees the diagnosis of schizophrenia as meaningful in that his understanding of the term accords with his observations of his brother (again Sam makes recourse to the notion of split personality (1)):-

DJ: I know you say you don't KNOW, but how would you diagnose what has happened to Charlie, do you see him as suffering from an illness?

SM: Oh definitely, definitely I mean they've said "schizophrenia" and that would . from what I understand of it would seem to be the illness. Because he does at

times behave rationally, he's still able to survive even when he's not well.

DJ: So what does schizophrenia mean to you?

SM: Well to me, as an ignorant person of mental terms, [it] is someone who behaves . who has got a split personality (1). And there is a time when you'll be talking to him and he's totally rational, and there is a time when you'll be talking to him when he'll be taking on board what you're saying. He'll sort of say 'OK yeah'. But it seems that when the pressure gets to him, you know he's OK with light situations he can cope with that, but it seems that when the pressure is there he reverts to this irrational sort of person . .and he doesn't realise the realities of life, he doesn't conform to anything that needs to be done - Because they're not important- he sort of hides himself in this irrational behaviour and reasoning . That's what it means to me and that's why it seems to fit.

Community Psychiatry - Opening Up Communication?

In this Health Authority, at the time of the interviews, there was a limited innovation of employing a Community Psychiatrist who would look after people with long-term problems living in the community. This did seem to involve more of a reaching out to relatives, including visits from the Consultant to discuss the situation. Two interviewees did seem to be getting more information from this newly developing system.

Elly Blacksmith felt pleased with the service that she and her son were given, receiving visits herself from the Community Psychiatry team. She appeared well aware of the contrast between the care her son and she had been receiving under the old regime and the new service under Community Psychiatry. This family's situation is described in more detail in Chapter 9 (page 280).

Mrs Karajac is another mother who describes a contrast in the way the Community Psychiatry system seemed to treat her compared with the hospital regime. Under the former arrangement there seemed to be very little communication between herself and professionals occurring, beyond the expression of mutual antipathy. She had, for

example, not been told of a diagnosis. This hiatus was perceived by her as being due to a view of her held by the professionals as being at least in part to blame. Mrs Karajac, in her turn, partly blamed the hospital's lack of interest in her daughter as being responsible for a suicide attempt. She felt that she has particular knowledge of her daughter (she has learnt to recognise when her daughter's mood might be fragile) which is ignored by professionals. In the following passage Mrs Karajac recalls being given information by a friendly family doctor some years before. What is interesting is that although this is rather gloomy (1), it is ultimately still welcome, since it accords with her experience:

. . the GP before died he told, he said "It's very confidential I will tell you one thing that I knew"- I don't know if it was from the University Hospital, or from the first doctor, that there is something in her mind that is not properly . . that's what he told me. That it goes round but when it comes to that part, then it gets worse. Sometimes she can be beautiful everything goes perfect and then all of a sudden pupff! and it goes back. Then he said to me that it is possible that it would get better, better and better or that it will get worse and each time she will get worse and worse and worse until there won't be nothing to be done about it, that's what he told me, and it is true. And it has come to that point when now is nothing- whatever you do, whatever medication you give her, whatever, there is nothing, she keeps on getting worse (1). .

Mrs Karajac goes on to discuss the Community Psychiatrist who has been visiting recently and has been more forthcoming. She now knows from him that her daughter has the diagnosis of schizophrenia. He has tried to explain something of what her daughter experiences (1) and has given advice about how her daughter may not like noise (2) and bright light (3). Whilst this is appreciated there were other things said in language that she did not understand (4). Mrs Karajac then explains that the doctor has not been at all optimistic about her daughter (5), whilst this was upsetting (6) again it does seem to fit with her experience (7):-

DJ: You said before that Dr B. has talked about schizophrenia has he said much about that, what it might mean?

MK: He told us that they have to have the medication because they hear voices and they listen to these voices .(1) . [edit] . . He also said that they can't stand noise (2), that is true she can't stand it. As well they don't like the light (3), I didn't know that . that's why she keeps her room dark, I couldn't understand it why she kept her curtains shut, but that affects them a lot, noise and light . Now I understand I never ask her any more . Now I realise why. Then he said once she had three other things . but I didn't understand the words he used (4) and I didn't like to stop him and ask I just couldn't! But there were two or three others he was saying about that he found out from the notes he took. . He said that the medicine would not make her better (5) but just make her sort of more quiet . .

DJ: That's what Dr B. said?

MK: Yes make her more quiet.

DJ: How did you feel about him saying that?

MK: I was not happy at all (6), but you have to take it that's a fact. We had come to the conclusion that it is true because the more we go on the more we realise that it isn't getting better it's getting worse (7).

It is clear that value is attached to these exchanges with the Community Psychiatrist. This is in spite of the fact that the Psychiatrist is not apparently being at all optimistic about her daughter's condition. Through these exchanges and the sharing of knowledge Mrs Karajac and the psychiatrist seem to be developing a common understanding of events.

iii) Beliefs about Treatment.

When considering the interpretation of events and the psychiatric knowledge that they have demonstrated it is possible to understand that these interviewees see their relatives as suffering from an illness. They do not, however, necessarily construe that illness in formal psychiatric terms. In fact, there seems to be rather an ambivalent relationship between themselves and professionals. Certainly, communication appears poor. It is also possible to explore in a little more detail the relationship these

relatives have with the institutions of the psy-complex (Ramon 1985) through their attitude to the forms of treatment that are made available to their ill family members.

These relatives' beliefs about psychiatric treatment are fairly easy to summarise: they are marked by ambivalence. There is a clear perception that the main treatment that is offered is drug treatment. Whilst, on the one hand, it was usually believed that medication was essential to avoid further deterioration or breakdown, on the other hand, there was scepticism about the efficacy of the medication. No one saw the medication as representing any kind of cure. There was also concern about the side-effects.

Similarly, there was frequently expressed ambivalence about the efficacy of psychiatric hospitals. Friern Hospital, particularly, was often seen as being an unpleasant environment, but was also seen as a port in the storm, where what little help that was available was accessible.

Some people wished there was more exploration of 'talking cures', or that the whole situation of their relatives needed to be addressed in a manner that had not been happening.

Medication.

Molly Quinn is quite typical here of someone who is not overtly hostile to the mental health professionals. She is, however, quite sceptical about what power they have to help her sister, and contrast is made with physical medicine (1):

DJ: Have you found that hospital staff and doctors have talked to you about what's going on?

MQ: Well not in great detail, no, not at all in fact . only what I've asked.

DJ: Have they been helpful when you've asked?

MQ: Yes they have been but you see it's, I suppose at any level of mental illness it's really experimenting, not experimenting but trying to stabilise each patient and it's a case of trying out different things, isn't it? So . it comes back to the old story, if you've got a broken leg people know exactly what to do, but with mental illness even the doctors sometimes are trying this, try that, sometimes aren't they?
(1)

Molly Quinn described with concern some serious side-effects which her sister has suffered from at one point. Nevertheless, when I ask her whether she thought the medication was helpful:

MQ: . . Without, it . . it seems to be the only thing that stabilises her, I don't know whether she would stabilise without it in time, I don't know. I just don't know. I think that she does need something to keep her fairly normal, because when she refuses to take something she goes completely . er . . well withdrawn, out of this world, I think, I don't know.

Similarly Diane Mason in this notable exchange (her mother MM is also present) explains that she values the medication in that it does control her brother Charlie in a way that enables him to play a part in family life. It enables him to fulfil a reasonably normal role as father when his estranged children visit. Without medication Charlie is considered too destructive which worries Diane particularly as she herself has a young child.

DJ: Do you think the medication is a big help?

DM: It's something he requires . . .

MM: Calms him down

DM: All the time, or even I mean it's something he needs at first and if he's on it all the time it should keep him on an even keel, so that he can fit in . you know like his children were down for Easter, even though he sort of didn't go round, take them out they were down and . I think he felt . .

MM: Oh yeah he was playing cards with them and things like that, don't talk a lot.

DM: The kids look forward, because what are they 15 now? They sort of came down to see their dad, that helps him a bit. Basically what it is, I mean he's lonely in the flat, . . . when he gets a bit aggressive, we can tolerate him for so long but then it is stressful for us to have him all the time if he is going to behave in a way that is not acceptable. . . I mean that upsets our lives as well, I've got a son, you can't have him swearing 'round him whatever. So we can only tolerate so much, if he's on medication, he's more acceptable he's more likely to be included in what we are doing. If he's not on medication then you know unfortunately he's not, he's not acceptable, his behaviour is not acceptable to us.

The Cooks were quite hostile to the professional services, feeling that they had particularly failed to understand their experiences as a black family. They saw them as having let their son down, and their view of medication fits in with this. When I ask about medication his mother tells me "Oh yes, the injections and the manner they have been given have not been satisfying at all, they just put him to sleep at night". The father then asks me if I heard the story that had recently been publicised about a black man in Broadmoor being killed by being given too large an injection. It is pointed out, with significance, that Arthur too has been forced to accept injections. Arthur's younger brother John expressed his opinion on medication when I asked the family whether they saw Arthur as ever getting better, becoming the person he had been. "No", John replied "for two reasons firstly, the length of time it's been now and secondly the amount of drugs he had will have a long-term effect."⁴

Jean Karajac describes an awareness of contradictory benefits of the medication that his sister receives. It is, again, interesting to note that his information comes not from professionals but from SANE:

DJ: Do you see the medication as being a big help?

JK: Well . . . if it weren't for SANE I know, basically the medication all it is is a hyped

⁴ This interview was not recorded, the father was initially particularly suspicious of my presence.

up tranquilliser. All it does is get rid of the voices, but on the other hand it removes the exhilaration - where she feels special for hearing voices and so on. Which is understandable, it's the only excitement in her life if you like. And then it brings the real depression forward into reality . . . the depression that is always with her but if you like is pushed below by other things going on in her life, in her mind. So the thing is the depression will hit her, I think it's beginning to, as the voices subside with the medication . but you need something to be substituted, you need to be motivated and coached in some way, otherwise the depression will take over and then in her mind it has been for quite some time, medication is associated . strong association with depression. Why should she be motivated to take medication?

To an extent, of course, the observations about medication might be said to merely reflect the reality of this group's circumstances. I have deliberately set out to talk to relatives of a group who are seen as having long-term difficulties, who by definition have not been 'cured'. Even amongst those who saw medication as being a great help, concern was still often expressed about the side-effects of the drugs.

Views About Hospital.

Jean Karajac's sister had just been admitted to an acute psychiatric ward in a general hospital. He was clearly sceptical about the value of hospital care (here he is not referring to Friern) as being anything other than a short term measure.

JK: Already it looks like she'll sit there for 28 days, and she's complaining herself, I went to see her last night, she's finally calmed down, she's been in for 5 days, she's on medication. OK she wanders off into the delusions and the voices . . . intermittently between that she'll say "What's the point of me being here? All I do is sit there? They don't make do anything." And you understand the fact that they are short-staffed and so on . but what is the point of going into hospital? It's going to be the same old cycle.

Fred Bryant referred to Friern as appearing "like something out of a horror movie" when he first saw it. He very forcefully expressed his antipathy toward Friern, focusing particularly on the apparent lack of contact that his son has with staff. Nevertheless, he does feel great conflict in that he also acknowledged that he has been

grateful to be able to turn to Friern as a place where he can get some refuge by them taking his son. Fred Bryant considers the hospital likely to have plenty of potential customers in the future with the economic recession:

the effects of what's happening to a lot of people now could mean mental breakdown either now or next year . So I say in ten years, Friern will be really needed, you know it should be . . I don't think it's working putting them back into the community, all these have to go back or they jump in front of tube trains which two of them have to my knowledge I don't know how many commit suicide, I don't know.

One quite common criticism of the hospital was that patients were just allowed to come and go as they pleased. The implication being that one thing the hospital could provide was custodial care. Typical were Mr and Mrs Regan who told several stories about how Mrs Regan's sister had wandered off the ward with few clothes, even in very cold weather. Or she had gone home and simply neglected herself. They very clearly wanted the hospital to take care, and custody of Cathy.

Summary: The Relationship with Psychiatry.

In summary, it does not seem as though psychiatry and the allied professions are directly forcing a medicalised view onto the families. In fact what emerges is a curious story in which the majority of relatives interviewed felt that professionals were very reluctant to share psychiatric information, or any other kind of information with them. Where people did seem to have considerable psychiatric knowledge they had usually obtained it elsewhere: from their own reading, from friends or groups such as the NSF or SANE. A picture that emerges is one where people are asking, even begging, for information which professionals, from the point of view of these interviewees, seem to withhold.

Sam Mason (p154-157, this chapter) seems to clearly perceive that the illness model not only provides meaning to him, but it provides instrumental meaning: if professionals recognise the medical nature of his brother's difficulties then they have

to shoulder more of the responsibility (the state taking responsibility for medical problems). Thus one explanation as to the existence of the antipathy between these interviewees and the professionals they have contact with is suggested here by Sam Mason's insight into the power struggle involved in the construction of his brother's difficulties. Power and knowledge are joined together in the construction of these people's mental health problems (Foucault 1967 1977). There is thus conflict in disputes over the communication and sharing of information.

The paltry level of information coming from psychiatrists and other professionals does suggest that these interviewees are not having a psychiatric model imposed upon them. What I want to argue is that these sections reveal that psychiatric models of mental illness perhaps have the same common roots in our culture as the 'lay beliefs' of these relatives. To understand attitudes toward people with mental health problems we would need to look beyond the models provided by professionals. These relatives do not seem to be simply adopting 'professional' models. Some support for this view comes from Nancy Tomes (1994) who studied families' communications with the staff of the Pennsylvania Asylum in the last century. She observed that "regardless of their varying levels of sophistication, the patrons [families] all employed the same basic language of disease: Individuals were spoken of as 'sick' or 'unwell'." (p92). Tomes argues that the Asylums were constructed through the active cooperation of medical staff and the patrons (that is families who were unable to cope). It would seem from examination of these interviews that these late 20th century families see their relatives' difficulties in straightforward terms of illness. Cooperation, however, is not a word that they would generally use about their relationships with mental health professionals.

The Professional View Of The Families: Case Note Material.

Clearly a better understanding of the communication difficulties that seem to exist between the families and professionals would be reached if the professionals' point of view could also be assessed. Unfortunately, the time and resource limitations of the study did not allow for interviews with professionals which no doubt would have

been very illuminating.

One window I did have onto the professionals' attitudes towards these families were the psychiatric notes of the identified patients. In examining these notes I was interested in analysing the terms that were used to talk about the relatives. I initially envisaged that this would be quite a significant part of the study. However what I found was that families were actually rarely mentioned at all, there was certainly very little impression of the family members existing as whole people to be gained through the psychiatric notes. I was struck by the contrast of this impression, with that of Michael MacDonald who in analysing the notebooks of the 17th century medic and astrologer Richard Napier, and the medical texts of Robert Burton, observes:

In both instances, the reader can detect many different voices, modulated at the writers pleasure, not a single voice, expressing only the author's personal opinion. Indeed it is occasionally difficult to separate the attitudes of Burton and Napier from those of their sources. (p113)

What is striking in reading the psychiatric notes of this study group is that the voices of the patients, their families or anyone else could not be heard. In fact you only really hear one voice- that of "psychiatry". It is probably fair to say that you rarely hear the voice of the psychiatrist even. Christine Perring (1990) drew attention to the lack of voice of the service user within the case notes she studied. It is also clear here that the voice of the families is not discernible either. There was often barely mention of the relatives made particularly if, as in the majority of cases, the person did not live with family. I would often make contact through a 'next of kin' address filled in for administrative purposes, or in one case there was no mention of parents made (Cook) but I made contact with them as the father had signed a Mental Health Act Section form some years previously.

Where the patient had been living at home, there was usually more mention made, but this was often derogatory. This is an example from a psychiatric report on someone whose family I was not able to make contact with. They were never in when I suggested times to visit, and they did not respond to any letters. Perhaps the tone

of this offers some clue as to their reluctance to talking to me, they may have had reason to feel badly treated:-

Psychiatric Report 1986: "His mother attempted to give me some information about him but I found that she herself is not too bright. I spoke to his eldest brother, who also did not make a great deal of an impression on me. It seems to me that virtually all the family members appear to be somewhat of low average intelligence."

Mrs Karajac felt blamed by hospital staff for her daughter's difficulties. The following extract of report written following psychiatric assessment (at a family therapy orientated unit) soon after Janice's difficulties were first noticed, suggests that she might have been justified in her feelings. The research models of mental illness discussed in chapter 2 are most definitely being influential here. There is reference to communication difficulties (1), the 'enmeshment' of the family is alluded to (2), and the "grossly abnormal pattern of relationships" (4), all of which are apparently "literally driving this girl mad" (3):-

"It became clear that the relationships within the family were extremely disturbed. In particular, there was a considerable conflict between father and mother, with little communication (1) and consequent unhappiness in all family members. The oldest child Jean, seemed to be used as a medium of communication for all family members, [edit]. We saw no evidence of psychotic disturbance in Janice. She did not appear to be hallucinating, nor did she mention such phenomena to other family members. There were no ideas of reference, delusions or thought disorder. We felt that she was suffering from an emotional disorder specific to adolescence and that her symptoms had a strong affective component, but also represented the manifestation of her struggle to psychologically detach herself from this family, as well as this family's resistance to this process. (2). . Although I do not wholly subscribe to the Laingian view of the psychogenesis of schizophrenic disorders, it did appear to us that this family was, literally, driving this girl mad (3). I understand when admitted to [a] Hospital she was exhibiting frankly psychotic symptoms. I believe that there will be considerable difficulties in her rehabilitation if she returns to the family with no attempt being made to rectify the grossly abnormal pattern of relationships.(4)"

Petra Gyradogc had also been living with her family, so there was more mention of them. This comes from a social work report in 1988:

"However, it is also felt likely that a permanent return to her family is not likely to avoid another major psychiatric breakdown in the near future. The feeling amongst nursing and medical staff is that Petra's emotional and personality problems are rooted in the diagnosis of her family. Whether her family can be worked with seems doubtful. Alternatively it may be that Petra would benefit from a careful separation from her family and an opportunity to grow and develop in another setting, eg a hostel. This will also be problematic because Petra is very keen to return to her family."

There is little description of the family, certainly not of their point of view. Indeed there seems to be little consideration of Petra's point of view. In spite of the recognition that she was keen to return to her family, she is a case whose problems are seen as being rooted in the "diagnosis of her family".

Other references to the families tended to be more banal, but it was still clear that they were being seen as part of a psychiatric construction. In one the psychiatric construction was the contemporary one of Expressed Emotion eg: Terry Blacksmith, psychiatric notes 19/12/90: "Mother High EE."

Other references were more in passing. For example from Charlie Mason's notes 20/12/92: "Because of family concern about his threatening manner we had a no. of family meetings but too late to establish their involvement in a care plan before compulsory admission became necessary . . ."

By contrast this report about Roberto Gazza was prepared in February 1982, following assessment at "The Italian Hospital. Queens Square". The contrast in tone between this and the other psychiatric reports is very strong. Perhaps this suggests some difference between Continental and Anglo-Saxon psychiatry.

"At the time of Mr Gazza's illness [Roberto's father became terminally ill] which he

died of in 1974] was diagnosed as terminal, Roberto obviously very distressed and disbelieving the doctors word, began developing defensive projective thought processes, almost exclusively focused on and against his mother, whom he accused of having caused of having caused her husbands illness by her criminal behaviour Throughout the interview I had with Roberto's mother on her own firstly, then with her and her daughter, I found her composed and dignified in her great sorrow. She only cried, and even then slightly when, to her direct question, I answered that I thought it improbable Roberto would ever become again the boy he was before the breakdown."

CHAPTER 6.

The Causes of Mental Illness.

"Sickness Made for Anyone."

This chapter explores in detail the theories that people held about the causes of their relatives' difficulties. The question of what explanations relatives had for the cause of the illness was something I was explicitly interested in, if the issue did not arise naturally in the course of conversation I would ask about it.

These relatives generally took a very eclectic view. Various theories would be referred to by the same person. An important feature of this style of interviewing is that it allows apparently contradictory ideas to emerge from subjects.

This chapter is written with the aim of looking beneath the eclecticism, to look behind the ideas that people give voice to, in order to chart the forces that are shaping those ideas.

1) Attached to the theories of cause there was often an immanent concern with moral responsibility. It becomes clear that people are very aware that theories of mental illness carry moral implications. The ill person was rarely seen as being responsible for their condition, but other people would often be accused.

2) It will be argued that the ways that people talked about cause were also being influenced by their own often unacknowledged feelings of aggression, guilt and shame. The ideas that people have cannot be separated from their emotions. That the methodology adopted in this study has allowed these points to be addressed, needs to be noted. I will be arguing that it is sometimes in the gaps, or in the seeming failure of dialogue during the interview itself, that something is being communicated.

3) One particularly interesting hypothesis of the cause, and one that perhaps did depart most from official explanations was that of a "broken heart". This leads to

consideration of the perception of, and importance attributed to, sexuality in the definition of normality.

The priority given to sexuality, which emerges alongside the influence of guilt, shame and aggression within theories of cause points to the importance of the analysis of the emotional nature of the interviewees' perceptions of, and their attachments to, their relatives.

Eclecticism.

Most people showed elements of a definitely eclectic approach to finding meaning. Kate Daley was perhaps an extreme example of that eclecticism. Her story is complicated by the fact that she has two sisters who have both had mental health problems. Her attitude to the two sisters provides useful contrast. Maeve, whom the interview was not primarily about, is seen as having severe problems under the label of manic depressive illness. Her other sister, Monica, is seen as having more amorphous difficulties. That the concern with finding a theory of cause is to do with a search for meaning is made clear in the questions that Kate voices (1). Here early on in the interview she describes seeing Monica's problems as being to do with drinking but wonders whether this might be connected to her early experience (2). Kate's rumination on the root of her sister Monica's problems leads her to highlight the limits of her own sense of responsibility (3), in that she does not "want to take her by the hand". There follows some justification for this stance in terms of her sister's own responsibility for her difficulties; "she doesn't want to work, she wants to drink" (4):

. . . I went to the psychiatrist at first because I was shocked, I said "What's happening?" and she just said "Maybe you can tell me". . So . why does somebody drink? You know, why does somebody not drink in the family? Why is somebody self-destructive? .(1) . you know you can see somebody in a predicament in another family survives better than the others . I mean I'm sure, she was the youngest of eight, you can go right back in to . I'm sure this is where problems start (2). I think she needs therapy, but I don't want to take her by the

hand (3). I have gone with her to an evening session where she talked with a counsellor but she thinks she's pulling the wool over their eyes. She thinks she's . it's them, they are concerned for her helping herself but she's got a strange attitude . she doesn't want to work, she wants to drink (4). She made herself, . I mean she must be sick to go to that extreme I realise, she made herself unemployable she's made herself . she's made sure she's got housing . you know she's pulled all the strings. You know she's got her one bedroom flat now. She, as I say, she lost all good will with the people that she lives with. I feel angry more than anything . I feel sorry for her but I've gone past that stage, really.

This was the only interview where blame seemed to be being overtly applied to the ill person (even in this case it was highly equivocal). In fact, according to Monica's medical notes, the psychiatrists have been very vague about diagnosis. She had once been diagnosed as suffering from schizophrenia (and so qualified for the sample) but since then had been variously described as 'alcoholic' or 'personality disordered'. It is interesting that the equivocation of the psychiatrists is mirrored by Kate Daley herself. It became clear in the previous chapter that relatives do not need psychiatric sanctioning to be convinced of the presence of illness. The similarity of view here does imply that professional diagnosis has much in common with 'lay' categories. Kate Daley makes great distinction between Monica and her other sister which is made plainer later in the interview. Maeve is seen as suffering from a definite mental illness. Monica's difficulties, although she is seen as having been psychotic (1), do not have the same status as "mental illness". Kate feels that they were induced by "dope and drink" (2) and that the problem is more of 'emotional weakness'(3). The implied lack of conviction in the specificity of the diagnostic categories (already discussed in the previous chapter) can also be noted (4):

KH: Oh I think she [Monica] freaked out, she had a psychotic breakdown (1) but it wasn't induced by her mental state it was induced by dope and drink (2). And I think they've done tests on her and they haven't found any schizophrenia or mental illness as such it's emotional weakness (3) I guess it is like that in the family, we're not a strong emotional family I mean there is illness of schizophrenia in our family . my elder sister, well . . 'manic depressive' I think they termed it as (4). But she does have to have medication all the time. .

Kate still goes on to wonder about the role of early experience in both her sisters' difficulties, which raises the issue of her own feeling of responsibility, as older sister. There seems to be some guilt at having left home, their mother having died and Monica being left at home at a "vulnerable age" (1):

. . . but er . . . yes I mean my mum died when Monica was 14 so she was that vulnerable age (1) and we were all adult and left home really- I'd left home. My sister, eldest sister, hadn't left home, but she did leave home, so Monica was left with my dad and my brother. And she always felt that she had to look after them and she hated us all . . . so yeah I'm sure it was a really stressful time for her and she never worked through that probably, you know. But . . . I'm sure this is part of the problem . . .

My pursuit of the distinction that Kate appears to make between her two sisters' difficulties leads to further elaboration and rumination. Maeve is seen as being more definitely ill, as she became more frankly out of this world (1). This does not rule out an "emotional" cause (2), but it may be more of "a personality thing" (3) which seems to be seen as something of a fixed characteristic, perhaps associated with genetics. The rumination on the cause is again associated with responsibility, there are some apparently guilty memories of not interfering with family fights (4). There is also a separate suggestion that drug use may have been a factor (5).

DJ: Do you think it's different from your older sister then, do you think she had more of an illness that needs to be treated?

KH: Who my older sister?

DJ: Yeah Maeve.

KH: Maeve . . . definitely was an illness with her . . . because she wouldn't be in this world sometimes, (1) . . . yes she'd go . . . she'd lose all sense of reality I think it is different. I'm trying to think of it in the early stages, you know . . . how it was . . . just very intelligent, highly strung - 14 taking an overdose, that's the first sort of strange thing that happened you know . . . But er . . . she used to clash a lot with my dad . . . so maybe it's emotional due to that because then there'd be violent rows

and she'd come off worse so it could be that only. . . It could again be an emotional thing, (2) you know . But I do think it is a bit of a personality thing as well with Maeve (3). . . . because I don't know . it's difficult isn't it to know whether something's, . is it caused . not genetically whether it's imposed by an environment . say if there was a violent row and she would get a clip and then my brother . my brother and her would argue my youngest brother and her would argue my dad would take my brother's side, so Maeve came off worse so . .and she was very, very stubborn and she would not back down so she created a hard situation for herself really, it shouldn't have happened though- that she got a clip, but she used to . yeah. And my dad realised that he shouldn't . . I think we used to say "Shut up Maeve, please shut up" (4) but she wouldn't . but I don't know . She was very bright, and very imaginative person, highly strung . She only became ill, . no she became ill after taking LSD (5) and going on a bad trip you might say and . .

Monica's difficulties, on the other hand, are seen as being distinctly different (1), they are somehow less physical (2), perhaps less legitimate - "just [] . emotional weakness" (3). Rumination continues as Kate considers the moral implications. It seems as though the idea of organic cause (4) is being contrasted with individual responsibility, in that people can perhaps find a way to change (5), in the passage below:

. . Monica sort of tries to identify with Maeve a bit but you know . it's not the same, it's not the same thing (1). And she was quite nervous cos they were going to do a scan, a brain scan on her I think she decided not to, . but I think eventually they did . but they found no schizophrenia in Monica (2)- if they can find it that way, I don't know . . no it was er . . it's not that . . I don't know what it is . I think it's just er . .it's an emotional weakness (3) but if it can be strengthened . .

DJ: Do you see that as being an organic thing, a genetic thing?

KD: With Monica I do, . . er You mean rather than being imposed by environment?

DJ: Mmmm

KD: But what about . some people suffer amazing, terrible things and it doesn't make them feel self-destructive does it?

DJ: Yes, yes so some people would say . .

KD: So I think it all must be organic. (4) . Or I think er . . . I think it's an attitude as well, you can learn to have a different attitude as well, it's very hard for people to change but if you can find the way to change, no matter how it's brought about (5), I think then um . . I think that can be effective, and the same for everyone, you know, but er . . and people don't always relate to the same sort of things . What about these people who are really quite mentally ill and who can come through painting or the creative arts . . I think, I think there is something as I was saying it takes someone with a lot of patience and . .

In summary, Kate Daley is prepared to consider a wide range of possible causes:

- 1) Organic illness.
- 2) Genetics.
- 3) Early experience.
- 4) Drug abuse.

These categories carry complex implications, often of a moral nature, within them. The 'Organic illness' hypothesis and 'Early experience' hypothesis would appear to absolve the sufferer of responsibility most clearly. The 'Organic' and 'Drug Abuse' categories absolve the relative most easily. The genetic hypothesis, carries with it ambivalence for the relative, an ambivalence that will be discussed further later on.

Moral Implications: Accusations of Blame.

An example of spontaneous use of a psychiatric diagnosis (schizophrenia) came from Mr Doors in the previous chapter (page 141). A strong feature of my conversations with Mr Doors were his feelings of guilt. His daughter's real mother, had died when April was three, he re-married a woman who treated her very badly. Mr Doors

ruminated a good deal on whether this ill treatment lay at the root of his daughter's difficulties, which perhaps in part explains why he was particularly anxious for information. It is a desire for information seemingly not satisfied by staff:

DJ: At these various points were they [psychiatric hospital staff] discussing with you what they thought was going on?

JD: Oh no, no! . . . I don't know if there was a change in the political climate as it were, I think in the past two, three years people actually telling me what they thought was wrong, before that either they didn't tell me or they wouldn't commit themselves. I said "Well is she manic-depressive?" [edit] either they didn't want to tell me or they didn't know . . . when I pushed the point they said "Well mental medicine isn't like physical, it isn't straightforward, it isn't black and white," . . . It's all very evasive. No-one was even able to tell me whether the treatment that April had from her step-mother - of course I should never have allowed to take place in the first place really - . . . um whether that affected her, or would it be in-born? And no-one could categorically say 'yes' or 'no'. Some people said "Well the general opinion is that it wouldn't".

Blame and Aggression.

To Mr Doors the medical illness model of schizophrenia is a source of some comfort in suggesting that his daughter's difficulties are not due to her stepmother's maltreatment (and his non-intervention). The organic illness model suggests that he is not to blame, morally it is more neutral. This pattern whereby the model that supposes a disease with organic roots is contrasted with a model that blames the family environment was not uncommon. It is demonstrated again here in this extract of an interview with Jean Karajac. Here, another dimension of 'moral responsibility' can be seen to emerge, as we can begin to sense some of the aggression which is shaping the accusation of blame. In supposing that he and his sister's upbringing was odd, and that his sister's difficulties might be caused by that upbringing, he reveals some feelings about his own upbringing. The family was isolated (2), perhaps he and his siblings were over-protected (3), and spoilt (4). Jean wonders if the reason for him not becoming ill was his own strength (5). However, the knowledge that he

acquired about the medical model of schizophrenia (from friends) has now 'tempered' this view (1). Hereditary is also considered (6):

DJ: What do you think happened now . . . have you any thoughts about why, what caused it?

JK: Er . I really don't know . It's been tempered (1) by what I know, from my friends that schizophrenia is a medical disease, they discovered that quite recently . I always [thought] about the family . . . we were a very close knit family, very isolated (2) all our relatives actually live abroad my father wasn't a very gregarious person he had a few choice, close friends, always protected us maybe too much (3), my mother definitely spoils us too much (4). She always believes her job was to look after us and do everything for us and I spent many a time in my adolescence sort of fighting that, trying to do my own thing! And I had the strength to do that (5), my sister never did, I'd say I had the confidence of a great circle of friends and my sister always found it very difficult to make friends, she was always very shy . I'd say I was shy when I was younger but I was fortunate in a lot of ways in having such good contacts I always had my own networks, she never did and that made it very difficult for her, coupled with the fact that me and my brother were academically successful in school and she wasn't. Which left her with a crisis of confidence, what was she going to be good at? Where is her niche in society? And I don't think she saw one, and all those pressures were pulled down on her, plus the fact on my dad's side I know there is schizophrenia runs through his side of the family (6) . . . I don't whether that can lead to it in any way.

Mr and Mrs Snellman saw hereditary factors being involved in their cousin's illness, but also felt that his upbringing might be involved as well. His mother died when he was young and he was brought up between his father and grandmother. The behaviour of Erik's grandmother and father was seen as being part of the problem. This hypothesis was raised with considerable feeling (they did not like his grandmother) revealing clearly a moral dimension. Later in the interview it becomes clear that the placing of responsibility elsewhere, in that he "had it rough from all sides" (1) forms part of a reasoning that allows the person or self of the sufferer to remain intact. He is still lovable and innocent "underneath it all" (2), the blame lies elsewhere:

Mrs S: Yes this was a poor young man who had it rough from all sides (1), and basically he was a lovable, loving child and everything has gone wrong and underneath it all there is still a loveable person (2). But you can hardly ever get to it, and you certainly can't get close. I mean when I said once, "Since we lost our daughter . . . we are frightened of the future, of getting old like everyone else . . .". . . Our son lives in Poole his wife is very nice, but it's all very different . and he sort of hugged me and said "Oh Peggy I'll always look after you", you know the heart is there, but the illness doesn't give him a chance . .

Liz Regan saw her sister's problems as being, in part, caused by her sister's son Ron, 'even before the breakdown'. This was a straightforward and forceful accusation of blame, the dislike was very intense.

Jason Manula saw his brother Harry's illness as being connected to his family experience, and the lack of consistent parental figures. Jason and his sister were brought up and loved by their grandmother. Harry on the other hand was 'shunted about' between their mother and father. Harry never experienced the stability and love of the grandparents that Jason experienced. It is clear that for Jason Manula the immediate family, particularly his father, who although living in this country is estranged from him, is a safe target. Jason very clearly expressed anger towards his father during the interview. Jason himself felt burdened by the responsibility of looking after Harry.

Fred Bryant, being separated from his son's mother, could perhaps also afford to lay blame at her door (1), although he also wonders about drug abuse (2). However, he also notes that his son was different earlier, as a teenager (3).

DJ: What do you think caused the illness?

FB: Well it maybe something from his mother (1), but she had two other children and they're perfectly alright . . .er it could have been, if stuff was put in his drink it could have been a real blummin' overdose of acid (2) which might have done something. He's certainly, since then, not been right at all. Before that he wasn't right, in that he wasn't mixing with people, he wasn't a teenager as such (3) he

was just keeping entirely on his own.

Later on in the interview the idea that John may have received a blow to the head is aired (1). Again the expression of anger (in this case directed against the police) is clear:

. . I don't know what happened that night he's supposed to have smashed up three police cars, I don't know if he was banged about the head (1), I really literally do not know . All I know that from that night when that incident took place John has not been, he's not been right. Where before he was strange, after that night he was gone. . .

Again we see how different theories can be held by the same person. The fact that Mr Bryant (like many other interviewees) could hold these different theories is an important point about this style of research. A very different impression may have been reached had people straightforwardly asked what they believed was the cause.

Mr Ajani was another father who wondered if ill treatment in the hands of authorities had made his son ill. To Mr Ajani the fact that his son was black was a factor leading to his being picked on by the police. Whilst Mr Ajani's observations may be legitimate, it is clear that some of his own feelings and experiences as a black man in Britain are being brought in here:

DJ: What do you think caused the problems in the first place?

MrA: I'm not a psychiatrist, nor a doctor. What I can say is that they did something to him, kick his head because he [] had a nose bleed . . They could have done something to him, I'm not very sure how it could have been done, I'm not an expert, but if certain wicked people want to do certain things as I just told you - the police were coming here looking for him because they promised him. A lot of things are wrong in this country . .

DJ: Do you think that it was as a black person that he was treated particularly badly?

MrA: Yes I'm sure it was. I'm not a racist - the people who looked after our children, who helped bring them up . were a good Christian English couple, we are still friends today. They came here we lived together since 1967. I am not racist at all, but I know- if you look at . . they think every black man is a thief . and if you are a black man you are bad. Forgetting that you take people as you find them, it's just . . I've been in this country . next June it will be 20 years, I got no single criminal record. But certain parts of the authorities especially the police, I hated them . especially this area they are no good. That's why, you must take people as you find them, you don't say that because he has done this before then he must have done this . You don't know!

Diane Mason also expressed anger about the racist environment that impacted on her brother, although she took a different view of its operation. She wondered if her observation of the over-representation (referred to earlier, p.156) of young black men on psychiatric wards was due to the fact that their difficulties were not picked up early enough. Perhaps their behaviour was too easily dismissed as being due to 'cultural differences'. Both Diane and her mother adopted theories that implied social causes of illness. They make no suggestion, however, that the family might be to blame. The social factors that were put forward were to do with relationship difficulties (with the mother of his children), unemployment (1) and subsequent poverty (2):

DJ: And from what you said he used to be very different.

MM: Oh yes he was . . he was never a lazy person . That's why I think it was work, I have a feeling, when he couldn't get a job (1).

DJ: That was the cause in the first place?

MM: Yeah. I think so, living in Wales, and as Diane said, the conditions weren't very suitable but because of the kiddies, he loved those kids he stayed on and then afterwards he couldn't get a job. Because he's always talking about money, especially when he's ill, money , money, money . he gets his money today and tomorrow he don't have a penny, he walk into the bookie or something and it's all gone he never has it to last him the week and he keeps coming to us we've got to give money, give him food or something . . all his problems are just money .

money, money (2) . I just feel that it is the cause of the problems.

DM: Yeah, because when he was in Wales he would be out of a job one day and the next day he would be working . . He was always able to get a job, but I think what happened it got to the stage when he wasn't able to get a job to feed the kids . or what ever he got was just enough for the children and like for himself he was just neglecting himself etc., and when he came back here . . he got a couple of jobs, but because of his condition he wasn't having any input from the psych' side . . .

DJ: And would see the cause in the same way as your mother was saying before, unemployment?

DM: Yes stress, emotional . not being able to . or a relationship that has gone wrong, not being able to find a job, not being able to maintain your pride or self-esteem . .

MB: That is one of the things for Charlie.

DB: That is the main thing with him, not being able to carry out his role as a man, not being able to fulfil that role, that's the main problem.

It is important to note that although social factors are seen as being causally responsible by this family, they still see Charlie as suffering from an illness, which in this case needs to be treated with medication. There is no difficulty in viewing what their relative suffered from as a 'real' illness, in spite of the fact that it might have a purely social aetiology.

Perhaps the fact that this family did not discuss the hereditary theory was quite surprising. Mrs Mason regularly attended a relatives' group, where they had talks about schizophrenia and mental illness. Her daughter was a nurse (general medical). It was difficult to believe that they hadn't come across the theory. I spent some considerable time with Mrs Mason in the following months and there was still no mention of a theory of hereditary cause. This raises what I have come to believe to be an important theme: the influence of shame. In that silence, in the omission of the

mention of the hereditary hypothesis, there is evidence of the affect of shame shaping ideas and experiences.

Shame and Genetics.

In order to explore the influence of shame in constructing people's thoughts and views further, it is worth spending some more time looking at the two interviews with Jacob Doors. This was a particularly 'open' interviewee, who used the interviews to think about his relationship to his daughter. It has already become clear (from p.175-176, this chapter) that Jacob Doors seemed to draw comfort from the organic theory of his daughter's difficulties. This seemed to free him from some feelings of responsibility and blame about her upbringing. Jacob also talked about his first wife (his daughter's mother) showing psychotic symptoms before her death. When talking to me he seemed to make no link between his late wife's difficulties and his daughter's. I was curious about this silence and so I asked him about it. I wondered what it might have meant to him; for his daughter to have started behaving in similar ways to his late wife. There is something about the hesitant and stumbling response which seems to betray a sense of fear and shame about there being a connection, perhaps a genetic link:

DJ: But I wonder how you felt when you realised that similar things were happening to April, that happened to her mother?

JD: Er . . . ?

DJ: It must affect the way you look at it?

JD: . . . I don't think I ever consciously faced the fact as a matter of fact, until you raised the point. I don't think I'd ever consciously raised the fact, I'd thought of it, put it down . and yes obviously borne it in mind, but I didn't actually sit down and . something I didn't want to face, didn't like to face that somebody was genetically condemned to something . I mean yes . obviously I've thought of that at times. I was just hoping that it would get better in April's case. Now admitted it's lasted a long time so perhaps I shouldn't think that, but when you see someone

acting in a bizarre fashion in that split second in time you don't actually get the whole picture. And er . it has . yes I do think about it .it's not . I don't deliberate upon it . I tend to . for instance I think of my son and he's OK, he's very calm . though you could . tiny little things, you don't want to start looking for anything wrong. He is very defensive at times and quite easily upset, although he puts a barrier over it, he's a police officer, and quite a good one at that so he is obviously someone who can handle things. I'm pleased it didn't come out in him, I wonder if he had children if it would come out again or if it watered down - however genetics work. Yes, it was disturbing yes, it was disturbing, but I didn't actually make a point of um . thinking about the connection over much

In an interview with Mary Galton when I ask about 'cause' she responds by suggesting that it was her sister's break-up with her boyfriend (see section on "Broken Heart" this chapter). However, later in the interview Mary herself, tentatively, mentions that she has been involved in a study looking at genetic links in her family. This is a subject that she switches to (1), it is mentioned out of the blue. It seems to be something that she is fearful about. Only after I have won some trust during the interview is she prepared to share that fear with me and, I think, seek advice or perhaps reassurance. Obviously I feel very put on the spot, wondering what reassurance I should offer (3). The fact that this only came out later in the interview does reinforce the notion of the hidden potency of shame. The use of the phrase "I must admit right . . ." (2) suggests Mary feels that this is something to confess. Even when she is acknowledging the fear, she displays very ambivalent feelings, on the one hand agreeing with the phrase I use, that it is "a big fear" (4) but then saying she does not "really pay it too much mind" (5):

DJ: Do you think they were interested in what you had to say . . as someone who knows Rachael?

MG: No they didn't seem to be. . . . No they didn't seem to be interested . . . Do you think that it runs in families? (1) I must admit right (2), some man, a doctor or other, he was doing a test to see if it ran in families, . I've been quite curious about that to be honest, but then again I don't really want to know, I'm curious but I don't want to know - if you know what I mean, because it might play on my mind.

DJ: Someone came to talk to you?

MG: My mum . . he wanted to see me and the one after me. Because we've not had any problems.

DJ: Erm . . Well, maybe you don't want to know but . it's something they're looking into really that is why that person was interested (3).

MG: Yeah, I was thinking "oh my god, it may not reach me but if it reaches my child oh my god what am I going to do, you know?" I look at him sometimes and think "Oh my god I don't want that to happen, I just don't want that to happen" I don't.

DJ: Is that a big fear?

MG: It is a big fear to be honest, it is a big fear (4), but I don't really pay it too much mind (5). It is a bit of a fear. Knowing what my mum went through, and what I went through with Rachael and Alison. I wouldn't even want it for Ben [her son], something that I wouldn't wish to happen. Or to me, you know. . . .

There is undoubtedly something "disturbing" about the idea of a genetic link. I will be arguing later (in Chapter 7, "Shame and Identity") that this is disturbing for reasons beyond the practical implications. I want to suggest that the idea of genetics makes concrete the psychological identifications people already feel to exist between family members. Talk of, and publicity about, the discoveries of genetical research cause anxiety because they feed into anxieties about selfhood which people already experience. In a significant way, at least unconsciously, it is as though people experience parts of themselves as belonging to or having come from others. When those others become ill, particularly in such a stigmatised way, how must they feel about themselves?

Ashamed of Blame.

What has emerged so far is the way that a wide range of hypotheses are marshalled in the strive for meaning. Discernible within these hypotheses are strong concerns

with moral responsibilities, and the expression of anger, which are immanent to the shaping of the theories. Knowledge and power are actively blended through the concern with blame and responsibility, and the expression of aggression.

In addition, there is a less tangible feeling of connection which is revealed by the concern with the genetic hypothesis. This feeling of connection seems to be buried by feelings of shame, such that it is difficult to talk about.

Another manifestation of shame occurs in the seeming reluctance of the interviewees to admit to feelings of self blame or to awareness of being blamed by others. Such reluctance to discuss something that is perhaps salient to their experience again can be seen as presenting a challenge to study with conventional methods.

Elly Blacksmith is someone whose ideas about cause, and her responses to my questioning about stigma, suggest feelings of shame. She, like other interviewees, mentions several possible causes of her son's difficulties. She thinks it possible that it was to do with smoking cannabis, his religious ideas (of rastifarianism), and the stress of studying. When I ask her what the doctors had told her, she takes care to tell me that her son's difficulties are not seen as to do with the brain (which is "perfect"), they are to do with "the mind".

When I ask her about stigma however, despite seeing her son's difficulties as being of the realm of mind, it becomes very clear that Mrs Blacksmith is adamant that her son's difficulties are those of illness. I do wonder whether the vehemence of her response to my questioning about feelings of stigma⁵, actually suggests that she does experience a certain amount of stigma or blame (1), and that the notion of illness or sickness (being used here to highlight the morally neutral condition of her son) is one that offers some protection from this stigma ("nobody go out and buy sickness, sickness made for anyone") (2):

⁵ This sort of response is taken up in more detail in the Chapter 8, "Shame and Identity".

DJ: Sometimes other family members often feel that other people look down on them because there is mental illness .

EB: Well nobody looked down on me 'cos you they doesn't you know . nobody looks . . I don't care if anybody want to. I don't care, you know, you've got to hold your head up high. I don't care what nobody says (1), nobody don't go out and buy sickness, sickness made for anyone.(2) So I don't care, my family they love him, all my family love him they do anything for him, you know if I'm not around they go to him, if I was to go away on holiday . . no not with my family because we're such a close knit family . .

Jean Karajac and Molly Quinn (siblings to Janice Karajac and Christine Connor respectively) both talked about how their parents had blamed themselves. Jean Karajac understands that his mother's current high level of involvement with his sister is a function of this feeling of guilt:

. . My mum is . she reacts so, she feels responsible, without a doubt, I think my father did as well, that's what ended up killing him. That it's their fault, they still do feel that, they come from . say an old fashioned view of mental illness. However much you tell them "Look don't put it all on yourself", she does. That's why she always visits the hospital everyday, she always cooks for my sister everyday, she doesn't understand why she doesn't react positively to that, and sometimes negatively, she doesn't realise that sometimes she is actually crowding my sister too much, you know.

Molly Quin's parents had separated and Molly had initially blamed this disrupted family for her sister's illness. Her mother's subsequent contact with the NSF had provided a different explanation, since there her mother met "couples that have had very happy marriage and very happy family unit and their children have still suffered the illness". This explanation was more palatable to Molly.

Both of these siblings had come across information which persuaded them that the 'dysfunctional family' model of cause was incorrect. It is interesting to observe that nobody interviewed volunteered themselves as being the cause of their relatives'

difficulties⁶. In fact I interviewed Jean Karajac's mother, on her own, and she did not tell me that she felt guilty in the way that Jean tells me she does. She did, however, ruminate a lot on what it was that might have happened to her daughter (and put some blame on her husband). I now wonder whether the admission of having feelings of guilt, which her son talked about, would have invoked such feelings of shame that they could not be easily expressed in an interview of this kind.

Upon reflection I think that an interview I carried out with Mrs Murray does provide some support for this notion. This was one of the more difficult interviews I did (referred to earlier in the section on those who refused to be recorded, p. 128). It took several visits to arrange; several times I appeared at the pre-arranged time only to be told that it would not be convenient as she was too busy just then. When I did manage to sit down and speak with Mrs Murray, she refused to be recorded and was quite hostile and suspicious. During the course of the interview I asked her whether any particular name of an illness had been mentioned, I was told that she had been informed that her daughter had "manic depressive illness". The atmosphere became more contentious when I tried to explore what that meant to her, or whether anyone explained what "manic depressive illness" might mean. Mrs Murray seemed to feel very put on the spot. She told me that the doctor at the time said that it was because of her family background, because she and her husband had split up. I attempted to explore how she felt about this accusation, she became very angry exclaiming "I don't want to go into my personal details with you!" I tried to calm things down, and explained that this sort of mental illness was often seen as just like any other illness, with a physical cause. Perhaps she had felt that others had seen it as her fault? Mrs Murray told me very firmly that she felt the family background was indeed responsible but that she herself did not feel blamed as it was her husband who had left her. Jane was the eldest and had had the most attention from them both, so she had been most affected by his departure. Her husband's new wife had then not wanted to have anything to do with the children, the explanation continued. I do not think it would be taking too many liberties with interpretation to suggest that Mrs

⁶ Mrs Land might be a partial exception to this, as discussed on p275, she felt that her choice of partner may have resulted in her son being damaged.

Murray actually felt acutely responsible for her daughter's illness, hence her initial ambivalence about the interview and aggressive response to some of my questioning which was probing about what had caused her daughter's difficulties.

Mr Reece was another parent who seemed to feel rather persecuted by my line of questioning on this matter. It is hard to say whether Mr Reece was harbouring explicit feelings of guilt about causing his son to become ill, but he had at one time taken an injunction out against his son to prevent him returning to the house because of his violence. In this extract from the interview Mr Reece has very tentatively proffered an idea that his son's difficulties might have been caused by smoking cannabis (he spoke to a young woman on a psychiatric ward who had told him that is what had caused her difficulties). When I try and pin him down to it he becomes quite defensive about not being able to control what children do and angry about exploitative drug pushers (1):

DJ: But you think maybe that was it, he was smoking?

MR: Well you can't tell. I just can't ell. 'Cos you asking him, he say "No". So how would I know? I never seen him. But this is what I'm saying, from the time your son or the daughter close that door, you is in here. They gone out, gone down that stairs, go up the road you don't know what they doing. You'll be lucky someone past them that knows you come in and say "Oh I see your girl talking to a boy, or I see your boy talking to a girl, they was smoking" or "They was this" , you will be lucky. Just can't tell. But lots of these young people, that is what got them like that. Drugs and smokes and all things like that. Killing themselves. People is making money whilst they is killing themselves (1).

I then (I think a little insensitively) pursue the matter of what he really believes about cause. As I do so Mr Reece's responses become shorter and shorter:

DJ: Have any doctors since then, or have the [Voluntary Care agency] people, talked about what might have happened?

MR: No. . I wish someone would tell me. . . Have you ever been in touch with

Eric?

DJ: No, no.

MR: Well I think as a matter of fact he's the one you should really get in touch with, try to find out what caused his illness or anything. Because most probably where he don't tell me, he might tell you. Who knows? And then have you ever been seen by [Voluntary Care Agency] people or anything like that?

DJ: No, no . .

MR: So who are you only seeing about Eric?

DJ: Just the families of people, to see how they see things .

MR: Yeah but how do you get to know about Eric?

DJ: Oh from the hospital, from the records.

MR: The hospital don't tell you nothing?

DJ: No, I just get the addresses, you see.

MR: Yeah well them is the people to ask, what can we tell you? Because they knows more than me really.

DJ: Yes, but I'm just wondering whether they talk to you, that's .

MR: No. No.

DJ: No?

MR: All they say to us, I know once we went down there- he's mentally disturbed.

DJ: Yeah . .

MR: What was this mentally disturbed I don't know.

DJ: It seems they haven't told you much at all, they haven't discussed things with you.

MR: Well people come around saying they want to find out this and they want to find out that, it's not a lot I can say to them really.

I sense that here is there not only a feeling of shame about what had happened; that perhaps he does feel responsible, but that he takes my line of questioning as suggesting that I think he ought to understand why his son had become ill. The one explanation he has been offered (smoking cannabis) by a patient on the ward is taken up, although with some scepticism since he noted that his son even finds tobacco smoke offensive. It seems as though professionals have not provided alternatives, which he experiences as persecutory. It is worth noting that here I am being bracketed with professionals since he finds my line of questioning persecutory.

The interview with Mrs Lord was also a difficult interview. She was initially suspicious (perhaps particularly of a white person), she saw her son as treated badly by the system⁷. She was very sceptical about the psychiatric system. She had heard that it "could be hereditary", but this made no sense since she didn't "have anything like it in my family or his father don't . . so how come?"

Later, perhaps after I had won a bit of trust, Mrs Lord reveals that she thinks that her son has been a victim of, if not racism, then at least cultural misunderstanding. I am told that " . . people who come to this country are different - maybe they like to sing to themselves and people say that they are mad and they are not . .I don't know, maybe things that they give him make him worse, make him like that, the place they put him maybe I don't know . maybe they do their best." Her reticence in being interviewed seems to reflect her feelings towards professionals and the way that she imagines they look at her.

Mrs Teague was also initially suspicious at my presence and refused to be recorded.

⁷ This interview was not recorded, but notes were taken at the time.

She seemed unsure and confused about whether she saw her son as suffering from an illness. At one point she thought his mental state was associated with "Bad company . and smoking the weed". Her husband used to smoke a bit, which was OK, but Simon would smoke all day. I asked if she thought that smoking had lead Simon to be ill like that, she told me that she thought "No, it wasn't illness, it was the company . " that Simon got into.

I wondered if anyone had talked to her about what had been happening, what was wrong with Simon? Her response was unequivocal: "No! No-one ever talked to me about what's wrong, just ask me to take him." Professionals seemed to have offered her no alternatives. She is left with the idea that her son has simply turned out bad. I cannot help feeling that it is likely that, as his mother, she has been left with the feeling that she is somehow responsible. This would be very painful and may well explain why she had for the time being cut off contact from him. The difficulty that interviewees experienced in coming to terms with changes in their relatives will be explored in Chapter 9.

A Broken Heart.

"Love is merely madness; and, I tell you, deserves as well a dark house and a whip as madness do; and the reason why they are not so punished as cured is, that the lunacy is so ordinary that the whippers are in love too."

As You Like It. Act 3 Sc 2. Lines 420-26.

The hypothesis that was most strikingly different from professional models was that of a 'broken heart'. This hypothesis supposed that the illness was caused through the person having had relationship difficulties or the trauma of unrequited love. This is perhaps a well established association as the above quotation would suggest.

For example the Christodoulou family thought that George's problems began when he made drastic attempts to lose weight in order to get a girlfriend. Bruce Dear's brother also, although not knowing of any specific relationship difficulties that his brother experienced, thought this might be an explanation.

DJ: What do you think caused it?

MrD: I think he must have been in love with someone, but she left him, and he went crazy . . . he's never said anything . but I think that's what happened. that's what has happened to most people who are like that.

There is something that is being considered self-evident here about a link between love and madness. Perhaps love, or 'being in love' is an experience of that people recognise within themselves as being akin to madness. Mary Galton, for example, very firmly saw her sister's difficulties as being triggered by a split with a boyfriend (p.136).

Mike Jenkins is a good example of someone who took quite an open minded, eclectic view. He wondered about ill treatment at the hands of police (2), and about stress. However he saw the 'trigger factor' for his son's difficulties as being the traumatic break from a girlfriend (1).

DJ: What do you think caused the illness?

MJ: Well he used to er . he had a girlfriend. And the girlfriend was having an affair with his friend (1), you see. And he tried to hurt . you know like lock himself in his room and tried to starve himself to death. We had to try and call [the] police to get him out the room, he was in there for about three weeks . . after that he was damaged. One time they arrested him, he told [me] they banged his head, they banged his head against the wall (2).

Chris Gyradogc sees his sister's difficulties as being:

"a really complex intermingling of so many aspects and it's just the way that she has accepted these things as well as maybe there being actual physical, genetic reasons for her illness."

I ask him to expand on the other reasons. He mentions the family being seen as different, perhaps stigmatised (1) and isolated (his parents were Polish immigrants)

(2):

DJ: What do you think the social reasons might be?

CG: It goes . I think there are so many, and there are so many that I don't know about, but er . she's always had the short end of the slimy stick, or the wrong end of the stick . in her dealings with people and er just the way that they've dealt with her. And I think that the fact that we . . initially we were quite poor and we didn't dress that cleanly and didn't wash that often (1) - we do now, and we didn't wash, those type of things did affect the way that people treated us. And maybe as much a cultural clash as well, because we didn't . . in a situation where we didn't have many family friends, (2) I mean I've got friends . lots of friends, but not many . . there are no family friends so there was a case where we cut ourselves off and I think that fact contributed to it?

Chris also remembers that Petra had a difficulties with peer relationships at school (1), particularly a close friendship, which Chris seemed to think perhaps had sexual overtones (2):-

. . the way that people treated her at that school affected (1) her as she seemed to be developing quite a good friendship with girls of her own . I was going to say girls of her own sex but! . contradiction in terms I suppose. But er . she sort of had a . it split, you know she seemed to be laying a lot on this one relationship, I don't think it was sexual, I mean maybe it would have developed, but not in that sense - like a best-friend thing and it just backfired and this friend almost became her enemy (2) what she started to do was playing truant from school because it's just up the road she used to come home, . .

Later Chris Gyradogc discusses how he would like to see things develop. He thinks it would be better if his sister lived away from home, which would help her to be less confused about sexuality, amongst other things:

to put her in an independent environment. Where she develops herself basically . . I don't think she has been in that situation . in fact she has never been in a situation where she has lived away from home, she's always lived here, apart from the times she's been up in hospital she has not developed- or had that time to

develop certain aspects of her personality. Like her social skills, her sexuality things like this . I think she's quite confused about quite a lot of aspects - quite a lot of things.

Mrs Karajac thought that unrequited love might have triggered her daughter's difficulties. There seems to have been no evidence for this, but again there seems to be something self-evident ("I suppose she must have . ") (1). Attending a single sex school is mentioned (2), and further episodes of unrequited love with a nurse (3) and a priest (4):

DJ: What do you think might have caused the problems?

MK: All the time that was on my mind. When my sister came she came here four times, the third time when she came my daughter who was about thirteen, and she came with one of my nephews and she didn't have any boyfriend or whatever, I suppose she must have fallen in love with him (1). They stayed for three weeks and went back I remember she suddenly changed, I suppose that must have started it I don't know. I have a feeling that must be that . .

DJ: She was rejected?

MK: No but naturally she couldn't go out she was allowed she had to work my husband would say 'Never,' in fact at that time if he had accepted that I am completely certain she wouldn't be like that now . . She wasn't allowed to go out and about do, . . not allowed to do this or that . . all the others used to go out and she couldn't. And she went to a girls' school not mixed (2). I don't know all the time I think about that I think maybe that must've been the beginning because when she was in [hospital], she was in [hospital] for one year there was a nurse, an Australian, he was very nice chap, very understanding and the first time she was there, [hospital] was very good at the beginning I must say. So she fell in love with that nurse, (3) but he was going to get married and that was the mistake they should have told her, nobody said it. When the time came for him to go, she became very ill, she did something very bad in hospital that was when the doctors knew about it, but it was too late. Each time, we are catholics, there was a young priest she's always attracted to, (4) but naturally they put her back in her place and that she doesn't like that . . because she didn't get what she wanted. . I have a

feeling that must have been the final thing but now it's too late, I'm sorry to say there's nothing to do about it.

When interviewed, the Cook family thought that Arthur's difficulties were caused by the break up of a relationship with his wife (him being seen as the victim of cruel behaviour) and being badly treated (by police amongst others), and the general pressures in life.

Vicky Reece firstly mentions her brother's unemployment and the subsequent boredom and lethargy (1), but there are also references to him not 'bothering' with relationships (3), and a mention of a "special friend" (2) which is not expanded upon:

DJ: What do you think caused the problem for Eric?

VR: I think depression, losing his job, bored. You know when people are bored, indoors, doing the same thing looking at the same four walls (1) . . not making an effort, things get on top of them, with Eric's case it was because, you know, he had money. He used to go pictures, he had a special friend (2) he used to see and it all started with . I think he wasn't feeling too well and the doctor give him some antibiotics and he didn't take them, but obviously there was more to it. So I put it down to depression and boredom. And being the only boy above three girls and we're going out and we had boyfriends, he just didn't bother (3).

The salience of relationships, particularly romantic love seems the point at which psychiatric models departed most from the beliefs of these interviewees. This view of the power and danger of "carnal love" was shared by "preachers, poets and medical writers" back in the 17th century according to MacDonald (1981) who quotes the medic Burton claiming that love turned people "into very slaves, drudges for the time, madmen fools, drizzards, abrabilar, besides themselves and blind as beetles."(p88).

That there should now be disparity between lay and medical theories in this particular area is hardly surprising given the difficulty that the social sciences have with the subjective world of the emotions discussed in Chapters 3 and 4.

Summary.

Placing Their Experience Within Discourse.

The picture I have been painting over the last two chapters is of the family members experiencing a break in the continuity in the behaviour of their relative. It seems that, whilst the events are construed (with hindsight at least) as being medical problems, the interviewees' relationship to psychiatric knowledge, and with mental health professionals, is not straightforward. The relatives report often poor relationships with professionals and an attitude of some scepticism towards psychiatric knowledge and forms of treatment.

This exploration of relatives' ideas about what caused the 'mental illness' reveals a highly eclectic approach, quite consistent with Furnham and Bower's (1992) study of lay theories of schizophrenia. Individuals are able to hold several parallel (or even contradictory beliefs). All interviewees were concerned with finding reasons of some kind. Some made particular effort to educate themselves in terms of psychiatric knowledge (Chapter 5, part ii). The gathering of ideas, and of terms, was helping to place themselves, and their experience, within meaningful frameworks which restores order and meaning to events. At times there is sense of there being a quite desperate scabbling for meaning, with no stone being left unturned in the search for the right theory. Perelberg (1983) in her study of families and mental illness referred to families being involved in a 'search for meaning'. However, analysis of what underlies this search suggests that it is better seen as "a struggle" for meaning. The theories are all shaped by a complex array of often powerful emotions. Feelings of anger, guilt and shame can all be traced within the theories that people held. The theories also carry complex moral implications. In searching out theories of cause, there is a concern with blame (as in what has happened in the past) and responsibility (as in what should happen now and in the future).

What has emerged in this chapter is the manner in which these so-called lay beliefs

are in themselves inseparable from Foucault's power and knowledge couple. This suggests that ideas about mental illness are not emerging solely from the scientific discourses, and power machinations, of professional elites but are immanent to much wider cultural needs. This supports Barham's (1992:140) view that the role of psychiatrists within the medicalisation and confinement of insanity has not been as "overlords of independent fiefdoms" but rather as "lieutenants" of more powerful social processes. Tomes (1994) also concludes of the American Asylum, that it "was not the sole creation of doctors or lay reformers, . . . but an institution sanctioned by the whole society to meet certain commonly perceived needs." (p12)

The need of people interviewed here was to find meaning, to find a place within discourse. This has been highlighted by Levi-Strauss (1969) as being the crucial role of, for example, the psychoanalyst of modern Western Society and the shamen of South American cultures. He describes the efficacy of the cure of the shamen of the South American Indian:

The cure would consist, therefore, in making explicit a situation originally existing on the emotional level and in rendering acceptable to the mind pains which the body refuses to tolerate. That the mythology of the shamen does not correspond to an objective reality does not matter. . . What she [the 'patient'] does not accept are the incoherent and arbitrary pains, which are an alien element in her system but which the shamen, calling upon myth, will re-integrate within a whole where everything is meaningful. (p197)

I think this parallels these interviewees' need for knowledge very well. In gathering terms, facts and figures about mental illness, or elaborating theories and scenarios they are defending themselves from what are otherwise "incoherent and arbitrary pains". This is an important theme which will be explored in greater detail in the following sections.

One hypothesis that was at variance from traditional psychiatry was the one which put particular significance on difficulties in relationships, particularly sexual ones. I think that this reflects a deeply held belief that such relationships are somehow fundamental to mental health. And also the understanding (not necessarily conscious) that sexuality

is bound up with close relationships and that the observance of sexual boundaries defines mental health in some way. This is an issue that will be returned to in Chapter 8 ("The Myth of the Family").

An important issue that has arisen in this section is the emergence of guilt and shame, often covertly, perhaps under a shroud of aggression. This point serves to highlight the significance of emotions particularly the often less visible and intimate emotions like shame.

The next section, therefore, provides an exploration of the emotional impact of having a family member suffer from such difficulties.

CHAPTER 7.

The Meaning of Relationships.

"Living on the edge of the world."

This chapter is an exploration of the emotional impact of events on the interviewees. In the previous sections attention has been drawn to the endeavour that the interviewees are engaged with in trying to apply meaning to the events surrounding their relatives' difficulties. In this, the work so far might be seen as a traditional ethnographic exercise, or one that largely falls within a sociological symbolic interactionist tradition. The contention has been that people are involved in an active struggle to giving meaning to the complex changes that have occurred in the behaviour of their relative.

It is being argued that an important aspect of the meaning that people are groping for is continuity within what they experience as precarious circumstances. A significant way of achieving some form of stable meaning is through finding that their experience can be understood by others. What people seek is the feeling that their experience is commensurate with some apparently stable structure which exists seemingly outside of themselves.

Arguments will be made in the following sections that the emotions that people experience need to be put into a system of meaning. Feelings too need to be put within discourse. In arguing this, the distinction between the emotional and the social domains is being questioned. I want to argue that emotions, and particularly what are often regarded as being the most intimate of emotions, such as grief and (importantly) shame, operate and find their significance at a 'structural' level. Shame guides and constrains people in ways that more abstract rules, couched in the terms of reason such as 'obligations' or 'reciprocity' (whilst no doubt having their place and their influence) cannot (Finch and Mason 1993).

In part (i), the most salient emotion of grief will be formulated as a complicated process of bereavement. Even the experience of grief, an apparently most private and

intimate matter, crucially involves the negotiation of meaning with the 'outside' social world.

In part (ii), the experience of stigma will be examined. Its connection to the affect of shame and a person's sense of identity will be highlighted and analysed. This gives some access to an understanding of the nature of these people's commitment to their relative: beyond the rules of reciprocity and obligation.

Part (iii) will look at some of the strategies employed by people in order to defend themselves from stigma. These strategies may be encountered by professionals who work with families.

(i) THE GRIEF.

"The fundamental crisis of bereavement arises, not from the loss of others, but the loss of self." (Marris 1987:27)

"Each single one of the memories and expectations in which the libido is bound to the object is brought up and hypercatheted, and detachment of the libido is accomplished in respect of it. Why this compromise by which the command of reality is carried out piecemeal should be so extraordinarily painful is not at all easy to explain in terms of mental economics alone" (Freud 1917:253)

To the perception of the people interviewed, their relatives had suffered a catastrophic change in personality. It was, in many ways, as if they had become different people. It is not surprising then that after the practical difficulties have been faced, grief is the most obvious feature of these relatives' experience. Creer (1975) drew attention to grief in her study of relatives. In this study too grief was very apparent.

As in Freud's summary given above, grief can be regarded as a process. Murray Parkes (1972), in his classic study of bereavement writes explicitly about the stages of grief as a natural process. To Murray Parkes it is a process consisting roughly of a phase of denial; followed by one of protest; followed by one of acceptance. Much of the writing about grief has been in a similar vein, highlighting cases where the successful pathway through the process has become complicated (Kubler-Ross 1973, Littlewood 1992, Wertheimer 1991). Following in this tradition I will be highlighting in this section the very complicated process of bereavement that these relatives had to cope with.

As Freud emphasises there are at least two facets of loss, firstly there is the loss of the person that was ("the memories"), and secondly, and more complexly, there is the experience of the loss of the previous possibilities ("expectations"). It is in the tension created between these two facets that the relatives interviewed here experienced particular stress.

Grief and Ambivalence.

A factor which has been emphasised as being a major complicating factor in interfering with the process of grief is, in its various forms, ambivalence (Freud 1917, Murray Parkes 1972, Marris 1987). Three sources of ambivalence can be identified:

- 1) The conservative impulse.
- 2) Ambivalent (often hostile) feelings.
- 3) The fear of betrayal.

i) The Conservative Impulse.

Marris (1987) argues that the whole grief process is marked by ambivalence in that the bereaved person is torn between wanting to remain attached to that which is lost and wanting to move on from that and find meaning in the new circumstances.

People who are bereaved will often express this quite directly: that they do not want to forget the person, that in going over memories, seeming to torture themselves with memories they are deriving some comfort from remaining with the person. There is no denial of the reality of the loss. Instead there is denial of the possibility of carrying on without the lost person. According to Marris bereavement is never straightforward. It is always a process that involves a struggle with mixed feelings. On the one hand we do not like change, yet on the other we know we must adapt and accommodate to change in order to carry on.

ii) Mixed Feelings.

Murray Parkes (1972) draws particular attention to situations in which the ambivalent, or sometimes frankly hostile, feelings which people felt towards someone before they died. Subsequent grief is then complicated by the ensuing feelings of guilt. One particular aspect of the ambivalent mourning of these relatives interviewed here is that they are likely to currently harbour ambivalent feelings towards the ill person. They

are not merely feeling guilty over feelings that they had in the past, but they currently experience those negative feelings. Previous sections have already highlighted the presence of anger, how it can be seen as contributing to the shaping of people's ideas about the causes of mental illness.

Anger itself is a seemingly common, perhaps ubiquitous, reaction to grief through loss or change. Bowlby argued that anger has its roots in an infant's protest at felt neglect, demanding of the mother's attention, and is therefore a normal aspect of grief (Murray Parkes 1972).

Anger is an emotion that people are often reluctant to express at the best of times. If Bowlby is correct in tracing its origins to infantile protest, such diffidence is not surprising, since the stimulant of the anger is also that which is most loved and valued. In the cases studied here the most obvious source of the anger is the ill person. However, this is someone who, as we have seen, is construed as being subject to an illness, and therefore as deserving of sympathy. Nevertheless, the ill person has also brought pain; pain through simply becoming something different, and pain from the ensuing traumatic and dramatic events. The difficulty of what to do with the aggression is amplified.

Few people, when interviewed, directly expressed anger toward the relative. We have seen in previous sections how assiduously the interviewees would protect their relatives from direct blame. However, I think that there was undoubtedly anger present, and it was provoked by the ill person. In the following extract I try to clarify Fred Bryant's attitude to the long-stay hospital where his son was resident, since his attitude had puzzled me. On the one hand the hospital was described as looking like "something out of a horror movie", on the other, he was angry about the closure plans. I don't think it takes too much interpretation to suggest that this particular ambivalence obscures some quite strong aggressive feelings towards his son. He would prefer him to jump in front of a tube train (1) than live his life in hospital. Fred feels that he suffers more than his son (2).

DJ: In the past people have spent their lives in Friern, would you want to see that . for John?

FB: . . . Well maybe to be perfectly brutal about it I'd prefer him to jump in front of a tube train (1) than spend his whole life from 22 to 69 or 70 locked away there. But Friern don't affect John, I don't think it affects a lot of them, it's the parents and the people that are helping that it drives . that sort of feel it (2). A lot of these patients, it doesn't bother them. You know they don't seem to bother as much as the people that are worried about them.

Elsewhere in the interview when I ask Fred Bryant about his own continuing involvement (this is a man who has made remarkable sacrifice see Appendix D) there is a mention of a sense of duty (1) and a confession of more negative feelings (2). As Fred Bryant continues to talk he mentions his own death (3) and then through further rumination there is an association to other patients who have committed suicide (4, 5).

DJ: What's made you be so involved? You said yourself before that a lot of families drop out, they can't cope any more, but you've kept going . . ?

FB: Well I suppose . . . it's really because he's my son (1), and there are certainly times when I just don't ever want to see him again (2). There's certainly those times . it's like . to really give you the answer to that, it's like I'm the only one there, there's no-one else for John, if I disappear that's it, . . when I die (3) I sort of think that maybe my son Peter will step in, I think that quite possibly . he's a publisher. He's doing well. John's brother is a publisher and his sister is a business analyst, they're both up there and he's down there. But I think when . if I die I do think that Peter will step in . . to some extent, not to the same extent as I have done, but I think he will step in to some extent, I don't know . . I just think that will possibly happen, knowing the nature of him. . But it is hard, I mean I know other parents that go there, the problems that they have, you see the amount of people there that just don't get anybody at all. One particular instance a woman called Pat I think she has an outside job. She lived in Ward 23, she jumped in front of a train and committed suicide (4), now what happened was that, they told the rest of the people on the ward that she had committed suicide. I raised the question: "what was the point, why didn't you say she'd just left?" They told me on the ward that

they'd find out through the newspaper or through someone else. They thought it were better to get it over with and let them know what's happened, well I thought it were wrong. Two years later Sara, a young girl that was on the ward at the time, did exactly the same thing. She jumped in front of a tube (5), and I sort of feel if they hadn't of been told then maybe she wouldn't have, although she had a history of attempted suicide, I just don't know, but at least she found out a way that she could do it and it would, . it would happen.

It does seem as though beyond the genuine anxiety, that for his son to commit suicide would be a kind of solution to what Fred sees as an intractable problem (one that he sees continuing beyond his death). The worry about 'what will become of them after my death' was frequently expressed during interviews and has been remarked upon elsewhere (Creer 1975). Erikson's (1963) notion that the final stage of later life involved the struggle between feelings of integrity versus despair may be one way of understanding this thinking. Erikson argued that for mental health in older age it was essential to develop a feeling that what you have done, what you have built and created with your unique life is valuable and worthwhile. The struggle is with the feeling of despair that what you have created is flawed or not worthwhile. Fred Bryant's talk of his own death suggests a concern with a review of his life, and what will happen when he has gone. The allusion to suicide implies dissatisfaction, that things are not as they should be, the world is not safe to let go of.

The allusion that Fred Bryant makes to suicide also suggests a degree of aggression. Fear of their relatives committing suicide was something that interviewees often brought up. Clearly it is a real fear and no doubt the grief they would feel would be great. However, I did begin to see the repeated references to suicide as containing aggressive feelings. I was able to explore this thought over a couple of extended interviews with Jacob Doors.

Jacob Doors made repeated references to his fears about his daughter committing suicide. After one of these, I remark on it to him. His response, in telling me that it is something he dreams about seems to make the element of wish fulfilment quite clear. In his sleep he gets rid of his daughter (1), but wakes with feelings of guilt

about how he should have done more for her. He then ruminates guiltily (2) on how busy he is as a businessman. In doing so he also allows himself to imagine how things might be if she were not around:

DJ: This is something that concerns you particularly the risk of suicide?

JD: Yes, now that you mention it, yes, yes. It's a bit at the back of my mind now because, she's taking the medication and she appears better, but it is, yes, . it is a worry yes. mmm . . it is a worry. Sometimes I wake up in a dream and think that it's happened (1) and I feel terrible about it. It doesn't happen very often but it does happen. . . I haven't got an awful lot of time for April (2) I've got my work, and if I don't work I won't eat, I'll sort of be bankrupt, I owe about . £35,000 I suppose, plus the mortgage . so right now I'm worth minus £100,000! . er . so I've got enough, there's enough cash coming in to eat so that people don't notice it. but I live a Maxwell situation in miniature, . so I've got to keep going. But it does bother me . I wake up in these dreams "Gosh I wish I'd spent more time with her" and things like that. It does bother me yes. . . There you are . . So yes that is the main . I think you've isolated the . what it's all about, that is the main worry at the bottom of it all.

Thus, it might be argued, the preoccupation with the risk of suicide serves to give expression to the aggression. Such a preoccupation allows someone to fantasise about the violent demise of another. They may also be allowing themselves to imagine how life would be after their relative's death. However, in imagining suicide there will also be feelings of self-recrimination and guilt immediately evoked. As an aggressive fantasy it is a non-threatening one for Jacob Doors to have, whilst the strong aggressive feelings he has are safely projected on to his daughter (the use of projection is discussed further in part iii of this chapter). A little later I feel brave enough to ask Jacob Doors directly about aggressive feelings towards his daughter. He has no hesitation in concurring (1). The two examples he gives are interesting, the first to do with her own self-destructiveness (2) the second to do with her breaking the 'sexual' boundaries in their relationship, as he suggests she was jealous of the attention he pays to a young woman (3). It can be argued that both of these produce aggression because they reveal aspects of the relationship which are beset with

ambivalence and are thus difficult to manage. Her own self-destructiveness accords too well with his own aggressive feelings towards her; the sexual boundary overstepped serves to reveal the libidinous nature of intimate ties. Perelberg (1983) identified the breaching of sexual boundaries as being an important factor in "the accusation" of mental illness within families. The importance of the observance of sexual boundaries will be explored further in Chapter 8. ("The Myth of the Family"):

DJ: Do you sometimes get very angry with her?

JD: Yes, yes . oh yes . often in fact (1). When she worked with me I'd be absolutely fuming, she'd do something, I don't know why. . . it was quite irrational, other people said it was quite embarrassing, oh yes . . . Yes definitely, I've hit her on a couple of occasions, just a clout around the ear on a couple of occasions. Happened . she never believed in smoking and neither do I, one day she came in when she was 18, came back from the pub with her boyfriend, Greek boyfriend Tony who she was with. And she came in stinking of cigarettes, stinking of cigarettes, she'd been smoking (2). And she says "So what?", me spending all of my life talking to her about smoking, and her agreeing with me! And just to say "So what?" so cheekily, I felt my hand go 'wop wop' and it was back by my side before I even thought. [edit] . . . The only other occasion I can think of, there were only two apart from when she was small and I used to smack her back-side when she did things like hurting snails or things like that . er it wasn't usual . . . [edit] . . . and another time was when we went, again when she was a bit deranged. We went to Sainsbury's that was when I was a bachelor, as it were, went to Sainsbury's and there was a girl there behind the counter and I started chattering to the cashier and I don't do that normally and on this occasion I did, she was about twenty I think. I said "Oh you look like a French girl like you see in French shops", which she did. 'Oh thank you, thanks a lot'. And April piped up "He says that to all the girls!", making me look some dirty old man, I don't actually. That so annoyed me, and er she was doing that to spoil me chatting to the girl so I think (3). .and then she said something else when we got back to the car, and I was unloading the groceries and that was when my hand came up she got a clout, before I reacted, she was clouted before I had time to think. The jealousy element there might well be some truth in that, she might well have been jealous of me chatting up, she was trying to spoil my chances with that girl then. So there might

well be some truth in it. [edit] Yes I 've been angry . . She's got the ability to get me annoyed very, very quickly I've got to control myself at all times.

In a second interview with Jacob Doors I felt able to go further and explore whether he was aware of harbouring 'murderous' feelings towards his daughter. I frame the question carefully:-

DJ: Some families say, when things are really bad . "Sometimes I wish they had taken that bottle of pills, they said they were going to take", - to kill themselves, things would be easier. Have you ever thought like that?

JD: Er . . I'd say it has crossed my mind, yes. Don't think I've, I don't think I've verbalised it, even in my own head. But erm . yes it has, it has . I have thought about this . rather than the terrible wait, yep. I imagine people feel guilty about it as well. . . . But it is a strain, and a strain is a strain, I mean I've . made it less of a strain by just cutting myself off from April unless it's necessary- to the point of being abrupt, abrupt with her, you know sort of down to earth. It keeps a barrier between me and her and also, I like to think it helps her as well, rather than sort of moping . "Oh dear I hope you don't hear those voices any more" I tend to be "Oh well you're not on about that again are you!?" or "Not this god lark!", you know . and er . so I don't know . I think it might do it better. But yes I can understand someone thinking that, yes, yes.

iii) The Fear of betrayal.

Whilst anger is very commonly present in grief it can be, as the above example highlights, particularly poignant when someone is seen as suffering from severe mental illness. There is another source of ambivalence that is perhaps more specific to these cases. We have seen how the people do see their relatives as having fundamentally altered in an important way. The ill persons 'self' is seen as having changed, or it is covered over by illness, almost as though they have become someone else. A fundamental discontinuity is experienced between the person that was with the person that has become. However, this is not the whole truth. In other ways the person is still around. Physically they are not altered. There are very often signs, or even appearances, of the old self still detectable (Creer 1975).

Therefore, another, and connected, aspect of the ambivalence in the case of the bereavement studied here is that there is difficulty in reconciling the person that is lost with the person that has become. This is a different, and perhaps more difficult, process to negotiate than the reconciliation that is associated with straightforward loss. In the latter the bereaved must come to terms with a new situation that includes the absence of the lost person. Here there is a rather different situation, the apparent loss of a person accompanied by the emergence of a different person.

One woman who was able to offer particularly valuable insight into the mourning process was Mrs Mansell, who has had experience as a bereavement counsellor. She makes it clear what a difficult grieving process is involved in accepting her husband's illness. She was separated from him at the time of interview but, since they shared a son, contact persisted. She describes feeling that he uses something up within her (1). However, she cannot move on from this because although she knows she is grieving, that she has lost the person he was, she still sees him. He is not dead (2):-

DJ: How do you feel about Alfred now?

IM: Part of me has to see him sometimes. One thing is I can't grieve properly, if he'd had died you know what to do, being a bereavement counsellor, I know what to expect, what to do and you can perhaps make a new beginning, but with Alfred he's never asked me whether I have a relationship with anybody, I haven't, but he just takes it for granted that I'm here. I don't think I have anything left for another relationship (1), [edit] . . If I see him, that shows me that he's not dead and that although I'm grieving (I know it's there it's true) I find it difficult to know that he's in the world, he's not dead (2) - why's he not with us, because we'd like to be a normal family with a teenager, he's 14 in April, I would dearly love [him] to have daddy, but acknowledging that daddy couldn't cope anyway. The rest of me can do with out that.

The ambivalence of grief is therefore doubly reinforced. To move on from the grief is not only difficult because it involves a betrayal of the memories of the past (as in 'normal' grief), but is difficult because the person is still around, however much altered.

Mrs Christian was very conspicuously caught in the middle of traumatic grief. I met with her several times with a gap of two years between two recorded interviews. The interviews were in many ways very similar. She was highly involved with her son, his condition seemed to dominate her life. She visited him in hospital every other day. During both interviews she became very tearful. Her feelings about her son and what had happened to him were clearly very painful. Twenty-five years on from his initial hospitalisation and diagnosis, she was still traumatised and grief-stricken. I believe that this can be understood in terms of her reluctance to let go of the hopes and love she had for the person that he had been. For her, to do so would feel like a betrayal of that person.

Mrs Christian herself came from an Irish family and her late husband from a Greek background both of which, at least according to stereotype, would suggest 'close families'. This was confirmed by Mrs Christian who indeed saw a great deal of a wider kin network. In spite of this, it seems as though Mrs Christian actually feels quite isolated by her experience with her son. She is isolated by the feeling that her experience cannot be understood by others. She gains a great deal of support from her local National Schizophrenia Fellowship (NSF) branch, where she meets those who have had similar experiences.

When I ask her about what support she gets, her first point of reference is her relatives (1). However, neither families nor friends can really understand what it is like; there is a gulf of understanding (2) in that she feels that people expect her to have got over the bereavement (her son had been diagnosed as suffering from schizophrenia at age 15, he was now 40). She then goes on to describe what happened to her as something that is "crippling" (3). This very direct appellation of her own distress is, however, then amended and effectively displaced from her. Mrs Christian recasts the description - the pain is then depicted as coming from "watching" her son suffer from "a crippling illness" (4). I think that within that couple of sentences is an important truth about these relatives' experiences. I think that Mrs Christian does feel *herself* to have been crippled by what has happened to her son. However, she

feels guilt at reporting the damage that has been done to her (by her son⁸), whilst she still sees her son as continuing to suffer. The only way to diminish her pain would be as though "turning [her] back on them" (5). As Marris (1987) has suggested ambivalence is at the core of the bereavement process. This is the central ambivalence of this grieving process, to move on and live life would feel like a betrayal, not just of a memory (in the case of loss through death) but of a person who is still very much around and suffering:

DJ: Do you have people you can turn to?

LC: Yes . I have lots of relatives (1) . . I think sometimes they think, relatives and friends, that you should be used to it now (2). I feel that's what they think, but you don't get used to it, how do you get used to such a crippling (3). . . , watching someone suffering from such a crippling illness (4). It's not on . . it would be turning your back on them (5). You can sometimes stand back, and I do, you know try and be objective, there's still the pain and the hurt is there. . . .

My train of thought here was fixed on stigma, so my next question is slightly out of sorts with what Mrs Christian is talking about which was her feelings of grief. However, I do pick up on what is being expressed about the gulf of understanding between herself and her family. I believe this consciousness about other people not being able to understand her experience to be terribly important in making it hard for her to negotiate her way through the grief process. Although her family are described as "good and concerned" (1), there is revealing reference to their (and her own) appreciation of Peter in the past tense (2, 3, 4). Mrs Christian jumps to talking about how Peter was some 20 odd years earlier when he was at school (5). I think what is being expressed here is how difficult it is for Mrs Christian to reconcile those memories of her son as a successful schoolboy with the experience of him as he is now. This is an ongoing conflict, not open to easy reconciliation; "I don't think that you can ever get used to it" (6). Mrs Christian then uses a startling phrase, that she feels as though she is "on the edge of the world" (8). Through this perturbing

⁸ Like Jacob Doors above it would be quite understandable if she harboured some aggressive thoughts about her son.

metaphor Mrs Christian gives voice to the feeling that her experience has isolated her. That as others cannot comprehend her experience, she is left feeling excluded, on the edge of the discourse of the wider community. It is toward the fellow members of the NSF that she turns for comfort (7). It is there that she finds some common understanding of the long term nature of the conflict.⁹

DJ: Is it something you find difficult to talk about, to people because they don't understand?

LC: Sometimes yes. My sisters are very good and very concerned about Peter (1), he was loved by all my family (2), he was such a pleasant child (3). He was never moody (4), never had problems with him . . . from an early age when he had homework he'd come home and start straight away (5). My family do care. Some relatives, I find, think I should be used to it. I don't think you can ever get used to it (6), and a lot of our members [of the NSF] (7), if you really talk to them, they would say that you just learn to cope with the rest of the family or for each other, you learn to cope that's all you do. Your living on the edge of the world sometimes, (8) but people find it very hard, I think, to know how I'm feeling, I don't wear my heart on my sleeve. I tend to say "I'm OK".

Mrs Christian goes on to make comparison with Tom, a cousin of her son, who has become a lawyer and a journalist. Mrs Christian seems to struggle with anxiety about the way that her son is not valued in ways that both he and she had perhaps hoped that he would be (through the early academic success).

Peter would ask me "How's Tom doing?", in the early days I found it hard to tell him that he's a journalist and a lawyer, doing very well (1). Peter would say "He must be very clever", I'd say 'Well, average he works hard for it'. Peter has this thing on his locker on the ward, something like "I am a genius I have a high IQ, if you don't believe me, ask the staff", he used to have it in the hostel as well. I said to him once, trying to get a reaction from him, 'Peter you're not living up to what it says on there, you could do lots of things, you could help yourself more, make life a lot easier for yourself'. "I suppose so he said". 'Why do you put it up there

⁹ There is more consideration given to both the phenomenon, and the implications, of 'group solidarity' given in the section on "Defence Against Threat To Identity".

Peter, we all know you're clever anyway', he said "I want people to think that I am a somebody, I'm not a nobody". I said: 'Of course Peter you're important, very important, don't ever forget it. You are a very important person to yourself, to me, to all the people you know'. It's very sad that he thinks that.

Hearing the contrast with the bold and angry statement of her son's worth at the end of that passage ("Peter you're important, very important, don't ever forget it") and the former exclusive references to early success, prompts me to ask about what he means to her now (1). I think her response is no exaggeration (2), there seems little doubt that the situation dominates her life. Again, there are echoes of Erikson's description of the struggle of integrity versus despair (1963, 1982). Mrs Christian suggests that it dominates because she is on her own with it. Professionals have failed, and family don't fully understand. Only with fellow members of the NSF is there some common understanding:-

DJ: What does Peter mean to you? (1)

LC: Everything really (2) . . . I will always fight for Peter, as he's not able to do it himself. I don't care who I upset along the way, I shouldn't have to do this . . . [becomes tearful] . . . it should have just been there, "Yes we'll try and help him, or find a suitable place for him", If I was pushed, I would take it to the European courts. The Fellowship have been absolutely fantastic, Dean Waddington [from her local NSF] he's a very strong man he knew I was on my own, he has a son (I don't think he's reached Peter's stage) . . . you never have to explain to them how you feel, they know exactly how it feels.

An interesting question to address would be why the group solidarity that Mrs Christian has experienced has not been sufficient to help her move on at all from her current position. I am honestly not in the position to suggest why, but I would guess that it is to do with other experiences she has had, to events within her own biography. Unfortunately, to really gain a better understanding would take more time and probing into areas that did not seem appropriate within the context of the research interviews.

Summary.

These relatives' experiences must be understood in terms of a bereavement process. It is, however, a highly complicated bereavement. Whilst the commonly considered bereavement processes that accompany loss can be seen as being beset with ambivalence, as Marris has argued, the process in this case is peculiarly prone to ambivalence because:

(1) Anger is likely to be a strong feature of their experience, and they are likely to feel anger toward the person who they also feel to be ill and therefore deserving of sympathy.

(2) Alongside the loss of the old person there is the experience of a new person to accommodate to. There is a fear of betraying the 'old' person.

There are yet further complicating factors to consider. The next section examines the influence of the stigmatising status of mental illness on the relatives. The process involved in the navigation through the bereavement process does not simply proceed in isolation, but involves an engagement with the wider community as continuity of meaning must be found. Wertheimer (1991) studied the experiences of people who have lost relatives through suicide. She describes how people were very positively helped in their grief by realising that other people loved and valued the person that had been lost. Thus comfort was drawn from the finding that their distress and their understanding of what has happened has a coherence and value within the discourse around them. Unfortunately for the relatives interviewed in this study, the feelings of shame and stigma that were associated with mental illness were often an impediment to engagement with the discourse of the wider community. As Mrs Christian put it so effectively, she feels "on the edge of the world". The issue of stigma will be explored in the next section.

(ii) SHAME AND IDENTITY.

Stigma or Threatened Identity.

The study of the association of stigma and mental illness has a long and distinguished history. To some the very existence of the concept of mental illness can be understood in terms of stigmatisation. There has been an impressive literature on the effects of labelling people as being mentally ill (Scheff 1975, Goffman 1961). I was therefore specifically interested in the relatives' experiences of stigma. If the topic did not arise naturally I would ask about it. I was interested because I thought that the experience of stigma would have implications for people in that it would limit their access to social support and restrict their willingness to seek help. Whilst this initial concern was undoubtedly highly relevant, what I found was that enquiry into the experience of stigma offers suggestive insight into the nature of identity and family relationships.

Some people were very open about their experience of stigma. For example Mr Ajani is quite candid in saying that he does not tell people about his son's difficulties because he feels they would look down on him.

DJ: Do you find it easy to talk to other people outside of the family about what's going on?

MrA: No, not that sort of thing in a society, in my society you don't talk about that sort of thing.

DJ: Why is that?

MrA: Because people would take the mickey out of you, you see what I mean?

DJ: People would look down on you?

MrA: Yeah.

Most interviewees were (perhaps paradigmatically) not so frank in talking about their experience of stigma. The problem people had with talking about issues that involved shame were noted in Chapter 6 ("The Causes of Mental Illness"). Merrell Lynd (1958:64) comments on how difficult it is for people to communicate about past experiences of shame, because to do so involves a reliving of those feelings. It might also be that talking about feelings and life events is seen as positive in our culture. To admit to feeling inhibited about talking about something may itself have been shameful.

Stigma By Association.

Goffman (1963) gives three classes of stigma: (1) Those involving physical deformities. (2) Those comprising of blemishes of character involving personal history such as criminal record, unemployment or mental illness. (3) Those which attach to groupings of "race, nation, and religion", including social class.

The stigma experienced by the people interviewed here does not quite fit comfortably into any one category. At first glance their experience might appear to be 'stigma by proxy'. These relatives are not experiencing a threat to their identity (to use Goffman's term) through being seen as mentally ill, but by association with someone who is seen as mentally ill. Yet, some of the interviewees in this study seemed to feel a very direct threat to their own identity, as though their identity were continuous with a person seen as being mentally ill.

Consideration of their experience may give us important insight into the nature of intimate relationships. This feature of identity can be construed as operating at both a psychological and social level. On the one hand it can be seen as an aspect of a psychological process of identification¹⁰, on the other it speaks of the social norms and beliefs that people hold about what it means to be 'related' to someone through

¹⁰ Note that this does not seem to have had to have been an early infantile identification. Mike H. (large sections of the interview are given in Appendix E) was eight before he met his sister who he now seems strongly attached to.

family.

Here the very distinction between the social and the psychological realms seems to dissolve: the more closely the private and intimate worlds of experience are examined the more the tangled amalgam of those experiences and the social meanings and constructions of those experiences becomes apparent.

The dilemma that these interviewees face is that the person who they are identified with is also seen as being someone who, in public eyes, is discredited. The people interviewed did experience parts of themselves to have come from others. Hence when that other person became discredited, so were they.

When I ask Mrs Peters and Carol Peters about stigma, Mrs Peters tells me first of all that she experiences stigma within the family (1). Carol suggests that her own acceptance of the situation has reduced her own feelings of being stigmatised (2). The significance of what acceptance means will be returned to (in Chapter 9). The strategies that people adopt to cope with stigma will be discussed in the next section of this chapter. For now it is worth noting the implication being made that the experience and affects of stigma are at least in part a matter of 'internal' dynamics. Carol is able to talk more freely about what has happened since she has accepted that things have changed. Mother and daughter then both angrily compare the large amount of publicity and funding that AIDS has received with the attention given to mental illness. They feel isolated and unhelped. The reference to AIDS here (3), with its associations to sexuality, death and shame is surely notable. In spite of the fact that Carol can talk about having ameliorated the effects of stigma by reaching an acceptance within herself, stigma still goes on.

DJ: Yes . often people have difficulty talking outside of the family . .

MP: Yes that is quite true, it is still a terrible stigma, there's no doubt about that. I mean I have aunts and things who never mention his name (1). They never ask after him, they ask after the girls, but they will never ask after him. It is a stigma yes it is.

CP: Mmm . I find actually myself, I will talk more freely than I did, I have to say, I suppose because after so many years of going through what we've gone through you accept it (2). And it's just a fact of life, it's there. And so . . . yes I do talk about it freely, but I think with certain people you can see a look cross their face because they're not made aware of it, it's not something that . you know there isn't a hell of a lot of publicity about it.

MP: Well we didn't know anything about it let's face it.

CP: No we didn't, we didn't know anything about it, but also it's not . it's not the sort of thing that's trendy to be part of. Do you know what I mean? I can't explain it, it's just . . .

MP: AIDS is of course (3).

CP: Everybody is going on about how ghastly AIDS is.

MP: It is ghastly.

CP: It is ghastly, people are dying of it, but people are also dying . . .

MP: Six hundred million pounds was given to AIDS at the last . . .

CP: The trendy charity, everybody is giving to, doing something for AIDS and nobody is doing anything for, let's face it, an illness which has been around for centuries. AIDS has just only come into being, I mean you know . . .

Carol Peters goes on to express her feeling that she is stigmatised, as a relative, within the hospital system (1). Both mother and daughter talk about how Donald feels ashamed of his illness (2,3), perhaps this enables them to talk about the feeling of shame without admitting that it is a feeling provoked within them by him:

MP: But people don't want to know [about mental illness], you see.

CP: But that's what I'm saying, mummy the staff don't even want to know as far as the family is concerned! (1) Let's face it. I mean not the nursing staff, they don't

want to talk about it to you. So that's what's got to change, the training of the staff has got to change right down on the bottom level of the ladder it's got to change and then the thinking will change, I think, going all the way up. You know it is an illness like any other illness. Like Donald prefers, he used at one point to say he'd got cancer didn't he? Because .

MP: He's ashamed (2).

CP: Because he . he is ashamed (3). And also with that psychotherapy, they made him feel ashamed. You know, "You've got to pull yourself together and get on with life", you know it's that sort of attitude.

Jason Manula was able to offer further eloquent insight into the nature of the connection that he feels with his brother. In the following extract I ask him about the communication he has with professionals about his brother. His answer is to tell me about the frustration he feels with professionals who are not responsive, in spite of the fact that he is revealing things about himself. The strong language that he used when talking about revealing himself to people (2) suggests, certainly anger, but also something else - perhaps disgust (again there is a sexual connotation suggested by his choice of word), as he attempts to share his experience, to be understood (1):-

DJ: Do doctors and other people talk to you about what they think .

JM: Do the doctors? No not at all. No they don't . . . you're the first person who has spoken to me about this, and normally when I have taken him to a hospital I have really tried to explain what it's like (1). I've tried to, in some cases, even exaggerate a little but just to make them take notice but, you know, it's so frustrating you know you walk away thinking 'Why the fuck (2) did I go in there in the first place? Why did I reveal all those personal things about myself and my family if they're not going to be responsive?' . OK they have a lot on their plates, that's how I justify some of their actions but I just . .

As the interview with Jason Manula continues things become plainer. Jason carries a strong reluctance about revealing himself to others. He does not trust others with information about his brother. This distrust is not confined to professionals but is

carried through to relationships with non-professionals. The meaning of the strong language he used becomes clearer. In talking about his brother he is revealing "this crap" (1); what he is revealing about himself is somehow something that others will find unacceptable. He would be revealing something shameful. Jason's conversation was by no means peppered with strong language. He swore only twice during the interview, on both occasions he was referring to self-revelation. Jason also expresses a dilemma that even though there is danger in self-disclosure, support from others is seen as essential. Jason feels that the fact that he has less support at the moment, due to other events in his life (2), has adversely affected his ability to cope with his brother as he becomes ill this time:

DJ: Have you had people that you can talk to, turn to for support?

JM: er . . . Friends, immediate friends. But even then after a while you don't want to encroach on their privacy, you don't want to take them for granted. And furthermore they begin to feel "I've heard this crap before" (1). And also I don't particularly want to go to people to relate this same thing year in year out 'Oh another crisis in the family', this type of thing, I mean people get fed up. And this time, as I said, I'm going through my own personal sort of problems as well, in terms of marriage and divorce etc.. And I've cut myself off from lots of people. I've less people to relate to this time now, at that level (2). And I think that's probably why this time I'm not even taking this illness on board.

Jason Manula feels reluctant to talk to others about his brother. He feels that he is stigmatised. This gets in the way of him getting support which he recognises helps him cope. Clearly this experience of stigma deserves more thought.

Shame.

The literature on stigma has been a largely sociological, or social psychological, one. This has meant that the focus has been upon the social processes involved in the formation of stigma, and the consequences of those processes. It will be argued here that there is much to be gained if the experience, the affects of the stigmatised individual are considered. It will be argued that the experience of stigma is tied to the

feeling of shame which Jason Manula expresses. There have been strong feelings expressed here involving a sense of disgust and anger. Jason's use of the words "fuck" and "crap"; the Peter's reference to AIDS suggests an involvement of the affect of shame.

The affect of shame has not been one that has been studied very much (other than obliquely through the study of stigma). Shame is the feeling invoked in us by what we feel to be inappropriate public exposure, or personal failing. To feel ashamed is to want to hide away, to hide our face. It is a powerful and elemental feeling.

Agnes Heller (1985) describes how the study of guilt has featured prominently within the field of moral philosophy, whilst the affect of shame has been quite neglected. Yet, as Heller points out, shame is interesting because it is apparently a most intimate of affects yet is one that cannot be conceived without culture. Most examples of shame involve the idea of having one's failings subject to public exposure. She argues for the great social significance of shame. It is therefore a concept which may be important in mapping the importance of subjectivity within the social realm.

It is notable that within the psychological, and even the psychoanalytic, literature the affect of shame has traditionally received little attention compared to the study of guilt. Since psychoanalysis takes as its subject matter the strong and intimate emotions it might be expected to have taken more interest. Thrane (1979) argues shame has received relatively little attention because "guilt is the less painful and repugnant. Shame is a more intimate and fearsome feeling" (p322). There is certainly no entry for 'shame' in Laplanche and Pontalis's comprehensive "The Language of Psychoanalysis" or Hinshelwood's (1991) more recent "A Dictionary of Kleinian thought". Further exploration of the reasons for the comparative neglect of shame by psychoanalysis is taken up in the section on the "Concluding Discussion" P.300).

When I go on to question Jason Manula directly about stigma it becomes clear that the credibility of his identity is at stake. It becomes apparent that the feelings of anger and disgust that he has expressed are serving to protect his identity (1) ("image" is

the word he uses) from the threat he feels he faces. There is a sense that there are parts of himself which are his brother, he carries around "traces" of him (2). Jason is concerned that the strong image that he would wish to project (3) is damaged by the traces of his brother which he imagines people perceive (4). He feels that others must conclude that he himself has a problem "deep down" (5). He therefore finds himself avoiding communication about this (6).

DJ: You mentioned feeling embarrassed before, is it something you have difficulty talking about to some people, you try and hide it?

JM: Yes I think the majority of cases, people who have a similar problem are embarrassed to talk about it . . . I mean sometimes it would be years later that you'd find out that somebody's mother, father, brother, sister has had a similar condition and at the time you discussed your problems they didn't relate that. . . Yes it is embarrassing I don't like talking about it especially to people I don't know very well. And also we all project a certain image (1) out there and once people will connect that flaw with you, they have a certain perception of you. I think some people for example, because when he gets into . a very, very bad condition people begin to think that there are traces of you . of him in you as well (2). When they open the door they look at you very closely to see how you look:- are you looking aggressive today or not?! . . . I mean it's like little subtleties . I mean it's the same thing the way I feel, if Harry knocks on the door right now the first thing I do I look, I look at him from top to bottom to see basically what mood is he in today, is he peaceful is he clean, is there a possible fight on the way? You know you just make an assessment the minute you open the door, and you can see other people doing similar things the way they assess you. I'm not saying it happens on a large, or overt scale but you can see that they seem to think that there is a weak chain in all the sort of image that you project . (3) . strong, confident whatever. Because obviously for your brother to be in that condition means that you can't be as strong as all that (4). In that you do have a problem deep down (5) as well and some people want you to talk about it, but you don't want to. Your family's life is likely to become simply a topic of conversation. If somebody is offering you concrete help then yes I tend to open up. But if it's simply while you're having a beer- "So how's Harry then? Is he still this, is he still that? What's he been up to?" If they want you to relate his latest antics, that I don't like (6).

Jason feels that people see that there is something lacking about him. His 'image' is damaged. For Jason it is as though his brother were a part of him. In a way Jason's identity is directly tainted. This is not stigma simply by proxy after all, the threat is more direct; part of him is "weak" because part of him is his brother.

Identification.

As the affect of shame seems triggered by fear that a person's identity, a person's sense of themselves, will be found lacking somehow: what do these people's experiences tell us about 'identity'? Goffman, typical of many social scientific approaches, sees the notion of identity in terms of 'demeanour'. As though our identities are like masks that we don for social purposes. Such a rationalistic notion of identity has been undermined for some time now. The most potent source of this subversion has been psychoanalysis. Laplanche and Pontalis (1988) give the following definition of the process of identification, through which identity is constituted:-

Psychological process whereby the subject assimilates an aspect, property or attribute of the other and is transformed wholly or partly after the model the other provides. It is by means of a series of identifications that the personality is constituted and specified. (p205)

As they go on to point out, (with my emphasis):-

In Freud's work the concept of identification comes little by little to have the central importance which makes it, not simply one psychical mechanism among others, *but the operation itself by whereby the human subject is constituted.*

Thus, our identities can be considered to be what we are. However, as the psychoanalysts have persistently underlined with their work on identification, this does not stop those identities from being complex and multi-faceted. Different aspects may be more or less prominent within different contexts. Identity has always been a notoriously difficult concept to fully define. Yet it would seem that an experience of

identity as being consistent is essential for a sense of well-being. Erikson (1968) defines identity as "a subjective sense of an invigorating sameness and continuity." (p19) He goes to elaborate this as being a process of constant interaction:-

. . . identity formation employs a process of simultaneous reflection and observation, a process taking place on all levels of mental functioning, by which the individual judges himself in the light of what he perceives to be the way in which others judge him in comparison of themselves and to a typology significant to them; while he judges their way of judging him in the light of how he perceives himself in comparison to them and to types that have become relevant to him. (p22).

Thus identity is a highly reflexive phenomenon, involving how we see ourselves and how we feel others see us. Berger and Luckman (1967:195) define identity as "a phenomenon that emerges from the dialectic between individual and society."

An argument for the importance of shame in the arrangement of identity, through its power to span the emotional world of the individual and the surrounding world, will be outlined.

Identity and Shame.

In the last ten years or so there has been an increasing interest within psychoanalysis in the affect of shame. The chief point of discrimination between shame and guilt is, crudely put, that guilt is about behaviour, shame is about being.

Piers and Singer (1953) produced an early formulation of shame the main themes of which have been developed in the more recent psychoanalytic literature (such as Chasseguet-Smirgel 1985, Kingston 1983, Broucek 1982, Rizzuto 1991). Piers and Singer (1953) distinguish guilt from shame in technical psychoanalytic terms: "Shame arises out of a tension between the ego and the ego-ideal, not between Ego and Super-Ego" (p147). In other words shame is the result of a person's perception of a discrepancy between their actual selves, and their own vision of their ideal self. Guilt on the other hand is a perceived discrepancy between actual behaviour and an

individual's idea of how they ought to behave. Jason Manula's use of 'image' (p. 222) is suggestive of this 'ideal self', the way he likes to be seen. This conception of shame and its relation to "ego-ideal" is one that is useful to this analysis. The concepts of super-ego and ego-ideal do not appear to have been distinguished entirely by Freud himself, the two terms being apparently conflated in his late work "The Ego and the Id" (1923). The distinction has been developed by theorists since then.

Briefly stated, the ego-ideal can be defined as constituting that which a person aspires to be. Chasseguet-Smirgel (1985), describes the ego-ideal as having its roots in very early infantile experience. Originally the infant is described as being in a state of blissful at-oneness with its environment. Only in time, and with the frustration of needs, does the awareness of separateness and thus of helplessness grow. In trying to reduce the ensuing anxiety the infant creates an ideal within itself (initially based on some idea of the maternal figure, according to psychoanalytic doctrine) with which it tries to accomplish unity. The infant tries to become itself the lost, blissful world it had experienced before separation occurred. The ego-ideal might thus be described as an unconscious vision (fantasy) of how things might be. In striving towards its own ideal an individual is striving to re-experience "the lost primary sense of at-oneness" (Chasseguet-Smirgel 1985:72) before the rude demands and deprivations of the outside world.¹¹

Piers and Singer on the one hand entirely concur with traditional psychoanalytic doctrine in arguing that an individual's ego-ideal is made up of:

the sum of the positive identifications with the parental images. Both the loving, the reassuring parent who explicitly and implicitly gives permission to become like him, and the narcissistically expecting parent and the parent who imposes his own unobtained ideals on the child . (p148).

However, they go further in claiming that the ego ideal will also be constituted of:

¹¹ According to Chasseguet-Smirgel, such intrusion will involve primitive feelings to do with sexuality and events such as toilet training. Jason Manula's use of strong language, "fuck" and "crap" might be seen as being indicative of this.

. . layers of later identifications, more superficial, to be sure, and more subject to change than the earlier ones, but of the greatest social importance. The 'social role' that an individual assumes in any given social situation, is largely determined by the structure of these developmentally later parts of his Ego-Ideal. There is a continuous psychological interchange between the individual Ego-Ideal and its projections in the form of collective ideals. It is important to recognise the images that go into the formation of this part of the Ego-Ideal do not have to be parental ones at all. The sibling groups and the peer groups are much more significant.

Parallels with sociological interest in the notion of identity are very clear in the above passage. It is this emphasis on identification and the social nature of those identifications which makes the notion of ego-ideal an important one. It is why Lasch (1985)¹², for example, can argue that this formulation of the ego-ideal "illuminates . . . the connections between psychic life and society", or Lowenfeld (1976) that it "preserv[es] social cohesion probably more effectively than do genuine moral standards." It is also important in helping to understand Jason Manula's and the other interviewees' experiences, as they feel that not only are their identities to be made up of parts of other people but that this identity is continuously constructed through interaction with others. Their dilemma is that a part of their identity is constructed around someone who is, in their eyes and in the eyes of the world, seen as having catastrophically altered.

I want to examine here one further interview with a sibling which usefully throws light onto the process whereby identity is constituted. This interview with Mary Galton is one where the effects of "tainted" identity became most marked. Her sister's illness seems to have had quite a dramatic impact on her. When I ask her how it has affected her, she uses the metaphor of being on "edge" (1). This was not the only interview where this metaphor of being on edge, or living on the edge, is used¹³. Here the words seem more to do with a feeling of nervousness, a feeling of frailty, or impending doom; as though the world itself is unsafe or unstable. Consistent

12 In the preface to Chasseguet-Smirgel's book.

13 Mrs Christian, in the previous section on "The Grief", suggests that what she has experienced and the difficulty that others have in understanding her experience leaves her "on the edge of the world".

meaning or the pattern of her life has been lost. In Mary Galton's case this can be understood in the context of her family history. Mary's father died when she was quite young. Her mother had emotional problems as did her younger sister so when Mary's elder sister became ill, even though Mary was already twenty-two, the impact was still very great. The identification with the sister seems likely to have been strong. Rachael was her "big sister", someone who could be depended on (2). It was not only a shock to discover that she could no longer depend on her, but it also "hurt" (3). This reference to an internal, subjective state of "hurt" suggests something beyond the practical burdens she goes on to describe following my prompting about "help" (4) - (showing I was perhaps failing to recognise the emotional significance of what Mary was saying at this point):

DJ: You say it scares you, I wonder in what other ways has it affected your life, seeing that happen to your sister?

MG: Um . . . Well you live on edge, you are on edge (1). Even now I'm on edge with my older sister, before . it was really shocking because when it first happened . . . ermm . . I'm going to be 28 . . . it must have happened when I was 22 . . And up until that time Rachael was my older sister: my big sister. She was my sister that I could count on, for god's sake! (2) And it was a hell of a shock to realise that I could not count on her. You know up until then whenever a problem it was like - she'll know what to do. And it hurt (3). It was a shock to realise that she couldn't help me, I had to help myself.

DJ: And you had to try and help her presumably? (4).

MG: And help her as well, and then I became . . and I still am now the boss, so to speak. What I say goes. To a certain extent if I . . she will come to me for advice I don't go to Rachael. She'll come to me for that advice . and it was a heavy burden.

DJ: So you became elder sister . .

MG: Yeah.

DJ: Overnight almost?

MG: Very, and I didn't like it! [laughing] I can tell you I didn't like that at all . . . For god's sake I'm not the eldest! That has put a huge responsibility on me and . . . Something that I do try to shrug off now and again, but it's something that is always there, it's always going to be there now, there's nothing I can do about it. When they've got a problem they come to Mary. So it has put a strain on me as well really.

Understandably there are practical burdens involved in taking on the role of elder sister. There is more to it than this, however. Mary does not visit her sister when she is in hospital. In part there seems to be something unsettling about the hospital itself; "it's too old, it's too horrible" (2). Perhaps the stigma attached to the hospital, its appearance and the atmosphere resonates too strongly with her own awareness of her threatened self, she feels the staff look at her as though she is discredited by her association with her sisters (1). There is also the suggestion of there being 'abuse' within the hospital (3).

DJ: Have you ever felt that, say people at the hospital, staff were blaming you, or the rest of the family, for what had happened?

MG: Well they did look on us as if to say, you know "Oh so your her sister, oh and your younger sister was in here" (1). As I say I cannot stand Friern Barnet, it's too old, it's too horrible, (2) the nurses don't seem to care and everything. Whenever I used to go . I did explain to them that, . . well I explained to my sisters once they were able to understand, it's not that I don't want to see them: I cannot stand that place. You know, so I didn't go as much as I should of, cos I'm only down the road, but I couldn't take it. I didn't like it at all.

DJ: It was upsetting to see her there?

MG: Yeah . I think . going back . that there is a lot of abuse there, I don't have any firm facts, but it's something that I feel and I know there is a lot of abuse in mental institutions (3) . . .

DJ: By staff?

MG: Sometimes. And by other people in there. .

Later this point, about abuse, is clarified when she talks about her sister having to be on mixed sex wards. She was not the only relative to mention this concern. That the anxiety is with sexual boundaries becomes clearer in the next chapter.

It was not only Mary's relationships with professionals, and with the psychiatric institutions, that were marred. Mary talked to no one about her sister's illness. She admits she does not even talk to close friends (1). Then, as if to underscore her feeling that she is isolated with the problem of her sister, Mary spontaneously tells me a story about her sister being taken to a party by some friends of hers, where she is sexually taken advantage of. It seems as though her friends and the outside world cannot be trusted to look after her sister. It might be argued that this is Mary expressing her own feelings of powerlessness to protect her sister.¹⁴ There seems also to be a concern with sexual boundaries and vulnerability. These are, of course, quite reasonable anxieties to have about her sister. However, what is remarkable is that the story is spontaneously associated to in response to my question about stigma. Chasseguet-Smirgel (1985), writing about the ego-ideal from a traditional Freudian perspective, links the affect of shame to primitive libidinal forces. It is certainly noteworthy that this was not the only interview where there were notably very emotional expressions of fear about the sexual violation of their relative. There is a very visceral quality to Mary's explanation, of why she does not talk to anyone else about her sisters' difficulties (1). There is something that is experienced as being a part of her. "It hurts" (2), "it just feels like a big pain in my chest" (3), the knowledge of her sister's exploitation has broken her heart (4). This visceral language demonstrates how literally, at a subjective level, the identification (incorporation) of others is experienced¹⁵.

14 This is perhaps an example of projection, which is discussed in more detail in the next section, "Defence Against threat to Identity". Perhaps she feels she cannot look after her sister and feels vulnerable herself.

15 Bott (1957/1968:149) discusses how kinship ties can feel very literal in her study of family and kinship.

DJ: Is this something you find it difficult to talk to other people about?

MG: Yeah, I don't tell anybody, even my closest friends. (1)

DJ: Why is that?

MG: It hurts to talk about it, it hurts (2), so I don't. I don't really discuss it with them.

DJ: What worries you about talking about it?

MG: Even to bring it out it just feels like a big pain in my chest (3). And . some of them people that, I know they know Rachael and they've seen what she's been up to . .

DJ: So they know that there is something wrong but you still don't talk about it .
.

MG: Mmm I mean like I nearly . two girls I know were up here, and she was desperate to go out and she rummaged in my wardrobe and found a dress and put it on. And somebody said "Look out of the window", and I saw the two of them taking her out to a party and I knew . .She was on medication at the time and she was drinking . and I told them earlier on- "Do not, do not, do not, if she comes round here" because one of the girls she was very close with that was her friend not really mine, it's just they were living close to here. I said to her "Don't take her out" and it broke my heart (4) to know that she . . that they was actually taking her out 'cos I knew they would not be able to look after her and they didn't. . . They didn't. For all she knew, . . she wanted was a good time, any man could have said whatever he wanted and got what he wanted . . . And that is exactly what happened. I didn't speak to them for over a year. I could have smashed their faces to be honest! But it wasn't their fault, I suppose it wasn't really their fault, what could they do?

Mary was a likeable, friendly woman, her talking about feeling she "could have smashed their faces" was surprising. The aggression is noteworthy (the next section discusses the relatives use of anger, as a "Defence against the threat to identity"). The degree of emotion being expressed, and perhaps the sense that she was telling me

something about her own vulnerability at this point, made me wonder about how stressed Mary really was. In response to my asking this directly (1), it eventually becomes clear just what a dramatic effect her sister's difficulties have had on her. Mary Galton has withdrawn into herself (2), she cannot trust people (3), she feels that people are laughing at her and her sister (4):

DJ: Do you ever feel all this is getting on top of you? (1)

MG: Yes I have, . . . I have. Even now sometimes I still feel like that. I don't feel I'm left to get on with what I want to do.

DJ: Have you ever tried to get help?

MG: What, for whom? Myself?

DJ: You, yes.

MG: Erm. No, not really . I haven't, no never actually . Never. I just become subdued sometimes just quiet. It's true you know, when you say . I'm very into my own self (2), a lot more than I used to be. I just find that you can't really trust people any more (3).

DJ: How do you mean?

MG: Well . . . I think I felt that with Rachael being like that, that they were looking on me and looking on her and just laughing . (4) .

DJ: People on the outside might look down on you .

MG: Yes . It doesn't really bother me as such, but just thinking about it sometimes I think 'oh god the latest episode of what she's got up to, bloody hell how am I going to be able to walk up the street!' [laughing].

By this point in the interview I am actually quite worried by her sense of distress and isolation, as the extent of the impact that her sisters' difficulties have had on her becomes apparent. I wonder whether she talks to anyone at all (1). Mary tells me

that she has considered getting help for how burdened she feels (2). She feels that forming sexual relationships has become difficult (3) because she feels that her own identity is so tainted (5), as she feels she is seen as someone who is susceptible to breakdown. She talks to no-one outside of the family. She feels that others just could not understand her experience (4). Unlike other interviewees, Mary could not even discuss her sister with others who had similar experiences (6). She sees no prospect of gaining a feeling of solidarity from sharing difficulties with others, such is the degree of the threat of exposure; in her own words there is something that is "locked away, shut away, . . . chucked away the keys" (7).

DJ: Do you talk to anyone about it (1)?

MG: No . . . no, no I don't.

DJ: That's quite a burden then?

MG: Doesn't feel like it. It's been on my shoulders for a long time . . . Doesn't feel like it. The next thing you'll be suggesting that I need some psychiatrist's help! [laughing] . . . Well actually I have thought sometimes, . . . I have thought about going to a psychologist just having a sitting out session of me telling 'em what the hell I want (2). But I haven't actually got 'round to that . . . Maybe one day when I've got some money I might do. So someone can listen to me for a change! . . . It's hard, I've cried a hell of a lot, . . . relationships I've had have broken up because of it (3). I find it very hard . . . um . . . in relationships to say that my sister has had a breakdown. I've even had relationships at the time when she's having a breakdown for them to even know that I've got a sister . . . Because you just don't know what she's going to do or say . . . And when they've found out . . . I've told them . . . when they've found out, they seem to you not, you know .

DJ: They way she behaves?

MG: They can't understand really . . . can't understand (4). and then they look at me and think "Well I wonder if she is going to turn out like that?" (5). In fact that can be a big issue really a lot of people think that I might have a breakdown or whatever . . . you know "I wonder if she's going to have a breakdown", I don't know . . .

DJ: How do you mean?

MG: Well . . . with Rachael . . . being . . . having a breakdown and my younger sister Alison having a breakdown and then with the other one being so bloody neurotic, you know! They might be thinking 'oh god this one going to be . . . have a problem' . . .

DJ: So just people looking at the family and thinking ohh .

MG: Yes, yes . . . They do, I think so. That's why I think I find it hard to discuss it really with anybody . . . I don't discuss it with anybody. Even at work, we have a temp' and her son is going through . . . has had a nervous breakdown and is in hospital at the moment and I wanted so say to her "I know what you're going through", but it wouldn't come out, it wouldn't come out (6)! And I was like looking at her when she was talking knowing exactly what she meant but I find it so hard to say "Oh, I know what you're going through" . . . It's just locked away, shut away . . . chucked away the keys, that's it. (7)

When I asked Mary whether her sister's difficulties had ever interfered with things like working, she explains that it certainly had. She felt she did not get a deserved promotion in work because the firm were aware of her sister's condition. She left the job and was working as a temporary member of staff in a financial company- "starting from zilch". Even her job prospects, she feels, have been adversely affected.

Mary Galton did seem to be in a considerable amount of turmoil and distress, which came over very strongly during the interview. To her, the chances of having her experience understood by others seemed so slim that it was not worth the further threat to her identity that would be involved in attempting to communicate with others. As will be discussed later on there do seem to be benefits in talking to others. In not feeling able to do this Mary is left feeling very isolated, confused and vulnerable.

Summary.

I think that shame was often an important part of these interviewees' experiences. The very nature of shame makes it difficult to discuss. To admit to feelings of shame in this context would have implications. Not only would it involve the exposure of a most intimate affect but would also mean acknowledging negative feelings toward the ill person. The issue of the difficulty of coming to terms with such negative feelings is one that will be returned to in Chapter 9.

What am I arguing in this section is that emotions, and particularly what are often regarded as being the most intimate of emotions, such as shame, operate and find their significance at the social level. Shame guides and constrains people in ways that more abstract rules, couched in the terms of reason like 'duty' or 'reciprocity' (whilst no doubt having their place and their influence) cannot. Both Jason Manula and Mary Galton have both been very involved in providing and seeking care for their siblings. Their commitment can be better understood in terms of the identification that they experience with their siblings, rather than through any appeal to the rules of obligation or reciprocity which rely on an economic model of behaviour. In trying to make good for their sibling they are making good parts of themselves. Their dilemma is that continuing contact with the real, 'discredited' sibling (if they cannot make them well again) will continue to threaten their sense of identity. It will continue to exclude them from the discourse of the wider community.

As Merrell Leaned (1958) suggests there is something about the experience of shame which implies a concern with meaning. In struggling with shame, with their own identity, these people are also involved in a struggle with the social meanings (in this case of mental illness) that they find around them. Hence the peculiarly mercurial quality of shame, being so personal and yet of such great social significance:-

Paradoxically, shame, an isolating, highly personal experience is also peculiarly related to one's conception of the universe and one's place in it. Apprehension that one's own life may be cut off from others, empty, void of significance is a terrifying thing, but fear that this isolation is true for others,

and that the world itself may hold no meaning is infinitely worse. Experience of shame may call into question, not only one's own adequacy and the validity of the codes of one's immediate society, but the meaning of the universe itself. (p.56)

The consideration of the role of the affect of shame in this context is important in elucidating the nature of stigma. It cannot simply be regarded as being a social process which operates exclusively outside of, and upon, the individual. For an individual to experience stigma they would not necessarily have had to experience disapproval from others. The discreditation, the discrepancy between how they are and how they would like to be seen may well exist within the individual. Penny O'Reilly in attempting to forcefully deny a feeling of being stigmatised as a result of her two brothers' mental health problems apprehends this dual aspect of stigma, it is how she feels about herself, but also involves feedback from others (1), her use of the word shame (2) suggests she is not as self-contained as she hopes:-

I think you really only experience that sort of feelings of rejection if you feel it yourself, if you feel stigmatised, if you feel that you could be tainted or you think people might think that you're mad as well that you experience that sort of feedback from people (1), you expect it. If you just say "I have two mentally ill brothers" people just think "Oh that's a shame (2), what a tragedy" and that's all, that's the only . the only feedback I've ever had from people: sympathy, pity, er . interest. People might ask questions but er . apart from that no, I've never felt that I wanted to deny that they existed.

The next section will consider some of the strategies adopted to protect themselves from the threats to their identity.

(iii) DEFENCE AGAINST THREAT TO IDENTITY.

I have been describing how continuing involvement with a family member who is seen as mentally ill is likely to have very ambivalent aspects. There is a complicated mourning process to negotiate. There is the felt loss of the familiar person to adjust to alongside the emergence of the new person (who is almost invariably seen as depleted compared to the old version). The feeling of loss is likely to elicit feelings of anger which people may have difficulty expressing.

In addition there is the exposure to threats to their own sense of identity; that sense of identity being dependent upon a coherent and consistent system of meaning which has been disrupted. Not surprisingly there appear to be identifiable strategies that people adopt to protect themselves from this threat to their identity, to ameliorate the feeling of shame which so threatens the coherence of the meaning that has been constructed. Anger may be provoked here too. Observers of the phenomenology of shame also note the common presence of anger (Nathanson 1987).

This section will discuss a number of strategies that these people appeared to use to cope with feelings that they might have otherwise found unmanageable, and with the threat to their identities that they experienced.

Splitting and Projection.

Melanie Klein developed the notions of splitting and projection as being key psychological processes. Briefly put, these processes involve the disavowal of unacceptably unpleasant feelings, such as aggression, through a number of mechanisms. Splitting involves dividing aspects of the world (including the self) into good and bad, perhaps serving to deny that unpleasant feelings are part of the self, or are part of a loved one. Projection involves the placing of unpleasant feelings onto someone, or something, else (Klein 1946, Hinshelwood 1991).

Shame involves the sensation that there is something lacking or flawed within a

person's self (Nathason 1987, Wurmser 1981). One could hypothesise from this that the triggered feelings of shame, perhaps involving feelings of inadequacy (or even self-disgust), may well be projected outwards. If there are feelings of anger and dissatisfaction around people will want to disown them and place them elsewhere. Indeed, we have seen in the previous section that shame appears to manifest itself in quite indirect ways.

As already outlined, the circumstances of the interviewed relatives were such that they were very likely to experience feelings of aggression towards someone who they also construe as a victim, and deserving of care and pity. Thus, a situation of considerable conflict is set up. The mechanisms of splitting and projection would seem to offer solutions. The way that some interviewees talked about fearing their relatives committing suicide, which was discussed in part (i) of this chapter as being a way of expressing aggression, could also be viewed as a form of projection. Their own aggressive feelings being disowned and projected onto their relative.

I will first of all present extracts from an interview which demonstrates the use of anger to erect a protective barrier to defend someone from feelings of stigmatisation. Following this, extracts from another interview will be presented in order to suggest that that anger can be further used to accomplish a withdrawal from the world.

Anger and Stigma.

When I ask Mrs Peters and her daughter Carol directly about their personal experience of stigma (some of their feelings of stigmatisation were discussed in the previous section p.217), Carol responds quite aggressively, this is surely very defensive laughter she is talking about here (1). Carol appears to use anger to protect herself. The anger she feels is being directed at others; the same fate is 'wished' upon others (2). Carol also seems to move to deny the significance of the judgement of the outside world on her. The outside world is belittled. She seems to just stop herself from saying "what you think doesn't matter" at the end of this passage (3):

DJ: Have you experienced people looking down on you because there is mental illness in the family?

MP: It's possible .

DJ: Besides staff. .

MP: No, no not the staff, I would think it was quite possible yes.

CP: You see I tend to er . like I'll laugh about it (1), "So what? I've got a brother with schizophrenia, there are an awful lot of schizophrenics around and that may happen to you!". That's my attitude - "It could be one of your children or it could be one of your, it could happen to your brother yet, or your sister", that's my attitude to it now. (2) [said quite aggressively]

MP: It isn't mine. [softly]

CP: It is mine. Lucinda's [Carol's sister] the same. We laugh - We will openly say- "So what? He's still a person he's still our brother, we still love him and that's that and what you think doesn't .(3) . really doesn't worry me any more, it did but not any more".

In the passage below the feeling about the outside world, her feeling that it is he who needs protecting from it (2), or at least from the adults in it, becomes clearer. Contrast is made with the innocent, non-judgemental child's perception of her brother (1):

CP: But what also comes into play, when he does get like that he'll phone us out of the blue . and if there are other people around, (I think this is what he is getting at mummy), when there are other people around and Donald is having an episode - our feelings towards it. We'll explain to those people that Donald has a problem and then we'll all try and deal with it there. I have to say, I've got a daughter of six and she . Uncle Donald is Uncle Donald, children don't see anything like that, which is marvellous about children (1). But she'll wonder why she hasn't seen him for so long like the last time she hadn't seen him for ages, and she kept saying "Well why not?"- "He's not very well" - "Well what's wrong with him?". And you sort of go

through that . And if there are other people in the house when he comes, . I warn them.

MP: Well he doesn't want to meet people.

CP: I do warn them, because I don't want them to make him feel like he's mentally ill. It's not like I'm protecting them, I'm protecting *him* (2)- because I know what he's like and if he feels sort of like this then he'll start acting funny anyway. But if people are normal with him and treat him as sort of my brother Donald then he'll be alright, but I do warn them.

There is a split of sorts. The outside world is derogated to an extent; it is the adults in it that make poor judgments. Thus, the threat to the integrity of their feelings towards Donald is averted.

Anger and Withdrawal.

Mrs Land's experiences feature in more detail in the Chapter 9 where it seems that she has particular difficulty coming to terms with the her son's circumstances (pages 270-276). With her, the anger seems to have gone further than with the Peters above. She appears to employ the anger to derogate and then to withdraw from the outside world. I spent some time questioning her about her experience of stigma. She reacted quite aggressively to my questioning her on this issue. Whilst she denied the experience, she actually denies any wish to talk to people outside of her family. The number of, very idealising, references to family (underlined in the following extract) are interesting and perhaps indicate a degree of splitting. I wondered if she has, in a sense, withdrawn into her family away from the outside world. In fact, elsewhere in the interview Mrs Land reveals that her family are not at all sympathetic to Brian and his problems (see p. 272), so the family which she withdraws into is a very idealised one. To say that the family she talks of is a 'fantasy' may not be too strong a word. The idea that the fantasy ideal or the myth of the family is an important organising feature of many of these people's lives will be returned to and developed in Chapter 8 ("The Myth Of The Family"). Meanwhile, and correspondingly the

'outside' world is derogated by Mrs Land, it is seen as useless and worthless, "I'm not interested in other people. I don't find people interesting . . ." (1):

DJ: Do you feel able to talk about Brian, to either friends, colleagues . .

ML: Only my sister . .

DJ: You don't talk to other people?

ML: No . .

DJ: Why is that?

ML: . . I don't have any friends . . . I only have my colleagues here at work, because I involve myself in my family. I find contentment with my family. I don't need to go out and find someone to talk to because I involve myself with my family, I'm happy, I'm quite happy to go shopping on my own, I do have women who like me to go and see them, I don't want to go, I'm a home-loving person. The only person I'll go with is my sister because we are very close, or I'll go with my daughters, or I'll go with my son, I'm not interested in other people. I don't find people interesting (1) because whether the people I associate with are only interested in talking about themselves . [edit] I can have conversations with them and we talk about different things . . but it's very personal to me . . If I spoke to someone who I felt could help me then I would associate with them, I haven't met anyone yet!

The way Mrs Land protects her identity is to withdraw. The threat to identity is not realised because she does not reveal what has happened to her son, she does not talk about it, it remains hidden. A process of splitting is already discernible, people outside of the family are seen as not good enough to share information with. To my quite indirect question, Mrs Land (below) denies that stigma has had any impact on her life (1). However, she doesn't think people will understand mental sickness (2) the only person with whom it is safe to share information with is someone else who has had a similar experience (3). It might be argued that such a person cannot be a threat because they are similarly threatened, they are in an equal position.

DJ: Do you think, maybe, that the difficulties with Brian made you more private?

ML: No I was always a quiet person (1), . . . although I'm happy go lucky - I'll walk around the office and I'll sing and I can talk to people and I can discuss my family with them . but when it comes to discussing a sickness, a mental sickness (2) I feel that people don't understand, because they type them . unless that person is actually experienced themselves, there is a girl here she had a nervous breakdown, she knows what it feels like, she has a brother-in-law he had a mental breakdown from drink . . . occasionally I talk to her about Brian because she understands (3), but I wouldn't discuss it with . I found the person that I am able to talk to, so I am able to talk to her. But the person sitting next to me, they're only interested in their own lives. 75% or maybe more are only interested in their own lives, they want to tell me about their families, they want to tell me about their sorrows and their joys.

When I ask more directly about stigma, Mrs Land's reaction is quite hostile. The vehemence of her denial surely betrays some insecurity. My questions are perceived as being aggressive. In fact I was aware of becoming more aggressive and almost confrontational at this point in a way that I was avoiding in other interviews. I think I was reacting to defend myself, and in doing so I was becoming quite aggressive, and so became part of that hostile world which Mrs Land withdraws from¹⁶:

DJ: Do you think people might look at you differently . . .

ML: No.

DJ: . . . if you told them about Brian?

ML: No. It doesn't bother me. To me mental sickness, and any illness, is an illness to me.

DJ: But I know other people say, they think other people will look at them differently, that others will look down on them?

ML: No . No. I don't feel that at all, I'm proud of my son .

DJ: I know *you* are, but I'm just saying that I know other people have said to me that they are reluctant to talk to friends and colleagues about their son or daughter because they think that they will be looked down on.

ML: No. You, . . . you see I feel confident enough that if I spoke to anyone about my

¹⁶ This could be seen as an example of 'projective identification', I have avoided the term since it is so open to conflicting interpretation (Hinshelwood 1991).

son I'm able to get across to them. Whereas there wouldn't be any of that, I don't believe that people would think that, because I know my own ability that when I start talking to someone they were able to understand. It's just the same to me as explaining to someone how to mend broken bones if I knew how to do it, and that's how I talk to people . .I've never found anyone yet, haven't met anyone yet who's been biased . I mean you hear about it, but I've never met anyone. And I feel that if I did meet somebody that I would talk them around it, so that they would understand, so I don't feel that someone's going to think my son's a loony, in layman's language, so it doesn't bother me.

The last sentence ("my son's a loony") brutally exposes some of the anxiety that she really feels and perhaps some of the aggressive thoughts that she harbours towards her son, which she busily projects onto others. Even in this interview, for a brief period, I become the aggressor, the purveyor of negative thoughts. Perhaps this helps her in her fight to maintain the integrity of her positive feelings towards her son.

This phenomenon of anger being directed outwards and the subsequent withdrawal from the world is one that is likely to be seen by professionals working with families. Its roots as a defence against the anxiety of a threat to identity are worth noting. Strategies adopted by professionals which exacerbated that anxiety (perhaps by appearing to lay blame at the relatives' door) would be counter-productive. They would very likely exacerbate the hostility and the withdrawal.

Group Solidarity.

The one person that Mrs Land did talk to, outside of her family, about her son was someone who had had similar experiences. Talking to others with similar experiences seemed to be an identifiable strategy used by some relatives. Again this can be understood as a defence against a threat to identity. Mrs Dear finds herself reluctant to talk to strangers about her son, like Mrs Land she does talk to someone she works with who also has a son with similar problems (1). A measure of how far this seems to set the two of them apart (which suggests splitting), is given by the turn of phrase here - "they don't have anything in common with us" (2):

DJ: What about talking about it to people outside of the family, are you able to do that or is it difficult?

MrsD: Most of my friends and people that know me, know that Bruce is not well, I don't hide it from them from the beginning . but to strangers I never really talk to them about it unless I have to, like now you come here I'll talk about it, but apart from that I don't really talk about it.

DJ: Why is that?

MrsD: Um . well partly because I think it is painful to talk about as well, you know, to strangers . . If I talk to anyone about it, there is somebody at work she has got a son who is sick as well like Bruce. And when she mentioned it to me then we can sit and talk about it as well, because I think we have something in common and she understands, you know we understand each other (1). Apart from that I don't see . I don't know, I don't think they might be interested to listen to us nattering away about our sick son, they don't have anything in common with us (2). But talking to Ivy, because she has been through the same thing she's got a sick son so we talk about it.

In this way the experience of stigma is avoided if exposure is restricted to those who have similarly threatened identities.

Group Solidarity in Formal Groups.

Several people were involved regularly in formal groups. The involvement seemed to perform two functions in that it offered not only the opportunity to share feelings with people who were not a threat, but seemed to play a role in providing people with knowledge (the importance of knowledge was discussed in Chapter 6 "The Causes of Mental Illness"). Mrs Christian was featured in the "The Grief" section (p.210-213) talking about how she found it difficult to talk to family because although they were sympathetic (there is no suggestion that they were any threat to her identity), they could not understand how impossible it was to get over that grief. She finds that understanding amongst fellow members of the NSF. It might be argued that there is danger of splitting here. The group being idealised and the rest of the world

derogated:

. . . . you never have to explain to them how you feel, they know exactly how it feels. They're maybe quite cheerful, but they know . . they know it's there, there doesn't have to be any words spoken. They were tremendous. I don't know what I would have done without them. Perhaps family wouldn't be the same because they're emotionally involved in a way.

Groups also seemed to be a source of horror stories, perhaps these provided reassurance that there were other people worse off. I did wonder whether the telling of these horror stories also served to give expression to their own very strong feelings, from the slightly safer vantage point of third person narrator. Mrs Peter's, for example, told me about a 70 year old couple who were terrorised by their son, and the psychiatric patient who became a paraplegic after a failed suicide attempt. He was then discharged with no back up or support: "He's killed himself now, actually, he made quite sure he did it properly next time."

Jean Karajac was the only other person interviewed who had any involvement with voluntary support groups. He got information from SANE, which he had heard about through a friend of the family. It was clear that the knowledge he gained was very important to him. He did not attend any support group, but obtained a lot of support from his network of friends, which he clearly valued. Some of these had studied psychology degrees and he found it helpful being able to talk with them.

Mrs Mason was someone who was not inhibited about talking to others, in fact she would talk to a lot of people about what had happened to her son, finding it gave her a feeling of 'release'. She still found the relatives' group she attended run by social services to be very important in that she heard from others in similar situations. It has been important to her to realise she was not alone in facing these difficulties. She also gained knowledge.

Big Families and Sharing.

Another feature of Mrs Mason's experience was that she had a large and closely knit family around her. They described sharing roles amongst themselves. At times they could alternate roles, giving one another a rest if they needed.

Being in large families seemed to be of considerable benefit to some. They were able to share information between themselves (group solidarity); they were also able to share practical tasks and burdens. The Cook family, for example, shared and seemed to gain considerable benefit from sharing tasks between them. The Blacksmith family took different roles within the family, allowing Terry to take up a particular new role. For Mrs Blacksmith herself, now in her 70s, she had other adult children who fulfilled particular expectations, such as having children and careers of their own.

Summary.

From the previous chapters we know that the relatives interviewed used what was essentially an illness model to explain what they perceived to be the fundamental alteration in their relatives' being.

In this chapter I have outlined some of the emotional consequences of having a close family member suffer in such a way. There is a very complicated grief process to negotiate. The identifications that exist between people are highly significant in determining how people respond to one another. Analysis of these relatives' experiences suggest that other people who are close to us are significant in our lives because we experience them as being a part of ourselves. Such a formulation of the basis for social action as involving essentially irrational processes is in contrast to the models that assume relations between social actors to be rooted in the rules of economics, such as the principle of reciprocity. These identifications whilst apparently being less rational do serve to explain people's continuing commitment to others' welfare. The next section will explore one of the strategies that people use to explain and bring order to this irrational world. It will explore the way that the language and imagery of 'the family' is used to structure aspects of emotional life.

CHAPTER 8.

The Myth of the Family.

"Love and all that business."

Introduction.

When I was interviewing relatives I often found myself very moved at the degree of commitment, and the deep concern, they showed for the ill family member. I also sometimes felt puzzlement. "Why should they be so concerned now? What keeps them involved in a relationship which often seems to be so painful, which they seem, on the face of it to get so little out of?" As has already been mentioned (p. 120-121) I was most aware of carrying an attitude of puzzlement to the interviewing with siblings. With hindsight, I think that I took parents' continuing involvement for granted as to me it fitted with how things are supposed to be. In my own world of assumptions: parents are supposed to be devoted to their children. It was only with siblings that I found myself, suspending 'common-sense' and asking 'why?' during the interview.

When I began to seek reasons for interviewees' continuing involvement, I often found my puzzlement, seemingly, matched by theirs. Not that they seriously questioned their own involvement, but that they found it hard to give explanations. Instead there were doubtful, shrugged phrases like "because she's my sister", or "he's family". I began to see that what was happening could be understood as though the words and imagery, the ideas that surround 'the family', were operating as a myth. There were things going on that could not be explicated in rational terms. In the same way that I had not really questioned parental involvement in rational terms, some of these relatives did not question their own involvement with each other.

For example, in this extract, Sam Mason uses the phrase "he's my brother" (1), very emphatically. It is a justification of his loyalty to his brother in the face of a society which may not comprehend, and also in the face of his own acknowledgement that

his relationship may be handicapping to himself in certain circumstances (2):-

DJ: Other people often say that they feel that outsiders might look down on them because there is mental illness in the family, has that ever occurred to you?

SM: I don't care to be honest . I mean initially, possibly . if you was walking down the High Road and if Charlie had an outburst or whatever . he used to think he was a boxer or whatever, he used to sort of box [laughing] . . or if you're sitting somewhere and he'll start pacing up and down . and initially I was concerned. But then after a while I thought 'Sod it' you know what I mean? OK he's er . .he's MY BROTHER! (1). He's my brother and it doesn't really matter what other people feel, you know if they had someone and they were physically sick which is more acceptable to society then they'd attend for them, they'd look after them and I sort of feel the same . if he's ill then I'll look after him. It limits the sort of places or whatever activities you can get him involved in . because . I don't know I suppose fortunately a lot of people that I associate with know him and know of his illness so it makes it acceptable. I don't know how I would think if I was going to take him to a family's home who was quite well-to-do and we was going to discuss or have a social evening that was going to somehow be beneficial to myself . .(2) (then I would worry about him being there if he wasn't rational at that time) [TAPE TURNED OVER] . . I don't but you can't take him to a concert or big do . Again it depends on his condition, if he's stable I'll take him anywhere. And I'll introduce him as my brother and if they were to ask I'd probably say "Well he's OK but he's got a bit of a problem" or whatever . But I don't shy away from telling people . . I don't really care what people think, I really don't, I don't.

Fred Bryant seems to make a similar recourse to stating the fact of his relationship as an explanation of his continuing involvement with his son (1). This is the reason at the age of 60 for his giving up his life in the North of England, living with his son in a squat, and then an unfurnished council flat:-

DJ: What's made you be so involved, you said yourself before that a lot of families drop out, they can't cope any more, but you've kept going . .?

FB: Well I suppose . . . it's really because he's my son (1), and there are certainly times when I just don't ever want to see him again. There's certainly those times

. it's like . to really give you the answer to that, it's like I'm the only one there, there's no one else for John, if I disappear that's it, . .

Also Martin Jenkins talking about his son:

DJ: Obviously it's financially difficult but also isn't it very draining, upsetting for you?

MJ: For me? No . It is what you produce it is your kid. It's your kid. He will upset a lot of people, some people aren't able to cope with it . . Some people won't but you has . because he's my son . I could say well alright I can't cope with him and push him in Friern Barnet or where for ever, you know what I mean?

Liz Regan also emphasises her familial ties to her sister, as explanation:-

DJ: What do you think is different about you compared to your brothers, what made you try and do something?

LR: I think I felt more closer to my sister than anyone, I've been more near to Cathy than I have my brothers . well even if my brothers wanted help or needed help I don't think I'd refuse. I'm not that sort of person. It's just that I had to do something . couldn't stand back and do nothing . .I mean she's family, if you can't help your family, you can't help nobody . . .

Mr Ajani makes recourse to the notion of blood:-

We didn't even get help from that time, we kept going there, they said "We have no social worker, we haven't got this", I said 'This boy is becoming' . . not a nuisance because we know what was happening . . to us, as a father, as parents, it is not a nuisance because he is our blood . I know something was wrong. But there wasn't any help.

Mrs Gazza also refers to blood when I say that some families find it so upsetting that they have to stop seeing the ill person. "No", the sister-in-law tells me, "he is their blood, to stop going there would be very hard".

I want to discuss the interview with Mike Harris which features in detail in Appendix (E). I was particularly struck, puzzled even, by his attachment to his sister. I therefore spent some time pursuing reasons for his continuing involvement, somehow convinced that there was an explanation. Mike has a great commitment to the welfare of his sister. Yet, they live very different lives. She periodically spends time sleeping rough in parks, Mike lives in nice house in Barnes (a rather leafy South-West London suburb). Yet the attachment to Marjorie does seem to have a visceral quality about, that the concern and protectiveness is extended to include her partner Ken is touching.

Mike was evacuated in the war (and then his return to London was delayed) and so was 13 years old before he met Marjorie. Any thoughts I might have had about the significance of early attachment and sibling identification (as in Goetting 1986) had to be revised. There does not seem to be much reciprocity in material or 'service' terms. The lack of reciprocity in what might be called conventional emotional terms was equally clear: Mike gets no obvious support from Marjorie; I was certainly not given the impression that she was someone Mike would turn to in a crisis. Somehow any notion that he is maintaining face, that he needs to be seen as the sort of person who cares for his sister seems woefully inadequate. Why does it happen? What is the nature of the commitment?

During the interview I used the contrast between his own commitment with the non-involvement of his brother to try and explore his motivation (1). Indeed words like "obligation" (2) and "duty" (3) do get used, but the situation is complex. He felt obliged to help his parents as they were elderly, they found it hard to cope with a daughter who could be violent. But his helping entailed the distress of forcing Marjorie back into hospital. These are no dry calculations being made. Twenty to thirty years after the events that distress is still tangible:-

DJ: Have you any idea what is different between you and your brother that's kept you involved? (1)

MH: Jim's involvement . . . I think secretly Jim was ashamed of Marjorie. Jim was like you, he was a University guy and he was a little bit, I'm not saying you're !.

, I mean I'm just . I just had a normal education. Jim did very well, he passed the 11 plus and he went to University and he did very well. And he . I don't know he . . almost wanted to brush . he wanted to brush that side away, it seemed. . . Um and of course I did to some extent have an obligation (2) to my parents, they needed help and . . I suppose it was being duty (3) bound to some extent. Because nobody wants to take responsibility for trying to get . to put anyone in hospital or to enforce - to make her go . . in the days just after she had become ill .

DJ: Was that something that you found quite upsetting?

MH: Yes, absolutely. Because a couple of times it literally became necessary to restrain her because if you . for instance you'd go into the room and say "Well Marjorie. We've got to go back now", you'd use all sorts of things to say "Well if you don't go back now you'll have to go there and you'll never come back again", or "Your opportunity for coming back at weekends will go, because . .", you know, and even then at times she'd resist that and it became in the end almost a case of getting hold of her and taking her to the car. And then she would kick and punch and swear and it was physical. It literally was physical. The . hmmmmm . . [looks upset] . and my father was infirm he just couldn't, he couldn't manage her. And there was no-one else really, I mean who? . . you see it wasn't a police matter, it wasn't . who else to call on to . in those circumstances?

DJ: Your brother was away was he?

MH: No, he lived quite close actually, but p'raps he wasn't as earthy as me, if that's a description! [laughing, but very sadly] . .

At another point Mike mentions a promise made to his mother:-

MH: . . And I always promised my mum that I would, my mum was absolutely fearful about what would happen to her when she died . er , .and I did promise my mum that I would look to Marjorie and see what was happening to her.

At several later points during the interview, I again push the question of what keeps him involved. At one point using his own observation of the lack of visitors some people have at Friern as contrast (1):

DJ: What do you think kept you involved, kept you visiting, as you noticed yourself a lot of people do drop . (1) .

MH: Drop off . yeah . . . um well . I suppose, she's my sister. It's indefinable . . . it's something that's there that you . . er . um . the visits did tail off, yes . . oh yes . 'cos my life took a turn, my wife's death made a difference . . . I mean I could reel off a number of cliches, it's difficult to say why you go . . you say you love her and all that business and you still do to some extent, there's got to be a spark there . . I can't really elaborate on that one.

And again a little later:-

DJ: Could you ever imagine dropping out, not wanting to see her?

MH: No I shall go on seeing her Yes because I want to. There's no other explanation or reason . . .

And yet again a little later:-

DJ: You seem very attached to her?

MH: I am, yes . . yes I am . she's got a . . you can't help feeling sorry for Marjorie she's . she's a very caring . she'll always give me a kiss and say . . um . . she'll say "I love you Mike" whether it's, I don't think it's born out of a desire to be, I don't think I'm an insurance policy of sorts, no . it's spontaneous. . . . It's a terrible thing to happen to anyone. Because it's . . she's gone from being a bright, nice looking girl, there's a picture . [gets up and gets photo from shelf] . that's a school picture . she was quite pretty, when she developed into a young girl of 16, 17 she was very pretty . . . now . . yeah she's let herself go . . it's been a total, total waste of a life. She's had to under go all that deprivation and . . in a way it's worse than . . in lots of ways it's worse than death. .

DJ: For you?

MH: Well it goes on and on . . there seems to be no end. I don't know what the recovery rates are, but I don't think there's hope of recovery . . .

The Myth.

What is apparent is that all my probing and questioning, my search for a rational explanation of these interviewee's involvement, kept on hitting a wall. Although Mike Harris raised the possibility of his sister staying involved with him for material gain, even that is dismissed. So far as explanations for his own involvement, we seem to hit a wall of what he refers to as "a number of cliches", such as - "she's my sister", "love and all that business". From hearing similar comments in other interviews I was led to think that what I was hitting could be seen as being the edge of rationality, or in Foucault's terms, the limits of discourse. Perhaps what was being expressed in the exasperation at the lack of words was the feeling that there is a world outside the scope of our rationality, that often there are not words to describe our experience. Maybe what has traditionally emerged to describe the links between people are 'rationalisations' that are summed up by terms such as 'obligation' or 'reciprocity'. Without these rationalisations we are left to fall back on what Mike refers to as "cliches":- " . . she's my sister. It's indefinableit's something that's there that you . .I mean I could reel off a number of cliches, it's difficult to say why you go . . you say you love her and all that business . . ." Words like "sister" seemed emblematic of something deeper. After a number of interviews where I met the same 'wall', I began to think of the use of words like family, brother, and sister as being used as though referring to something 'magical' or 'mythical' that was invoked to 'explain' what was otherwise inexplicable.

Levi-Strauss (1972) has argued that family relationships are the natural territory of myth. For family is the space where biology and culture come face to face. Levi-Strauss has argued that the Oedipal myth of Sophocles:

. . . has to do with the inability, for a culture which holds the belief that mankind is autochthonous . . . to find a satisfactory transition between this theory and the knowledge that human beings are actually born from the union of man and woman.(1972:216)

He goes on to argue that Freud's use of the Oedipal myth is consistent with this

interpretation in that Freud applies it to a situation to 'explain' how we are born of two, but feel as though we have one ancestor. I wonder, however, whether the Oedipal myth of Freud is better seen as bearing upon the inconsistency of our experience of ourselves as being of culture (rational) and yet our knowing that we are born of biology (irrational). According to Freudian doctrine the infant's introduction to the Oedipal conflict is the point where the infant's instinctual drives run up against culture, the point where society 'enters' the individual. As Frosch (1987:49) writes "The oedipal matrix is thus a symbolic matrix . . . It is the realisation by the child of the sexual and power structures of reality, of how the world is organised." Myths provide a structure to live by, they hold society together.

Of further relevance here is Schneider's (1980) study of "American Kinship", which was referred to in Chapter 1. He highlights the pivotal role of the family in contemporary American culture, in balancing "the order of nature on the one hand, and the order of law, the rule of reason, the human as distinct from the animal, on the other hand". (1980:36) On Schneider's analysis the two orders must exist side by side, and it is the family which "resolves the radical opposition between nature and human reason, bringing the two together in a workable, livable human arrangement." (1980:37). Schneider also draws attention to the way that relations of blood are privileged relationships. The belief that "Blood is thicker than water", Schneider argues, is such a taken for granted as a fundamental truth of Western culture that, like a myth, it is not questioned (Schneider 1984).

Freud (1921) had observed how other groups, besides families, cohere to a, perhaps, surprising extent. He notes the meekness with which individuals submit to group expectations, and believes only libidinal forces can explain this. Lacan, picking up on Freud's work argues that such a "bond of love between members of the church or comrades in arms was established by discourse" (quoted in Descombes 1980:106). In other words it is discourse, the shared understandings and meanings, which provides the structure which holds people together in groups and societies. That structure, however, although it may be analyzable in rational terms, is itself made up of forces that are essentially primitive and irrational (in Freudian terms, they are libidinal).

"The family" can thus be justly regarded as a myth. By this I do not mean a mere invention, or chimera, but a device that offers a means of structuring what might otherwise be alarmingly powerful and arbitrary fragments of emotional experience.

For someone to feel that their experiences are beyond discourse, that the social myths (of which family myths are particularly potent) are no longer coherent can be extremely alarming¹. As Mrs Christian described to me, she feels as though she is on the edge of the world (and thus produced the subtitle for Chapter 7, see p. 211).

Levi-Strauss's depiction of parallels between the function of the shaman and the psychoanalyst, observing how they both seek to establish people within discourse was referred to in Chapter 6 (p196-198). The suggestion being made is that it is very uncomfortable for people to live without a coherent framework of meaning. The ministrations of the shaman and the psychoanalyst (and the counsellor, the psychotherapist, or the priest) give meaning and structure to people's experience, which would otherwise remain private, inexplicable and therefore without order and ultimately frightening.

Whilst the discourse of the family has a rationalising function, the substance of family relationships has little to do with rationality and economics. The 'myth of the family' gives meaning to troubling and disparate forces. It might be seen as a useful sack in which the uneasy emotions of human experience like love and hate can be placed and kept separate within its own discourse, away from the required rationality of the rest of society, the market place in particular. As Busfield (1974:170) writes of family relations: "They are subject to a set of ideas, values and beliefs that do not readily correspond with those that dominate other social relations . . . family relations are one of the few bastions of values that are antithetical to capitalism."

However, as Roland Barthes protests, myth is not simply a passive vessel into which we can pour our experience but (1973:117) " . myth has in fact a double function:

¹ Perhaps also witness the particular and devastating distress caused by child sexual abuse, where the sexual boundaries within families have been flouted.(La Fontaine 1990).

it points out and it notifies, it makes us understand something and it imposes it on us." Myths do more than cover up, myths direct and order us. To Barthes this role of myth carries with it a sinister political function:

. . . myth is depoliticized speech. . . . Myth does not deny things, on the contrary, its function is to talk about them; simply, it purifies them, it makes them innocent, it gives them a natural and eternal justification, it gives them a clarity which is not that of explanation but that of a statement of fact. If I state the fact of French imperialism without explaining it, I am very near to finding that it is natural and goes without saying: I am reassured. In passing from history to nature, myth acts economically: it abolishes the complexity of human acts, it gives them the simplicity of essences, it does away with all dialectics, with any going back beyond what is immediately visible, it organises a world which is without contradictions because it is without depth, a world wide open and wallowing in the evident, it establishes a blissful clarity: things appear to mean something by themselves.(p143)

Such admonition being attached to myth resonates with critiques of the family, particularly the feminist critique which sees the family as a construct which serves to "naturalise" the patriarchal status quo (Barrett and Macintosh 1982).

On the one hand, then, the myth, or discourse, of the family is an important structure to which otherwise troubling feelings can be attached and hence given meaning, this will be explored further in terms of the 'Wishes Framed By Family'. On the other, it is a force which shapes and constrains, playing an important role in ordering intimate, particularly sexual mores.

Sexual Mores.

Denise Jodelet (1991) studied the difficulties encountered in the integration of a group of psychiatric patients in an "ordinary" rural community in France. She concludes her study by focusing on the fears that the resident population had about transgressions of sexual boundaries that might occur through their taking psychiatric patients into their families. These fears of contamination, she argues, were a major obstacle to integration.

The particular significance attached to sexual mores or the breaching of those rules could often be seen in the material of this thesis. What was also apparent in studying these families who had someone who was seen as "insane" already amongst them was the manner in which the ideals of family, the ideal of successful relationships were prominent in their aspirations. The people I was interviewing did not have, or certainly had not chosen, the option of complete exclusion from "the insane". The concern with sexual boundaries can first of all be seen in the importance given to the recognition and rupturing of sexual boundaries in the initial recognition of mental illness.

i) Sexual Boundaries As A Signal Of Difficulties.

Perelberg (1983) in her study of families and mental illness observed the breaking of sexual boundaries was often the trigger to the "accusation" of mental illness. I have already drawn attention to the significance of the sexual boundaries between Jacob Doors and his daughter (p206-7). He also remembers what made him face that she was becoming disturbed. He recalled her coming home at age 15 telling him that a bus conductor had broadcast accusations that she was "a slut" to everyone else on the bus. It was then he thought "that someone slightly eccentric was actually hearing voices [and] didn't quite know how to cope with it".

Mr and Mrs Snellman mention one of the first things they noticed about their cousin becoming ill was that he began to imagine he had girlfriends, firstly imagining intimacy between himself and their daughter and later pestering a young woman where he worked until she made a complaint about him. Mr and Mrs Coles found their son's overtly sexual behaviour (bringing home sexually explicit magazines and discussing sexual matters with them) very difficult to cope with. George Christodoulou's sister-in-law felt that he made inappropriate sexualised advances to her, which she found very upsetting and difficult to manage.

ii) Concern with Sexual Vulnerability.

As well as sexual behaviour sometimes appearing to be a signal that there were difficulties, there was more often a concern with the vulnerability of their relative; a fear that they will be sexually taken advantage of. This is important in that it suggests that Jodelet's (1991) interpretations of people's fear of contamination through contact with insanity needs to be considered further. On the face of it, my own observations might suggest the opposite; that these relatives were worried about their own ill relative becoming contaminated by the outside community. Perhaps this emphasises how the central anxiety is with the observance of the boundaries themselves, rather than necessarily with contamination by what lies on one particular side. Conceivably the reactions of the citizens of Ainay-le-Chateau, studied by Jodelet, are not symptomatic of their fear of insanity itself, but of the way insanity, by definition, does not recognise the boundaries and rules which are seen as necessary to live by.

The interview with Mike Harris, which appears in detail in Appendix (E), showed him getting emotional (and angry) early in the interview about feeling that his sister was taken advantage of sexually 30 years earlier (p332). Fred Bryant's sacrifice in moving to London to look after his son can be understood as a reaction to the apparent sexual exploitation his son had suffered in becoming involved in male prostitution.

Mary Galton in the section on "Shame and Identity" presented her angrily emotional description of friends taking her sister to a party where she was taken advantage of (pages 229-230). She was also very angry and upset that her sister lived on a mixed ward, where she might be 'abused'.

It was notable that anxiety was also expressed about male sexuality. It did seem that, according to these interviewees, it is not exclusively female sexuality which must be protected or controlled. Penny O'Reilly was disapproving of her brother being on mixed wards when he stayed in hospital. Jason Manula worried about his brother's

vulnerability when he is not well, spending time in Kings Cross, and mixing with prostitutes.

Wishes Framed by Family.

In contrast to the fears about sexual vulnerability, when Jason Manula describes his brother when he is well, he focuses particularly on his ability to sustain a relationship with a girlfriend (1) and behave well towards her. This is perhaps the flip-side (to use Jason's word) of the concern with sexual vulnerability, that to be successfully involved within a long-term relationship is seen as highly desirable:-

DJ: You said he has been quite well for the last couple of years . what has he been like then?

JM: My brother is a very different person when he's well, he's calm, quiet, loving, considerate, helpful you name it. It's the flip-side of the coin . .he's very different when he's well, he's a good communicator he's fun to be with . . um . and he's responsible very responsible . . when he's well, for example in the case of relationships he devotes himself to one girlfriend (1) at the time and he'll give her his all, he'll share his last penny with her, he's that sort of person. So you can imagine to see that transformation, you know it's painful . . and it's very worrying because as I said earlier you're not sure whether he's going to survive or not because every illness has become deeper . you just don't know what's going to happen, what the outcome will be.

In Chapter 6, ('The Causes of Mental Illness') it was shown that some people thought that their relative had become ill in response to having been rejected in love. That such theories can be held is testament to the assumed power of intimate romantic relationships. It perhaps also suggests that the achievement of romantic fulfilment was seen as a very significant goal. This is confirmed by the following sections that refer to the loss of the family ideal, or of the family aspirations that people have.

The most important observation of the manifestation of the ideal of the family was

the way in which the relatives' hopes for the ill person were often framed in family terms: having a family of their own or at least a girlfriend/boyfriend. To be successfully involved in such a relationship is to partake in the rules, to be included in what is seen as an essential aspect of social discourse; to be part of the structure.

Mr and Mrs Snellman, for example, do not apparently have to worry about their cousin's financial future, as his grandmother is leaving money in trust for him (1). However, their worries are for his "purpose in life" (2), his aims seem unrealistic (3). There is an apparent lack of structure, of any continuity with his own past (4). What he endures is having "no real personal relationships, no girlfriend" (5) :

DJ: Well, how do you see Erik's future?

Mr: We just don't know, the only thing one can say is that when his grandmother dies there should be sufficient money from this trust for him to be able to live comfortably (1) . . . But that isn't the point, he's got no purpose in life (2), no motivation . . .

Mrs: He's either chasing rainbows (3), like the sort of life he would have had imagined himself to have whatever that is, he doesn't really know . . . I asked him quite recently, "Erik, when were you happy, what do you remember?" Dear, oh dear, what could he think back to? Nothing. Not really anything. (4)

Mr: He's had no real personal relationships, no girlfriends as far as we know (5) .

Mrs Rivers thought the fact that her daughter had always been quiet may have meant that problems stayed wrapped up inside, causing her difficulties (1). Becoming an adult is seen as a vulnerable period, when children might become bad, become a thief (2) or a prostitute, or have children (too young presumably) (3). She also noted the fact that her daughter did not have a boyfriend (4) which she felt might have provided her with a reason to get better (5). To have a boyfriend would be normal, it would be protection from deviancy (again it is sexual deviancy which is salient):-

MR: . . you don't know why - because I couldn't take it at first when it's happened to her, when she took sick, because I said to myself "Oh a 16 year old girl having a nervous breakdown? - Nothing to worry about" but it's happened younger than her. You see because she is quiet is the thing about it, quietness has a lot to do with it, I'm sure quietness has a lot to do with it as well. because when she quiet everything is wrapped up, see? Everything wrapped up inside (1). If a person coming out from the children stage, some kids coming out from teens, reaching teens, and they turn bad they become really violent thief (2), some come like prostitutes, some have children . (3) . it's very hard growing up . . you know what I mean, it's a hard life and she is not like say she have a boyfriend (4) she has something out there to fight to get better for, you see, she don't have nothing to fight for. (5) So it's harder with her. . . .

Mary Galton believed very firmly that her sister should fulfil her family duty and take more responsibility for her son who is cared for by the father. She also responds to my very open question about the future with a wish that her sister finds somebody nice, settles down and gets married. (1) This wish is associated with protection from breakdown (2).

DJ: How do you see the future for Rachael, for yourself?

MG: For Rachael, . . I said to her you know, I hope she's able to find somebody nice she's got so many guys after her, she's unable to make a choice. I said to her 'Sometimes you just can't have everything, you know'? . If at least if there are some qualities you can work at it. . . I hope she finds somebody really nice, settles down and gets married. (1) Doesn't have to . . erm have another breakdown (2).

Similarly Vicky Reece hopes that her brother: "gets a job and is living a normal life. But at the moment he is refusing to work, he says he is still not well enough to work, . . and for him to come off the medication, have a girlfriend and settle down."

Sam Mason was painfully aware that he could not take Charlie into his own family (1), this left his brother without a family (2), without the motivation to keep himself well (3):-

. . I'm not sure if we can ever find a solution, sometimes I just accept that it's going to be an ongoing thing because . . we can't take Charlie in you know, we can't fully take him in to our family (1) . he hasn't got a family of his own (2) so to speak, he hasn't got a relationship so the stimulation and motivation that he needs are not going to be provided (3). So you sense that he's going to come back to a point where he has to be put back into hospital . .

Molly Quinn does admit that she experiences giving support to her sister as quite a burden on her (1), it is a struggle for her. However, she sums up the attitude of many relatives in seeing that the support that she gives as the only positive thing in her sister's life (2):

. . even now sometimes if I'm fraught when she rings, I feel 'oh god', you know?
(1) Yes I still feel that, but I try to master that for her sake because I feel she doesn't have much in this world, you know sort of ., all she's got is the support of her family which if we withdrew that she would have nothing (2).

Elly Blacksmith also draws attention to how crucial she feels 'family' is to her son Terry's current welfare, and how little her son would have if he did not have them. If family were not around it would have to be replaced, social workers for example would have to do more.

In a rather different way, Jean Karajac reflects on his own and his sister's life (1). There is a sense that Jean's fate is entwined with his sister's somehow. That his sister is poor at handling relationships has particular significance (2). For her to be normal would be to be a housewife, have relationships and a job (3). What is striking is his own feeling of commitment to his sister's future. The impression I got from listening to him, was that it was a rather grim, determined commitment. He tried to get a job with the mental health charity and campaigning group SANE in order that she might be able to work there too (4). He now hopes that he, with his girlfriend's help can do something for her:

. . It's getting to the case when I reflect on it I'm 25, my sister is 26 (1), if she's still the same, trapped within the same environment say within the next four years,

forget it, there's no hope. I mean you've got to look at reality; it would be too far, she would be too old to be given a chance of getting back into society and re-adjusting. She will really be just too old. I mean now, she's 26, she's got the maturity of a 14-15 year old, especially in relations (2), her handling of situations, which is a hell of a gap to make up. Now, if you can imagine the next ten years time it's almost impossible to imagine her being normal; being a house-wife, having relationships, having a job (3) . she's that far down the road and that's scary. I mean I also know the stat's about the numbers of schizophrenics who do end up killing themselves however much aid you do give them . . they're just facts.

DJ: Is that how you would . obviously you would like to see her like that, how hopeful are you that in ten years time she will be like that, home of her own with good relationships?

JK: Erm . . . I suppose the optimistic side of me says yes- we can do this, we can do that. Like I was thinking if I got the job with SANE (4) then I could have got involved, somehow dragged her to the office, sit her down, make [her] fill envelopes, make the tea or something make her feel useful. I kept thinking yeh that would be great, I progressed down that line of thought, it didn't happen so it's back to square one. What else can I do to get her involved? Hopefully . . my girlfriend gets along with people pretty well, she's worked for charities herself and I know she's taken some mentally handicapped peopled away for summer-camp for a week she's good at people, she's like that, . . and somehow she's never been able to get friendly with Janice, I hope that will work out so we can take her out and she'll feel confident, use a bus, she'll gradually become used to interacting with people, that's what I'm hoping. And then maybe get involved with, take her along to some kind of [?] . . there again if the opportunities do not arise then I don't think I can see a future. . .

As appears in Appendix (E) Mike Harris describes his feeling that his sister finding a partner was "the best thing that ever happened to Marjorie . he is her absolute companion" (p.328). Jacob Doors explains that in the past he used to hope that his daughter might meet a nice man who would look after her and get married (1,2). However, he has now come to the conclusion that his daughter's state somehow, crucially, precludes such a relationship (3). He explicitly associates insanity with the inability to love, to sustain relationships:

DJ: What do you think will end up happening to her?

JD: Ohhh this is one of these things I don't like to face actually. Realistically, . . . when I was younger, a few years ago . . . of course she's very attractive looking, and delicate, nice voice, I thought she might attract a man (1), possibly someone older than her, someone of gentle philosophical nature, sort of person who smokes a pipe and wears a velvet jacket. I thought it might attract her attention, and get married to her and look after her (2), that's what I thought, like David Copperfield and his child-wife. She is, however, quite a snappy, difficult person and think she'd reject David Copperfield and er . . . [edit] . . . So er . . . unless she fell in love with someone who fell in love with her . . . and looking at it logically I don't think April or someone in her state, I'm talking for all patients: none can fall in love, on a long-term basis. I think love and commitment and all the feeling, they need to come from someone who is sane, if they are not sane they can only love themselves (3). That's my view for what it's worth, I might be wrong, I hope I am wrong . . . I don't think so. I don't see . . . in order to love people you have got to understand people and feel for them, do things for them. If you are tormented by your own problems, there's no way you can understand or feel for another person and anybody that would perhaps spend time with you and try to be kind with you- it might by some sort of peculiar perversion might make you turn on them, I don't know why it should be but I just believe it to be the case. I don't know, I think it would make for tormented relationships one way or the other.

Promises To The Dead.

A very concrete manifestation of people's concern with living up to the ideal of family appeared as several interviewees mentioned having been asked to look after their ill siblings by parents who were dying. Mike Harris, for example, promised his mother he would look after his sister. Jean Karajac was told by his father when he was ill, just before he died, that it would be up to him to hold the family together. Kate Daley's mother asked that she and her sisters look after the ill ones. Kate was, however, disturbed that she did not feel she was doing that very well.

The Loss of Family Possibilities.

To some of the people interviewed the occurrence of mental illness has robbed them of something that can be understood in terms of a diminution of their own family.

Penny O'Reilly expresses very directly how she feels her brother's difficulties have left her, in mid-adulthood, with a diminished (extended) family. The question I ask is how she felt her brothers' difficulties (both being diagnosed as suffering from schizophrenia) affected her parents. The answer quickly comes around to herself and her awareness of how things might have been different. The loss is of the idyll of the extended family, of all the possibilities (1):-

PO: It's a fucking tragedy isn't it let's face it! I mean . . . I can't . . . I can't think how different their life would have been if it hadn't happened [sigh shrugs] It would be totally different, wouldn't it? . . . A totally different life. I mean you'd have two elder brothers most probably married with wives and children .it would be a different thing entirely . I'd have extra nieces and nephews, and two sister-in-laws and a much larger . and even so we've got three of us, and most English people only have two and we've got three who are normal, but to have five it would be . so you think of all the possibilities (1) like that. . .

One last, sad, example is Mrs Teague who was 73 years old when interviewed. Her husband had died ten years earlier. She does not get on with her other son. Her daughter, who is quite supportive, lives some distance away. Her son, Simon, has become ill and this has left her particularly bereft. She lamented how Simon had been such a good boy, nice, helpful and hard-working. How had he not become ill - "He would have been my hand and my foot."

Obviously the felt 'loss' of Simon is acute. He would be looking after her now. Instead she feels her future to be very insecure.

Summary.

This chapter has emphasised the very deep attachment that interviewees often had for their ill relative. Siblings' involvement was notable and surprised me, indeed there have been few very studies of sibling relationships and mental illness. The assumptions of one such study are significant and stand in contrast to the findings of this study. Horwitz et al. (1992) begin their study, of the strength and utility of sibling ties when someone suffers from severe mental illness, from a position of concern that siblings will not provide great support for the patient group, as:- "[t]he principle of reciprocity, rather than obligation, may underlie much assistance between siblings so that the flows of assistance run equally between both siblings" (p234). It is assumed that the sibling relationship is a voluntary one, and therefore will only be sustained by mutual benefit. From Horwitz et al.'s standpoint: "little instrumental advantage emerges for the sibling who provides care for another". Whilst their data are highly equivocal and suggest that siblings do often stay involved with an ill sibling, there appears to be a hierarchy of obligation operating so that siblings will not provide support in the same way as parents, spouses, or children. The most significant point about the study, however, is the model of kin relations that is being used and which deserves some further explication. The terms upon which the study is based have become very common currency within studies of contemporary kinship. The underlying assumption is that kinship networks function on the terms of the exchange of goods and services.

A recently published book reporting a quite substantial study which focuses on family support and helping behaviour in Britain is worth considering in some detail. Its frames of reference are highly emblematic of rationalistic social research, despite the fact that they present a lot of "qualitative material". Finch and Mason (1993:34) mark out the territory for their study by referring to previous work:

In much of the existing literature on kinship the concept of reciprocity is a key idea which is used in explaining the foundations of mutual aid in families. It refers to the way in which people exchange goods and services as part of

an ongoing and two-way process. Receiving a gift creates the expectation that a counter-gift will be given at the appropriate time. Though reciprocity can take different forms, it is widely seen as being central to the dynamics of kin relations.

However, Finch and Mason do see a limit to the usefulness of considering only the negotiation of the exchange of goods and services (1993:129). They introduce the 'moral dimension' by borrowing Goffman's term, "demeanour", or social reputation. They contend that material sacrifices might be made in order to maintain an image. There is thus a highly rational process seen to be going on. A calculation is being made with material costs and benefits being considered alongside gains in 'image' if people are seen to make material sacrifice. To Finch and Mason family relationships seem to be mere calculations, material losses are balanced against the positive benefits of enhanced public standing. Parents, even, give gifts to their children in order to "establish their identities as 'generous parents'" (1993:146).

The role of the maintenance of public identity or even the role of the exchange of material goods cannot be ignored as factors influencing family relationships. However, I hope that material presented in this and previous chapters illustrates that there are other important factors.

There are strong irrational feelings involved which are held together within myths, which considered as discourses, as well as giving meaning to our experience, serve to guide and constrain our behaviour. The notion of 'the family' can be justly considered to be such a myth. A myth which, in part, serves the function of bringing a degree of order to the affective ties between people, in particular the troubling world of affect we label 'sexuality'. The concern with sexuality came out in a number of ways. Interviewees showed how the rupturing of sexual boundaries could operate as a signal of difficulties, they also had fears about the sexual exploitation of their relative. The importance of the latter point was indicated by the profoundly emotional way that such fears were brought to my attention.

One of the most pressing difficulties facing the interviewees was that in coming to terms with significant change in their relative they were also having to come to terms with a seeming violation of the ideal of family. Their lives no longer seemed to fit the pattern of assumptions, of the discourses, which they found around them. The process by which people were able to adapt to this situation and negotiate new relationships will be considered in the next chapter.

CHAPTER 9.

MANAGING MYTHS: Levels Of Acceptance.

Family relationships are in many ways impossible relationships. The hopes invested in them, perhaps unconsciously, can be enormous and might be impossible to realise. What is important is the way that the gap between fantasy and reality is negotiated.

For any negotiation to take place, all pertinent factors must be allowed into the process. The many and varied aspects of the relatives' experiences have been highlighted through the preceding chapters. There is the struggle to construct coherent meaning around the confusing and frightening series of events. There is the complicated mourning process, the tussle with feelings of shame and the experience of stigmatisation: all taking place within the wider web of feelings, beliefs and expectations that are shaped by and within the narrative of 'the family'.

From listening to these relatives, it became possible to identify three groups who each took a different view of the current situation. These could be characterised as being representing different levels of progress along a road towards the acceptance of a changed situation. Whilst it would be wrong to suggest that there is any one correct way of progressing, it did seem that, the closer to the third level here, the more likely the interviewees were to experience a degree of equilibrium and contentment. The three levels that will be discussed here are:-

- 1) An acceptance that there has been an illness operating as an agent of change.
- 2) An acceptance of the long-term nature of the changes that were perceived to have taken place.
- 3) An acceptance of the person who had emerged from that process of change. This involves the renegotiation of the relationship. Perhaps also a certain distancing, or process of separation, is inevitable.

What will be particularly highlighted throughout this section is the way that the emotional aspects of people's experiences must be available to be taken into the process of negotiation. The powerful and often distressing feelings that people have, must take their place in the renegotiation. This is not always easy. Previous sections have highlighted the great ambivalence that is often involved in people's experiences. The problem is how do you renegotiate a relationship when part of your experience of that relationship is denied; when aspects of that experience are not based on rational judgements and choices, but apparently irrational feelings and impulses?

i) Acceptance of Illness Construction.

As seen in previous sections nearly all interviewees had come to an understanding of their relatives' behaviour as being due to illness. Mrs Teague and Mrs Lord were the only partial exceptions and even they were rather equivocal. These both felt particularly alienated from the health and social services, which was reflected in their attitude to me. Both were initially very suspicious of my presence, and refused to be tape-recorded.

Mrs Teague was ambivalent about how she saw things. She told me that she does not see her son's problems as being due to illness (it was the bad company, and smoking), but on the other hand she had got her doctor involved when Simon started behaving differently. She had not seen her son now for six months. Initially during the interview she was worried that I was there to persuade her to have him live with her.

Mrs Lord did not really see things in terms of illness and blamed the medical system for producing the difficulties he had. Neither woman had seen their son for a while, though neither was really able to discuss the negative feelings that they were perhaps harbouring. It must be said that my understanding of these two people is limited as they were not really engaged with the interview. In neither of these people was there a sense of their being engaged in a dialogue, with anyone, through which alternative understandings might develop. They were left feeling isolated, upset, angry and

possibly ashamed and guilty.

ii) The Acceptance of the Long-Term Nature of Change, and Acceptance of the Need for Long-Term Support.

The next stage of acceptance could be described as where the interviewees were acknowledging the long-term nature of the change in their relative, alongside an emerging acceptance that they are likely to continue to need long-term support.

Mrs Gazza and her sister-in-law were perhaps typical in that they are caught in a degree of ambivalence about Mrs Gazza's son. On the one hand they see him as being someone who needs full-time care for the foreseeable future, but Mrs Gazza still wondered about brain scans and wistfully said at one point "He used to be very kind, a nice boy. I would do anything to make him better. If only it was something like a brain tumour that could be operated on."

Mrs Land is a good example of someone who saw her relative as being changed by illness, but who had difficulty in accepting the long-term nature of those changes. She was a woman who seemed to be carrying a great deal of anger around with her. She had a prickly, brittle surface (which came out with me when I ask about stigma- see p. 239-242). She is angry with professionals, and angry with her family for not doing more. Her son has had very equivocal diagnoses from professionals. Arguably, perhaps, this has not helped her to become more reconciled to the present situation (what shared understanding can there be when there is no understanding?). It was very plain that she carries a dream of curing him. There is painful difficulty in reconciling the way he actually is, and what their relationship amounts to, with what she hopes it to be.

When I ask how Brian used to be, her first response is to mention having tape recordings of him as a child (1). Perhaps this, otherwise odd reference, reflects how solid and fixed is the memory of Brian's old childhood self which Mrs Land carries around. There is a lack of continuity between those memories and the way he is now.

His old self is not part of a developing, organic whole, but one that is frozen in time, like a voice trapped on audio-tape. Brian is described as a happy, talented child. I am given a quick run through of his achievements. He learnt to play the guitar, he wrote music (2). He was an electrician, becoming qualified very quickly (3). Then there is his relationship with his mother, the present tense is used "he's very close to me" (4), but not to others.

DJ: Did he use to be very different?

ML: Oh yes I've got tape recordings of him as a child (1), he was so happy go lucky, joking and he's very, very talented . He taught himself to play the guitar, he's even written his own music (2). And he went for exams to play guitar, he was disillusioned because he put himself up at such a level that was too high for him, he graded himself to a grade seven, in fact he was probably a grade five . He went for music lessons, he went . he was working . he was working up at [a shopping centre] he was an electrician. He qualified as an electrician within three years rather than five. (3) . And yet he was not interested in his school but he qualified as an electrician after 16, and he wrote this music . He even took music lessons with [guitarist], you've heard of him? . .So he's not stupid, not a stupid boy, he's very, very sensitive. And he's very close to me (4), but he will react against other people he says they don't care about him.

Sadly, as I ask her to expand on their relationship in my next question (1), there seems to be some self delusion here, an unwillingness to fully face the current situation. These seem to be small scraps of hope and intimacy being gathered up. The description of the shopping expedition is poignant as the significance it is accorded contrasts with the apparent superficiality of the communication between them. The most valuable moment seems to be when he becomes "his old self" (2), and takes on what sounds to be a child-like role ("What shall we do now mum?") (3). Again it seems to be the past that is being referred to here. A past where he is the child and she is the mother who takes him shopping and buys him clothes. She is also the mother who can look after him and make things better (4).

DJ: So he does talk to you now? (1)

ML: Yeh. Uh, I went to see him and all he would say was "yes, . no, I'm alright, don't worry about me", for several weeks and then I arranged to take him out and buy him some clothes and I took him to the shop and all he wanted was a pair of shoes. I took him to the shop and bought him these trainers and when he came out of there for a brief moment he was his old self (2), "Now what shall we do now mum?" (3), I said "Well what would you like to do?" And he said, "Oh I don't know anything you'd like to do", so he was back to his old self with me, alone. Then I looked at my watch and I said "Oh it's 5 o'clock I think you have to get back to the hospital because of your dinner ". . . He said "Yes I'd think I'd better". Any way we walked back, I walked back to the hospital with him . and he said "Goodbye", and while he was walking through to go into the ward I could see him and several times he turned 'round to see if I was still there or whether he had this feeling he was being watched, I couldn't say . . But myself in my position . . I have a feeling that if I had him home myself . he may begin to improve (4), he may agree to go to the hospital and have something done with his leg . . .But living at home with his family, with his sisters and that, I don't think it would work .

However, at the end of that passage, there appears to be a chink in the optimism: she doesn't really think it would work. As I ask her why not (1), Mrs Land goes on to give reasons why she could not have him home. They are all sensible reasons no doubt - her daughter and family live with her (2), and they are not sympathetic to Brian. (3) Her daughter is against the idea since she thinks that Mrs Land would not be able to stand the pressure again (4). However, these are all factors external to herself, and they do protect her from thinking about how he really is now and how difficult she finds that to cope with. She is able to continue to hope that she will be able to make everything alright ("when he was on his own with me, he was different") (5), if only the circumstances were right. Mrs Land's own personal myth of her family is protected:-

DJ: Why? (1)

ML: Because my youngest daughter is 25 now, at first she didn't believe there was anything wrong with him, she said it was put on and she would tell him off, try to talk to him, he wouldn't listen . . And then because he wouldn't listen she began to ignore him, which made it worse . . Now she lives with me, (2) she's got two

grandchildren, I've got two grandchildren . so and her husband lives with me and they both feel the same way about Brian .(3) .

DJ: She still does then?

ML: She still does, although she knows he's sick, she doesn't think that I could stand the pressure (4) and it began to get to me . . what with one on the one side and one on the other side, I just couldn't handle it. I began to lose weight, I began to worry, my mind was in a whirl I couldn't control him, and yet when he was on his own with me, he was different (5).

A little later I ask her what affect things have had on her (1). There is more anger expressed at professionals not doing enough. As discussed previously (p. 239) there is a sense that in her anger she is withdrawing into herself, where she can keep control of events (3) (she is referring here to have taken a social worker's advice in asking him to leave her home some years before). At the same time, what is really notable here is that she speaks of guilt (2). Then there is a very, very sad portrayal of her most recent contact with him when he had visited the family home. It is, however, a sadness which she seemed cut off from. She was presenting this to me as though it was a pleasant story, a story of hope. Again, it is although she is trying to get comfort from scraps of intimacy which might reinforce the myth of her family. She again evokes a time when he is the young child and she is the mother (3). Ultimately, however, there is sadness, there is no point in her getting off the bus. (4)

DJ: What sort of affect has this had on you? (1)

ML: Terrible, I worry about my son. I feel guilty about what I've done .(2) .

DJ: Guilty?

ML: I blame myself for putting my son out on the street. Listening to somebody else when I should have followed my own instincts. (3) . . I don't feel that the hospital is doing enough, they're doing quite a bit in one sense, they're keeping him there . . .Looking after him, he's not on the streets, the last time I saw him, was a couple, . . about a month ago. [edit] . . Anyway the last time [sigh] he came [sat

down for a while] then he went out of the door, five minutes later he came back and he started asking me for money. That's what he came back for. So I said to him "Well, Brian you get an allowance" I said "I suggest that you ask the nurse at the hospital"- that deals with his money, because he doesn't control his own money, she has to give him so much a day, 'cos he'll go out and spend it. "I suggest you go and ask her, because you are allowed so much a day". So he said "Oh alright mum", like a child (3), and off he went. And I haven't seen him since. So whether he's got disillusioned with me again because I didn't give him money, I have the feeling that's it. Occasionally, I see him walking down the street and I'm on the bus. By the time I get off the bus he's way off, gone. So I know there's no point in me getting off the bus (4).

Later Mrs Land talks of the dream she has of making things better. This involves being with him all the time (1), getting the best treatment in a private nursing home (2); treatment that would involve the family and her in particular (3). This hope, this dream she has, confines her to a relationship with her son in which she assumes full responsibility. Emotionally it is a mothering relationship where he might be a young boy. However, chronologically she is approaching retirement and he is nearly 40:

. . . if I was rich, if I had lots of money I would do the things for my son that I could do.

DJ: What would you like to do?

ML: I would take him out of there, .[edit]. . I would be with my son all the time (1) and then I would have him taken to a private nursing home, where he would get the best treatment, (2) maybe not the best maybe they are giving him the best now, but . . he would get treatment every day, counselling . . . people that he was able to associate with, people that would be able to bring out his interests through the family so that I could tell them what he likes what he doesn't like (3). That way I feel sure that he would be cured, but you've got to have money to do this and I haven't got that sort of money. That's why I feel so angry . . more anger than frustration . I know what I could do if I could. And in a way, I'm hoping that the hospital will do this, but if it comes to retirement and I find . . . I'll give myself a certain amount of time, . . that my son is not being helped I shall get angry enough to try and get them to do something. At the moment I know that my son needs to

recuperate to get to that point. That's why, I think, in the last six months nothing has been done about him. But when I retire, then I'll have the time to be able to try and do something more for him.

My asking her about her feelings about how much he has changed, again elicits a great deal of guilt (1), that Brian was damaged by her choice of partner (2):-

DJ: You said before how much he has changed, that must be very painful to you to see him very different?

ML: It's terrible to see my son go from what he was, and what he is now . . . I feel that it is all my fault . . . because of his . . . my personal circumstances and the things that he went through changed him from a happy go lucky boy into . . . a . . . very nervous boy. He was . . . beaten, because I was beaten. He tried to defend me, he was beaten.

DJ: By who?

ML: By the person I was living with (2), who was himself a schizophrenic . . . And he got so scared he left home. That was the beginning . . . well actually it wasn't the beginning . . . The beginning started when he was about ten years of age, when all this started. Then by the time he was 17, he wanted to leave home, and he had been affected emotionally . . . He couldn't stand what was going on, and eventually he did leave, but the damage had already been done, my son had changed. He was happy-go-lucky with me . . . and he was on a friendly basis with his brothers and sister but the damage had been done, the nervousness had started, you see.

It is in this context that we can see how difficult it would be to accept how different, how 'damaged' Brian is now, because in her own mind she feels herself as being responsible for that damage. She feels that the family that Brian was born into was not good enough, that it did him harm. Now she is stuck with the feeling that she wants to fulfil the role of mother, caring and providing for Brian. However there is another part of her which seems to realise that she cannot do this. She cannot even have him live with her, she cannot come to terms with the way he is now.

There is no sense of Mrs Land being able to work out a liveable arrangement at present. She appears to feel great responsibility and terrible guilt. As discussed in the previous sections, there is likely to be a strong measure of aggression being felt towards her son. Those disparate and contradictory feelings remained to be reconciled at the time of interview. They cannot be acknowledged, there is not space for dialogue to take place from which a new understanding might emerge. The anger, the shame and the stigma she experiences effectively keeps her out of dialogue with professionals, with colleagues and friends, with the rest of her family and even with Brian himself. Similarly, there was no space for dialogue for the two of us to talk about her feelings of stigma (p241-242).

Difficulty in physically seeing relative.

The acceptance of the illness model and of the long-term nature of the change in their relative, involve losses. What is most important is how these losses are accommodated to - or not. Mrs Land is someone who seems unable to face the reality of her son's current situation, so she actually does not see him. Chris Gryadogc seems able to acknowledge that his sister has changed and can talk about it, but has difficulty in accepting her as the person she is now. He lives just a couple of miles from Friern Hospital, but has not, in over 12 months visited her there. To see her in hospital would be to face what part of him sees as the "inevitability" (1) of "her illness", which is represented all too concretely by the stigmatising (3) institution. Chris himself suggests an association with the poor communication with the institution and the health authority (2). Since no communication is taking place, negotiation is not possible.

DJ: You mentioned feeling very upset, too upset to visit her [in hospital]. .

CG: Er..yeah . maybe that's tied in with what I can maybe see as her illness as being an inevitability (1), maybe it's going to go on for the rest of her life. I think I came to the conclusion that it would, you know. Unless something really radical was done, but I don't think, in the foreseeable future, it can be done because of the situation we're in here . And because we haven't been in communication in an

understanding relationship with the institution and the health authority (2). . That's the other thing the institution is locked up . and the whole idea . going back to the stigma of the institution (3), it's somewhere where they go and are seen to.

Later, the nature of the difficulty that Chris has in seeing his sister becomes clearer. He has mixed feelings about her returning to live at home, because he would really want the old, "childhood self" (1,3) of his sister to come home. However, Chris thinks he is wrong, and should "just accept her and her illness" (2).

DJ: How do you feel about Petra coming back here to live?

CG . . Er . . I'd accept it, you know as much as . because I'd have to and that's the way things are, you know. It's just readily accepted . I mean hopefully when she comes back she'll be better, she'll be more calm . . so she'll be more pleasant to deal with and she will be more pleasant . so . you know I do miss her, like I do miss . . . well I miss her yeah, the old her (1). But maybe that's . .er what I shouldn't be doing, you know, I should just accept her and her illness (2) . . and not expect her to get well- back to her old, her old self, her old childhood self (3) which I don't think is possible anyway.

On one level Chris Gyradogc knows that his sister has changed, however on another level, one that might be described as an emotional one, he does have difficulty accepting the person that she is now. So he does not visit her in hospital and does not look forward to her coming home. To see her in the flesh brings home the contrast between the old and the new. He does not know what kind of relationship he should have with the new person.

There appears to be an important distinction between what people 'know' at an intellectual level and what people believe, or feel, at an emotional level. One issue that I have been concerned with highlighting in this thesis is how important it seems to be for people to be able to incorporate the emotions they experience within coherent systems of meaning. The difficulty is that in order for emotions to be put within discourse they must be acknowledged and brought to the surface.

The Cook family were finding it very hard to reconcile the old, eldest son, with the new. Their son is now in his early forties, yet there are still references to his doing well in his O'levels (at around age 16 presumably) (1). There was a great deal of distress within the family. A lot of anger is expressed towards the hospital and the services provided (or not provided). Underneath this hostility the hope that he will become the person he was, if only the right services are provided is preserved:-

Mrs C: How will he get better when he is sent to such a degrading place [B&B]. . . such a bright boy. He got nine O'levels (1) at one sitting, didn't go to University straight away because he wanted some experience first. He worked for a firm, they said he should go to university, that they would employ him afterwards. He was so well thought of. He needs a place where we can visit him, where he can entertain people, he like to do that. He can't have visitors there, you phone up and nobody wants to say where he is.

Jason Manula sees his brother Harry as being ill, but does not really want to accept the new person that has emerged through illness. His brother has been reasonably well for a few years. Jason has had his brother back (3) over this period, but now feels he is losing him as he feels his brother is now deteriorating again. Jason is now thinking of leaving the country, in part, because he feels he will not be able to cope this time. Jason Manula seems not willing to accept his brother as a changed person, although he clearly "knows it" on another level. There is a weariness in Jason's account here as he describes what it was like to have had his brother back over the past three years (3), and there is rage and despair at the feeling of losing him again (1). The effect on Jason of his brother's illness is not minor, it leaves him "unsettled", "frightened" and "uncertain" (2).:-

DJ: How would you like to see things turning out in the future for Harry?

JM: You mean ideally?

DJ: Yeah ideally.

JM: Oh ideally, . . . I'm so accustomed to wishing the minimum for him. That all I

would wish is that he remains well and continues to live the way he has lived the last three years. That's all I would want, that's all I would want for him. Because that way I know he's well, he's looking after himself, he's got no major external pressures. Because I think external pressures will trigger off his illness. And I hate this illness (1), because it leaves me unsettled, it leaves me frightened it leaves me uncertain (2). I mean every time I hear the door now I always think is it him? Or is it the police bringing me bad news? -when he's ill. When he's well he'll come and visit me once a week, we'll sit, we'll cook, have a few beers we'll go out on a Friday night, enjoy ourselves go out, go over to his . . and relate like brothers. And the last three years, for example, I've basically got to know my brother- I got my brother back (3). And now I'm losing him again. . . And this time I'm not sure if I'll be able to regain the relation I had with him over the last three years I mean this was the first time I could relate to him as a brother and as a man. . So that's all I would wish for him because we are so used to seeing him in the doldrums and going through hell basically that both my sister and I just wish for him- good health that's all. Not even a career or anything we'd given up on that years ago.

Mr Ajani, does seem resigned to his son's difficulties as being long-term. There is no sense of reconciliation, however, his future without his son getting better is bleak:

DJ: In what way has all this affected you?

MrA: Life for me can never be the same, because I often think of it because there is no way you can bring him back to as the same . . and job opportunities for him are minimal. When people are in trouble they do change. But if your brain is damaged, that is an endemic problem. It affects us, we always talk about it we want to help him. We still try to help, but it is affecting me .[indistinct very quiet] . the future is bleak . .

Mrs Dear is acutely aware of how changed her son seems to her. The awareness, however, is nothing but painful:-

DJ: In what way has it affected you, Bruce's illness?

MrsD: [Long pause- tears] . It has affect me a lot, because you know to see how Bruce was, the sort of person he was and to see him now, he doesn't do anything.

Sit around sleeping all day . . you know that's the most thing he does now. Compared to how he was he used to like going to work and everything, going off with his friends . he doesn't hardly do anything like that now. . . So it does affect me because I like to see him the way he was Not only me anyway, I think it affects his brothers and sister the same that it affects me. . . .

Others who fit into this category are Cathy Hanlon who keeps her sister at arms length and Mrs Light who had for a while not been able to see her son even though she fully understood that he had changed.

iii) Acceptance of the New Person, and Their Role.

For some there was acceptance not only of the long-term nature of the change, but also of the changed person. To talk of acceptance, however, must be qualified. It is certainly not a joyous acceptance, but more often one of often painful resignation.

Mrs Blacksmith sees her son Terry as permanently ill, in need of support, if not from her (1) then somebody else (2,3).

DJ: Does he get that way now [unable to cope]?

EB: No, no, no he don't have to because I attend to him, I do his meals, if I don't see him come around I go around (1), you know . whilst he has me, but if I should go then he needs somebody to go in (2), because he has his social worker Liz and she is very good to him, they need people like those, they do need people to help (3).

What was notable about this situation was that although she sees her son as needing support, he also appears to have a role himself. He helps her with household tasks, doing cleaning (1), getting bills paid (2). Whilst this might sound uncomfortable to some; a 30 year old doing odd jobs for his mum, this was about the most reconciled situation I came across. Perhaps part of this was that he had a role that allowed him to be valued for what he did now (even so she was aware of the loss of the person he had been (3)).

DJ: It's an awful lot for you, obviously.

EB: Yes, . not much . because him help me too you know. He go to the shop and do cleaning, sweeping he do everything for me (1) . He help me very well. Yes he's very helpful like that . he helps me a lot, pay the bills if I don't want to go to the telephone or to the light or the gas he does it (2). He helps me a lot, you know, sometimes he takes all my clothes all to the laundry, so you see I would miss him too . takes my clothes to the laundry and he wash and he fold them . he's very good. At least he was a blessed son I would say, growing up he was a very good boy, decent nice boy . but it is a pity you know (3) . . . and he was bright at school, he went to [a] college he got a lot of certificates he passed through college with distinction you know, oh he was so bright, very good . .

However, it seemed that this acceptance of the current situation was not something that had happened immediately, it had taken time to develop. She has got used to things as they are now (1):-

DJ: What affect has all this had on you?

EB: Well I get so used to it, it doesn't trouble me any more (1) . the first time it used to, you know . . it used to trouble me a lot, I worry, I fret, I cry . . but now it don't matter it don't trouble me, I only feel sorry of him, they only thing I felt now was sorry, .. pity for him, but for myself no trouble me no-more because you know you get used to it, from 1980 I think it's time I get used to it! [laughing] It's full time I get used to it.

It should also be noted that there were other children in this family who Mrs Blacksmith regarded as successful. It may be that her own needs as a mother; to have produced a son who was successful, had a job, was married, and perhaps had children of his own, had been met by others. It did also appear that Terry himself is part of that understanding in that he accepted the role he had within the family. Of course, although I did briefly meet Terry, I did not spend much time with him so could not be entirely sure he did not feel otherwise.

Process.

There is evidence from these interviewees that there has been a process whereby relationships have altered, new relationships have been negotiated. This is in contrast to the tendency of social science models (as discussed in the "Concluding Discussion" chapter) to see adult family relationships as rather static (Greene and Boxer 1986, Cook and Cohler 1986).

Molly Quinn was very conscious of there being a process which she has gone through in order to reach a position of reasonable equilibrium in her relationship with her sister. The metaphor she uses is that of a journey that she has completed. She has now arrived (1) at a point where visits are circumscribed, her sister visits for dinner every Sunday (2). There was a realisation by both parties that visits had to be limited, but it took years to negotiate (3). It was a long journey, which has not arrived at some simple peaceful nirvana, it is still painful, certainly for Molly Quinn. She still has to cope with negative feelings towards her sister. However, this she does as her sister is family and needs her support (4):-

DJ: Some families reach the point where they feel that they can't have much to do with the ill person any more, withdraw . have you ever felt like that?

MQ: Oh yes I have yes, I've gone through phases where I never want to see her again, but now I've arrived at that level (1) . . where she comes down, she's invited down once a week for her dinner on Sunday (2). Now when I say that, that is a decision that was made that she couldn't come and go because that we found it too upsetting and that she realises that too. So we've arrived at a situation where she's very welcome to come down on a Sunday which she does most Sundays, not every Sunday. And then we phone, I phone her almost daily or she phones me. But no I wouldn't want full contact, I can quite relate to that, very much so, and we've arrived a situation where we're both happy on that score, but again it's taken years (3). Oh yes I've gone through that phase and even now sometimes if I'm fraught when she rings, I feel 'oh god', you know? Yes I still feel that, but I try to master that for her sake because I feel she doesn't have much in this world you know sort of . all she's got is the support of her family which if we withdrew that she would

have nothing (4).

An important aspect of the acceptance that Molly Quinn had reached was that she was able to accept having these sometimes very negative feelings towards her sister. Before I left, Molly told me how important friends have been to her. That she could say things like "I wish she was dead" and not feel guilty, being able to retract it the next day - her friends understood what she meant. For her to be able to admit and understand her own strong negative feelings was surely important in being able to negotiate a workable relationship with her sister now. For others, less able to accept that they do have negative feelings, renegotiation of the relationship is more difficult since those negative feelings whilst unacknowledged cannot be taken into account in the negotiation. Molly Quinn was able to acknowledge that she needed space between her and her sister. They were thus able to set out a workable arrangement.

Renegotiation.

This idea of there being a renegotiation of the relationship is a key one. A new relationship has to be negotiated on the terms of the present circumstances. For this to occur the most relevant factors must be available to be included in the re-negotiation. In Molly Quinn's case it was important for her to be able to acknowledge that she had, at times, very strong negative feelings towards her sister. This could then be taken into consideration as they worked out a liveable arrangement.

At interview Mrs Peters and her daughter Carol, whilst as upset as anyone about what had happened, showed a particularly conspicuous affection for Donald, as he was now. They talked warmly of his ability at art and his humour. Whilst still seeing him as being different from the person that he was, it seemed as though their relationship had developed. What appeared to be critical to this development was a re-negotiation of their relationship based on a shared understanding of what had happened.

I interviewed Mary Peters and her daughter Carol together. There was plenty of sadness about what had happened but the current situation, as it emerged during the

interview, had none of the 'storm und drang' that others had. I asked them what I asked everyone - what had kept them involved? Mrs Peters answers in terms that might be seen as duty, - "he's my son" (1), but which can also be seen as forming part of her own myth or beliefs. She feels herself stuck in the role of a mother to a dependent child, and that her role as a mother caring for her son will continue to the end of her life. This makes her philosophical about the difficulties she faces: him not wanting to see her and the risk of violence. Carol, Donald's sister, responds differently. To her the crucial point is her own acceptance of the fact of his illness (2). What has happened to her brother is bracketed alongside cancer, it is firmly medicalised and there is no doubt that he is now different from what he was. It is also noteworthy that Carol is aware of stigmatising forces in the world around her (3). However, she says very directly that this stigma does not interfere with what she wants to do. This supplies some confirmation to the idea, discussed in Chapter 7 (parts ii and iii) that to be stigmatised is at least in part an internal state. Carol has accommodated to change and difference herself and so whilst still experiencing 'stigma' can clearly identify the 'disapproval' of her brother as belonging elsewhere:

DJ: This is maybe a difficult question but what do you think has kept you involved?

MP: Well I don't think I'm different from others, from many others, but, . . . Because he's my son and I think it's my duty to be as supportive as I possibly can (1). And I don't see what else I can do to be honest with you. When he is appallingly abusive- he doesn't want to see me anyway, .[edit] . but no, I think you have a son and it's your duty to er . support him. I mean as one gets old, this is what worries me, when one isn't able, and we all worry in our group - what happens when we are gone? Because this is the thing that does stick in all our minds.

CP: I think there is another thing as well, that we've accepted that he has a mental illness (2), and that it has to be dealt with like any other illness or if anyone else was in hospital you go and visit them whether it's cancer or a mental illness and I think, from our point of view, yes we accept there is mental illness and we deal with that accordingly, I think we don't really differentiate between that illness or any other. I mean, you know when I'm in hospital, mummy comes to see me if there is something wrong and I think that probably is also there, apart from being

her son, it is also something that you naturally do for a friend or for a brother or for anybody which you know well . you're not going to get put off by the stigma attached because that is other peoples' failings, I think (3). Not ours, not as a unit anyway.

This issue is expanded upon later in the interview. Donald's difficulties are medicalised, but the impact of those difficulties is in no way diminished. To Carol there is loss in terms the idea of family (1), what Donald's place in the family might have meant if things had been different. However, Carol and her mother clearly recognise a fundamental discontinuity between their memories of how Donald used to be and how he is now (2,3). There is acceptance that things are now different, that it "will never be the family that it was, ever again" (5). If there is anger, and anger there is, then it is directed to the illness in an abstract form, the ignorance and the lack of funding, the lack of research into finding a cure (4):-

DJ: Another difficult question, can you say what affect this has had on your life?

MP: Oh shattering actually for all of us, as far as I'm concerned absolutely shattering. I mean it's . . oh I think it's just about the worst thing that could ever happen really. I mean I think for anyone who has a child who is ill in any way of an extreme nature . . which will never end.

CP: It's like a terminal illness of any kind really . . You know it's like coping with somebody that's in a wheel chair. One of your children lives in a wheel chair.

MP: As far as I'm concerned I think about him all the time.

CP: Well you think, like all of us, when we think about . when you think about your family you think about the four of us, you don't think about Donald being somewhere else, you just think about all of us as a unit . And er . . I mean . . you know my sister and I we sort of . we . . I suppose at the beginning you think "My god I've lost a brother" because that's what it feels like (1).

MP: In fact you have lost him when he's ill . .

CP: When he's ill, I mean totally, he's just not there.

MP: . . he's not the same at all (2).

CP: You know there's the three of you as children and you've all grown up together, you've all gone to school together . . all of a sudden he's not there because he's just . it's a completely different person it's not the Donald that you know (3). And as I say you have to accept it in some form or another, but yes I mean for a mother I would have thought it is the worst thing that can happen is a child being as ill as that. I think it's . only because of the stigma attached to it as well, on the other side?

MP: Well it's not . no . I mean the fact that he is ill this is what is the shocking thing .

CP: That's right but there's no help either! That's the thing.

MP: . . and the fact that it is a mental illness, but not because so much of the stigma, but it's such an unknown . we know the psychiatrists they just don't know about the brain and I mean it's the rear part of the brain, am I right? -they don't know what that controls, there are parts of the brain they just don't know what they're for. One doesn't see . I mean there is research into it, schizophrenia, but it gets so little money 500 thousand a year I believe goes into research into schizophrenia, which is ridiculous. How can they ever, ever, ever um find out (4).

CP: Yes, it's just a life-long thing really. I mean I think we're all resigned to the fact that this is going to go on for all of our lives and [sigh] we will have to cope with things as and when they come up ..

MP: Yes . which we do.

CP: And it will never be the family that it was, ever again (5).

During the interview I noticed how crucial to them, this acceptance seemed to be. When I suggest this, the point is luke-warmly agreed with (1), but what seems to be felt as even more crucial to them is Donald's own acceptance of his illness status (2). This, in retrospect, is regarded as a crucial moment in the family finding a more even keel:-

DJ: It sounds as though your accepting of him becoming somewhat different has been important in being able to cope.

CP: Um . .yeh . I don't know, I suppose so (1). Because not that it's important, I just think that is something that you have to do, it's not that it's important I just think . .

MP: It was when he accepted it, that was a great milestone, when he accepted that he was ill (2), he didn't for a long-time. . .

CP: Yes that's right. . He didn't . one's been through so much that . there's so much that's gone through and you tend to feel . . 'well at what stage did you accept it?' and I suppose one accepted it when he accepted it. It was a big thing for all of us.

DJ: What happened then?

CP: Nothing . he just started talking about it openly.

MP: Talking about it openly which he never did before, and he wouldn't accept that there was anything wrong with him.

CP: You know he kept saying that . .

MP: 'It was all rubbish, everyone was', . . I can't remember . 'the doctors were making it all up' . .

CP: Yes, that 'they were victimising him and that work were victimising him, the company were victimising him, they wanted to put him somewhere where they wouldn't have to look at him', and all this sort of thing . it was all sort . everybody else . . And then all of a sudden he just started talking about . .

MP: I can't remember now . .

CP: . the hospital and the fact that he couldn't work and he knew he couldn't work

MP: And never will work.

CP: . . and never will work and that really one's got to look at it like he were an invalid . remember that, when he was going on about "really I'm an invalid" . .

MP: Mmmm . well he does get a disability pension.

CP: Yes . .he wasn't going on about the pension but he was going about the fact that he was an invalid.

MP: Well he was quite pleased about that!

CP: Yes . you see this is the thing, you know he's still our brother and that's all there is really.

It has been clear in other analyses that a medical model of events is commonly accepted by virtually all the people interviewed. However what I want to highlight here is that what seems to lead this to be a less troubled situation is not just acceptance of the medical model of events, nor of the acceptance of the long-term nature of those difficulties - but the acceptance of the long-term nature of the changes at an everyday emotional level. Although recognising that he has changed, this family is able to accept Donald as the person that he is.

Barham and Hayward (1991), in their study of the experiences of people with psychiatric histories, give prominence to the desire, of the people that they talked to, to be accepted 'as people' rather than as mental patients. Barham and Hayward (1991:139-142) draw on Charles Taylor's (Taylor 1989) ideas on the construction of modern selfhood. Value and meaning are derived from our ability to construct stories about ourselves, in which we can orientate ourselves within the moral narratives we find around us.

What the Peters family seem to be telling me here is that they feel they have developed a shared narrative. The family's acceptance is apparently matched by Donald's own, and shared by the professionals they (now) have contact with. They share a discourse, which functions to explain what has happened: why Donald lives as he does, behaves as he does, and why he (to an extent) needs looking after. For

the family, there is a coherent web of meaning that holds events together. They are therefore able to relate in a real emotional way (with affection for example) to the person that Donald is. To Carol Peters, Donald's humour, his art, as well as his violence and strange ideas are part of a person that is "still our brother".

Far more common amongst the relatives I spoke to was a failure to develop such a shared understanding. Whilst the disagreement took different forms it often involved the family seeing the problem as being one of illness, this view (or at least the model of the illness) not being shared by professionals or the person themselves.

Mrs Mason was someone who I spent time with over a six month period and she undoubtedly took the view that her son suffered from a long-term disorder. What seemed very striking was the way that she repeatedly complained that her son would not accept that he was ill. He would refuse to talk about it. This caused her a great deal of distress. I think this difference between them can be understood as being an obstacle to them sharing a discourse. To be unable to share such an understanding with someone close is distressing, the grounds for negotiating a continuing relationship are not agreed upon.

Stepping Back.

Another important point about the Peters' situation was that they actually lived in different part of London from Donald. Generally, amongst families where a more stable situation had been reached there was commonly a belief that there was a limit to how much they could do. This was not a situation that they were going to be able resolve completely. Specifically, it was realised they could not live together, as Molly Quinn acknowledged above (p.282).

When I interviewed Mr and Mrs Snellman about their relationship to their cousin, they talked about realising that they could not cope with being involved as intensively as they had done. They admitted that they were now "stepping back a bit". They had previously gone to great lengths at different times to trace their cousin when he had

gone missing. They had now reached a point where they realised there was little they could do when he went away, that they had to get on with their own lives anyway. Perhaps a certain amount of withdrawal is inevitable, if a more workable relationship is to continue.

I met with Mrs Sutherland twice over a two year period. Over this time there was a discernible change in her attitude towards her husband. When he first became ill, she had gone to considerable effort to get help for him, trying to get different treatments, to see different specialists, different counsellors. She wanted him back to normal. When this did not work, she had then gone through a period of rejection, where she could not tolerate seeing him. When I first interviewed her she had not seen him for about a month and was hoping that he was going to be found somewhere to live out of the area. Two years on she had become more accepting of him (although in her terms he was certainly not better). He came to the house regularly, she was glad to see him, pleased to see that he was alright, and she had a real concern for him. However, the acceptance of him was on different terms. She no longer had the expectations of him as a husband, they had in fact legally separated.

For these relatives to be unable to accept the long-term nature of change is to render themselves in a position of conflict. Mr Doors was someone who had not fully accepted his daughter's changed condition and status. He still had hopes which I felt he knew on one level were not realisable: hence some of his strongly conflicting feelings about his daughter. I wonder whether it was the managing of this conflict which he found to be so draining (1), and led him to want to 'escape' (2):-

DJ: Some families do get to the point where they can't really have any contact with the ill person because they just find it so distressing.

JD: Well it is my case . it is my case up to a point that there is this drain, which is something on, I'd say it's on a psychic level. I feel absolutely drained now (1), people might say you're imagining things- you've read too many occult books. But my son who is a down-to-earth person felt the same feeling of draining when she was there, . .[edit] .

DJ: Could you feel so drained that you might, say, go to France [he had mentioned a dream of going to live in France earlier in the interview], to escape?

JD: That might have something to do with it actually. That might have something to do with it . but er I'd feel guilty . and the guilt is stronger than the idea to escape (2). But er, the draining is terrific, terrific, it's very tiring.

Mr Doors talked about he had tried to cope with April at home for a number of years. He speaks of a moment of realisation that he was not going to be able to continue coping when he became aware that his daughter did not take the medication unless he physically gave it to her. This was a degree of dependency which he could not really tolerate. He had to give up the idea that she suffered from the sort of illness that was going to be simply mended in hospital (1):

. . So it was then that I realised, it all came to me, that unless I was physically present she would not take the pills. So how . . because I was entering the room set her in panic. So that was when I said 'I can't cope', it's me who's taking the pill, not April. I mean I've got to take them three times a day, in effect. If I don't do, then she doesn't, she will stop and she will revert to the state she was then. So then I made it plain - "Well please yourself don't take them, I'm not doing it any more" - and then as she deteriorated again then she went . I said "I can't cope".

DJ: You realised she needed full-time care . .

JD: Yes, yes it took some time to work that out. Because before when she went to hospital for quite a while it was like going to hospital - as if you've got something physically wrong with you- you get mended and you come back home (1). I then realised it wasn't on, I certainly couldn't cope unless I made it a full-time job. If I did nothing else but making sure she took those pills. Seems rather pointless as an existence, for her, for anybody . . .

Mr Doors was also able to talk about the difficulty of knowing what sort of relationship was appropriate between him and a 27 year old daughter who had not become adult in conventional terms. Again the problem seems to be that the ground on which a new relationship could be negotiated was in question. He was, however,

able to reflect on a tension that maybe many parents feel about adult children:

. . part of me never wants to see the children grow up because it's so nice when they're small and then they turn into horrible grown ups. It is difficult yes . I try to be . er . I try to be adult with her, I think I manage quite well. I try to keep on serious adult lines, most of the time. And then she discusses her boyfriends, and talks about contraceptives I sort of say "You can knock that on the head, I am your father", he-he . doesn't seem to worry her, seems to have an open mind on lots of things.

Living With Mental Illness?

Given the seeming importance of strategies that involve a certain amount of distancing or stepping back, what of the people who do share a household with other members of their family? The important point to note is how few people there were still sharing a household.

Mr Jenkins had been living with his son, until his recent hospitalisation, but this was not likely to continue. Fred Bryant had been sharing a flat with his son, but he was in hospital at the time of interview. Fred Bryant felt that he would not be able have his son live with him again.

George Christodoulou was living at home with this mother, but this was felt by his brother to be a very unsatisfactory situation. Janice Karajac had been living with her mother but was admitted to hospital during the study period. Petra Gryadogc had been in hospital for 12 months and it was not clear whether or not she should return home to her parents.

Jane Murray was living in an apparently stable way with her mother. It is perhaps not irrelevant that she was the only person in full-time employment, and did certainly have spells where she was well. The Pickles family also seemed to have reached a position of equilibrium. The Rivers family could be characterised by dogged acceptance and fierce pride in being able to look after their own daughter (perhaps

shame as well, not wanting to ask for too much help and thus advertise her illness). She went to a day-centre everyday which was undoubtedly important.

Summary.

To reach a degree of equilibrium so that the relationship can continue means that relatives have a series of adjustments to contend with. There is the loss of the person who used to be. There is then the acceptance of the new person that has emerged and the accommodation to that new person. A new relationship has to be re-negotiated. A couple of key factors have been identified in this section:-

1) For re-negotiation to take place there has to be a reasonable degree of shared common understanding of what is going on. It can be enormously beneficial if some sort of shared understanding of what has happened can be reached between the ill person and the relative. Additionally, some sort of common understanding of what has happened must develop between the relatives and the outside world (most particularly professionals).

2) People must be able to tolerate having strongly ambivalent feelings towards their ill relative. For various reasons people are likely to experience strong negative feelings towards the ill person. If these are denied, it is then very hard to renegotiate a liveable arrangement, as some of the vital factors are missing from the negotiation.

Throughout this chapter, the theme that has run through the thesis has become clearer: that people need to be involved in dialogue in order to work out liveable and meaningful solutions.

CONCLUDING DISCUSSION.

LIVING WITH AMBIVALENCE.

Carol's questions.

This thesis began by referring, in the Introduction, to Carol Peter's questions, which she raised during an interview with me about how she feels about her brother's difficulties:-

"How can we deal with this? How are we meant to react? What do you want us to do? . . [edit] [C]an you explain to us what is going on in his brain that he is suddenly screaming and shouting at us, and abusing us and everything else, do you know why?"

What I have tried to do in this thesis is to highlight the importance of the 'struggle' for meaning that is going on underneath that questioning. One reading, or one hearing, of those questions could lead someone to provide answers in terms of practical action. The 'Expressed Emotion' specialist might suggest they take a non-critical accepting stance. Leaflets and information might be provided by a psychoeducationalist, outlining the status of current knowledge of neurology, biochemistry or twin studies. All these responses might no doubt have their place, they might perhaps be invaluable. But on their own they would be to miss the point somewhat. Such a simple hearing of the questions would be to blot out the deeper meaning of those questions which can only be understood in the context of the pain and confusion that Carol experiences.

What has become clear in this thesis is the importance of the meaning that events hold for the participants. Whilst we cannot prescribe for Carol how she should live her life, what we can do is to listen and understand the difficulties that she faces. For, like Gadamer has suggested of the hermeneutic understanding of others, in understanding Carol's difficulties we are opening a dialogue in which we can develop

a better understanding of our own. A theme throughout the thesis has been that there was benefit for the interviewees in being able to enter dialogue about their experiences, to put their experiences 'within discourse'. The response to want to provide information, to suggest coping strategies (whether based on expressed emotion or any other model) is to present the families with a professional discourse which they may feel excludes their experience. Of course most of the families felt their voices had not actually been heard at all, and that they were presented with very little.

The attachment and commitment to their relatives, existing alongside the grief, anger and disappointment caused by them, seemed often to be something that simply could not be apprehended by the traditional discourse of the social sciences. The commitment of the relatives was generally not something that could be explained in terms of rational rules of obligation, or reciprocity, which seem to have become the shibboleth of contemporary kin studies. Some of the causes of aggressive feelings, and the difficulty of coping with them have been discussed. It is likely that the difficulty of integrating conflicting feelings is compounded by the 'professional' discourse that they find around them which effectively marginalises 'feeling', particularly complex and negative feelings.

Hence there really is '*a struggle*' for meaning. On one level it is an intrapsychic struggle with unpleasant and unacceptable feelings, but it is also a struggle over whose voice is heard, whose language is used, whose interests, and whose understanding informs the narrative. Some of the wider philosophical issues raised by this study will be returned to.

Summary of Findings.

The people interviewed had a strong belief that something had happened to their relative which was manifested through a significant alteration in behaviour and personality. This change was generally perceived to be comprehensible in terms that

could be described as a form of medical model. Despite such apparent accord with the medical model, relationships with the institutions of psychiatry were often very poor and there was considerable scepticism towards available treatments. People did not seem to be obtaining their construction of events from professionals (Chapter 5). Further examination of the ideas that the interviewees had about the causes of their relatives' difficulties revealed that people often held several, sometimes contradictory, ideas (Chapter 6). Analysis of the theories showed that the models of illness used were shaped by the moral implications of different theories and the often hidden, yet powerful emotions of anger, guilt and shame experienced by the families. These emotions are explored in greater detail in Chapter 7 as the experiences of the relatives are examined in term of a grief process. This is a grief process that is profoundly enmeshed with the forceful social constructions surrounding mental illness, notably stigma. Chapter 8 explores how the idea of 'the family' is an important social vehicle for the control and containment of many of these powerful feelings. The attachments felt between people would seem hard to understand in terms of the very rational models of family behaviour that have been recently favoured in studies of British family life (Finch and Mason 1993). Instead, as this study suggests, the relationships are better understood as being rather less rational and steeped with powerful and ambivalent feelings. Chapter 9 suggests that one way that people are ultimately able to live more comfortably was to be able to reach a degree of acceptance that their ill relative had changed, and that a new understanding of the relative and the situation could be negotiated with significant people around them. An important component of this process was dialogue through which different understandings could be reached. Benefit seemed to be being derived when the relatives were able to enter dialogue with, particularly, their ill family member, and professionals. It is usually only through dialogue of some kind, after all, that new shared understandings can be reached.

The significance of the findings of this thesis can be discussed under four headings. Firstly, it can be argued that 'the family' as it emerges in this study cannot be entirely understood in terms of households, nor through the observation of rules of reciprocity or obligation. Yet it is this family, the functional nuclear family which is often

studied and argued to be in decline. Secondly, it can be argued that the study suggests that families ought to be considered more by those who make and implement policies in regard to people with long term mental health problems. Thirdly, it will be argued that the study points up some quite specific issues for mental health practitioners. Fourthly, some reflections on the method used will be offered.

D) The Family in Decline? Understanding and Researching the Family.

There is currently a great deal of debate about the decline of the family. Figures on divorce, cohabitation, single parenthood and births outside wedlock are held up as evidence of the decline of the family (Poponoe 1993², for example). Yet as this thesis has highlighted, the family seems to be a concept that can carry an enormous weight of significance to people. Such apparent discrepancy is explained by understanding what is meant by the family. The family of 'the family in decline' debate seems to be the functionalist nuclear family limited to the household (Bourdieu 1995). Poponoe (1993:529), for example, defines the family as "a group in which people typically live together in a household and function as a cooperative unit, particularly through the sharing of economic resources, in the pursuit of domestic activities." Although he is careful to include non-married couples, gay families and stepfamilies, this is still a very different understanding of the family than the one that has emerged through this thesis. Here 'the family' has to be understood in a much wider sense than a domestic space in which children are raised. It was a highly meaningful construct for the adult lives considered here. It could be seen as operating as a myth (Barthes 1973) or a narrative (Plummer 1995), which shapes and orders what are otherwise troubling and disparate emotions and forces.

The difficulty that the mainstream social sciences have in grasping such affairs can be explained by reference to the methodological difficulties of studying people's subjective worlds that have been outlined in the Methodology section (Chapter 3). However, perhaps this is an issue that goes deeper than methodology. After all, it

² Features as a special edition of the "Journal of Marriage and The Family".

must also be noted that psychoanalysis, which was presented in the Methodology chapter as a discipline that had avoided some of the pitfalls of positivism, has also been quite neglectful in these several areas. Perhaps such a state of affairs becomes comprehensible in terms of the difficulties that researchers (and clinicians) have to face in reflecting on the painful and contradictory emotions that are immanent to human experience (Alford 1989, Clough 1992, Kleinman and Copp 1993, Flax 1990).

Neglected Areas of Family Study.

Three specific areas can be identified which have emerged as relatively important issues in this study, yet have remained rather marginal issues within mainstream social science. Firstly, there is the issue of change and development in adult family relationships. Secondly, there is the importance of sibling relationships in adulthood. Thirdly, there is the importance of shame in relation to identity, particularly in family relationships.

1) The Study of Older Adulthood, Change and Development.

In a sense this thesis has been involved with reaching for an understanding of how adults are able to develop and accommodate to change, within the context of family relationships. Several associated lacunae in traditional research endeavours can thus be identified. Firstly, there has been little work generally on development during the second half of life (Erikson 1982, Guttman 1987, Levinson 1978, Jacques 1965, Vaillant 1977). Secondly, there is little on the notion of the re-negotiation of family relationships over time particularly as 'children' go through processes of adult development themselves (Greene and Boxer 1986). Thirdly, there has been little work on the reciprocal developmental influences between children (particularly as adults) and parents (Cook and Cohler 1986).

There has been quite a lot of research work covering parenthood as a development event (Benedek 1973, Raphael-Leff 1991, for example), but much less on the impact,

and developmental aspects, of the experience of having growing and adult children. This neglect is quite consistent with the prevalent psychological and geropsychiatric model that sees human development as reaching a peak in early adulthood followed by a long period of plateau and then of a phase characterised by loss and decline, leading to death. These models have survived in spite of contradictory evidence, (Bond, Coleman and Peace 1993, Guttman 1987).

The findings of this thesis (particularly Chapters 7, 8 and 9) portray people involved in struggles to accept and accommodate themselves to change and to modify their own expectations. This suggests that more work could profitably be done which examines the psychological development of adult family relationships further.

Apart from Erikson's work on adult development (Erikson 1982), psychoanalysis has generally been notably neglectful of older age as a developmental period (although there is growing interest - Hildebrand 1987, Hinze 1987, King 1974, King 1980, Grotjahn 1955). Abraham et al. (1980) argue that psychoanalysis has a very paradoxical attitude toward ageing:

On the one hand, psychoanalysis has extolled the father- and mother- images as key figures in the dynamics of the psyche, while on the other hand, in practice, it has deemed the elderly as unworthy both of systematic investigation and of possible treatment. (p149.)

Far from being paradoxical, it could be argued that the two points made are consistent and revealing. Older adults have been seen as unworthy of consideration precisely *because* they are also seen as the key figures in the development of the psyche. On logical grounds the older adult is therefore an object which 'causes' psychic states in others. Just as in the Family Therapy paradigm (described in Chapter 2) the parental behaviour is assumed to be the cause of, and not the recipient of, change. On a more psychological level psychoanalysts (and anyone else working in this field) are being asked to consider their own parental figures not as shadowy, almost mythical objects within their own psyches but as fleshed out individuals who change and develop and also, of course, decline and die.

2) The Study of Adult Sibling Relationships.

There has been very little work on sibling relationships in adulthood (Goetting 1986, Lamb and Sutton-Smith 1982), yet it has been observed within this thesis how strong sibling relationships in adulthood can be. It is certainly striking that, despite the large welfare and social science industry surrounding the family, for several decades social and behavioural scientists have lamented the lack of research on adult sibling relationships (Lee et al. 1990). Certainly beyond childhood, the sibling relationship has been quite neglected by workers in psychology, sociology, or social science. Whilst this study suggests that sibling relationships can certainly be a valuable source of support, the relationships themselves can be complicated and they would surely reward further study.

3) The Family, Shame and The Connection Between People.

This thesis has highlighted the influence of the affect of shame and the importance of the identifications that people have with each other and with the myths and ideals that they live by. These are important constructs that provide explanations for people's behaviour in ways that traditional models that assume that people internalise rules or obligations (Johnson 1987, Parsons 1955 and reviewed by Finch 1989), or that they act out of instrumental self-interest, cannot (Finch and Mason 1993). Giddens (1991) argues that shame and its connection to identity is emerging as an increasingly important cultural force which can be seen as a symptom of important historical shift in a "post-traditional order". Giddens (1991:67) rightly notes that "shame has been relegated to a minor place in psychoanalytic literature". This might seem odd for a discipline which takes as its focus the role of emotions in human affairs. The notion of shame and its relationship to the ego-ideal has been largely over-looked with far more attention being paid to guilt and its relationship to the super-ego. The super-ego is said to consist of the internalisation of parental norms. Here again the bias is towards studying the unilateral transmission of knowledge from parents to children. Harland (1987:37) points out that:

The concept of a separate super-ego has been crucial to the development of ego-analysis. Ego analysis is the pre-eminent school of Anglo-Saxon psychiatry, the school of Kris, Hartman, Loewenstein and Anna Freud ³. The concept of a separate super-ego allows the ego analysts to think of society's part in the constitution of the subject as relatively superficial, a final superstructural addition on top of the more basic Id and Ego.

A shift in emphasis away from the super-ego towards the ego-ideal, allows for consideration of the way society operates in the very constitution of the self. This finds echo within Foucault's work. Power, he has argued, is not simply about repression, but is involved in the positive construction of the self, it is not simply a set of rules imposed after the subject has been constituted (Foucault 1979). So rather than simply exerting influence through the super-ego which will repress instinctual drives, society is involved in the building of the ego-ideal, the character of which guides and constrains people in more subtle (and thus more powerful ways) than does the super-ego.

Agnes Heller (1985) writing from the point of view of moral philosophy, points out that although shame is an affect, it is one that cannot be conceived without culture. Shame is highly relational, it exists only through relation to others. A shift in emphasis toward the ego-ideal, highlights the importance of what might be called horizontal relationships; as opposed to the vertical influences that are accentuated by study of the super-ego.

Why The Misrepresentation?

One theme can be used to draw these observations together. It is that adults are consistently being construed as independent, autonomous and rational objects. There is an overwhelming concentration upon the unilateral influence that parents have on children's development, to the exclusion of the consideration of influences in later life, or more lateral or reciprocal influences. Recently there has also been a

³ The quite overt conservative forces operating on the development of psychoanalysis, particularly in America, were discussed in Chapter 2.

concentration on a understanding of family relationships in relatively rational and instrumental terms (Finch and Mason 1993).

The counter-argument which this thesis is concerned with is that people are dynamic, developing beings that can only be understood in relation. Why should the former model be so dominant, and currently unquestioned? To answer this question we need to go back to issues that were raised in the Methodology chapter.

Power and Knowledge / Masculinity and Objectivity.

Carol Gilligan claims that a stress on autonomy and independence can be associated with masculine ways of construing the world (Gilligan 1982). She argues that this mode of thinking has become normalised and institutionalised, so that even within studies of the development of thought and morality this emphasis prevails over a mode of thought that is more embedded within human relationships and social contexts and is associated with femininity (Gilligan 1982). Thus the model of the person as being independent and autonomous that has been described seems to fit with what can be characterized as a very masculine style of functioning.

This masculine style has been described (in Chapter 3) as dominating the development of science. Fox Keller's (1985) argument, discussed in Chapter 3, is that science has developed as an essentially masculine enterprise, which seeks to separate the object from the researcher. It can be argued that much conventional family research is distorted by the need to see people as autonomous objects. Consideration of the developmental, relational links between people is too often conventionally restricted to those that young children have with their parents. Successful development is seen as being through individuation, separation and the achievement of autonomy. Developing a similar argument through studying ethnography in particular, Clough (1992) picks up on Freud's drafting of the oedipus complex as something that is never completely resolved: "Sexual identity is always informed with the loss of the mother as well as the refusal of that loss."(p4) That loss, and the essential failure of identity is denied: "a coherence of identity is imagined in order to disavow and supplement

the failure of identity" through an identification with a fantasy of the unified, autonomous self. When the vision of the researcher turns to the society around them, perhaps to family relations in particular, there will be a defensive desire to see authoritative order emanating from solid and omnipotent parental figures (the original objects of identification). Similarly there will be the desire to see self as autonomous and coherent, not relational and contradictory. As discussed in the Methodology section, Kleinian psychoanalytic theory has been used to understand how instrumental rationality has become such an important discourse as a defence against the less easily managed worlds of emotions and interdependence (Alford 1989). However, what has emerged through these relatives' accounts is the importance of the less instrumental elements of people's experiences within contemporary social life (such as the beliefs about family). These are the very elements which importantly shape people's understanding and behaviour yet they are also those which social science practices have had difficulty in apprehending.

Perhaps the difficulty that an objective, positivistic approach has is crystallised most clearly in the study of shame (Wurmser 1981:66). The fact that shame is associated with the most personal world of the intimate emotions and yet simultaneously belongs to the social world of relationship, has made it an unlikely subject of scientific instrumental inquiry.

The difficulty of the 'objective' approach, riven with fantasy as it is, comes when real people in families who are dealing with real situations and sorrows with ordinary human confusion and ambivalence are studied. Perhaps they are in danger of becoming the target of the social researchers' and professionals' fantasies of how things ought to be, fantasies which those real families can never live up to. The data of this thesis suggest that the decline of the family (if it is happening at all) is unlikely to be traced by counting households or measuring attitudes, but must involve a much deeper and more subtle analysis.

II) The Study And Its Implications For Policy.

This study has highlighted the fact that the family is better understood, not as a household nor in simple instrumental terms, but as a complex ideal loaded with myth and emotion. What policy implications does this observation have in this field?

Families as a Resource.

As discussed in the Chapter 1, the difficulties of the group who have been called the 'new long-stay' are salient to any rearrangement in the delivery of mental health services. The group are often portrayed as being rootless, particularly those in more urban areas. This study, taking place in an urban district of London, suggests that families are often very emotionally involved and can provide a very useful resource. They need to be considered by professionals even when they are not living under the same roof as the ill person. Even assuming that there has been a measure of self-selectivity (see page 311) in the families talked to, they potentially represent a major source of anchorage for a group of people who often live lives of sad neglect. Larger scale work, perhaps of a quantitative nature, may help to clarify how frequently families might be able to support this vulnerable group.

The Carers Act (DoH 1995) certainly assumes that partnership between family carers (whether co-resident or not) is highly desirable. Judging by references made in the case-notes, and the reports of the families themselves in this thesis, professionals barely considered families at all. The finding that family members often felt angry and alienated from professionals is consistent with other studies (Creer 1975, Shepherd et al. 1996, Strong 1997). Concerted effort to improve relationships between professionals and families is likely to be necessary. Those concerned with the organisation of services could find that the encouragement of training initiatives aimed at enhancing professionals' understanding of the families' perspective, would enable more constructive work with families.

III) The Study And Its Implications for Practice.

Working With Ambivalence.

The study has highlighted a number of aspects of the families' experiences which, if better understood, might help professionals to work constructively with such families. There are two issues here, firstly what does the study suggest that can offer an enhanced understanding of the families' experiences and secondly, how might staff work with these issues?

1) Better Understanding of the Families.

If families are to be more involved then they need to be better understood. This study makes several contributions towards a better understanding of the feelings and experiences of those families. This thesis has highlighted the very complex and contradictory emotions that families experience. They have not only a very complex bereavement process to negotiate, but this is compounded by the involvement of emotions such as shame and the experience of stigma. All these things having to be woven together in a cultural ideal of family life.

i) The Complex Loss.

The seemingly most central and common experience was the feeling that the person they had known who had become ill had gone away, they had become like another person. This defies our normal sense of the consistency of the self, where we see ourselves and others as, if not unchanging, at least as consisting of a developing whole (Vaillant 1977). Many of the relatives' experiences and views can be understood as an attempt to come to terms with this experience of discontinuity and loss.

ii) Grief and Ambivalence.

As Freud (1917) highlighted in his classic *Mourning and Melancholia*, the bereaved

person is coping with the loss of the person that was, and secondly, and more complexly, there is the experience of the loss of the previous possibilities. When we lose someone close to us we forfeit something of our own future. For families, parents in particular, this feeling of the loss of future expectations they may have of their children can be terribly poignant.

For some time now grief has been construed as being the process through which people accommodate to loss and find fresh meaning (Murray Parkes 1972). The grief of these relatives, as discussed in Chapter 7, is complicated by certain features: the fact that the lost person has not really gone away; the presence of strong emotions, such as anger, that can be difficult to manage; the stigma and shame of mental illness which means communicating with others about how they feel can be difficult.

iii) Families: Living With Ambivalence.

Amongst the families that I visited, the ones where there seemed to be a degree of contentment (discussed in Chapter 9) were those that had reached a greater level of acceptance of the person and the situation as it now was. This involved accepting their own ambivalent, and sometimes frankly negative, feelings in addition to accepting their relative as having changed. They were able to let go of the memories and hopes they had and were able to integrate the reality of the person as they now were and move on, rather than simply holding on to memories.

iv) The Meaning of Mental Illness.

It has been very clear (through Chapters 5 and 6 particularly) that the relatives interviewed had a strong investment in the medical model of events. This might sit uncomfortably with those that have identified the medicalisation of mental distress (Boyle 1990, Laing 1967, Scheff 1975, Szasz 1970) as being a major impediment to progress and understanding. As discussed in Chapter 1, the views and experiences of the families actually constitute a significant thread of the cultural fabric which

surrounds 'mental illness'. Anyone concerned with the habitat in which people suffering mental distress live needs to take this into account. The findings of this thesis suggest that the medicalisation of madness is unlikely to disappear if the Asylums and hospital units are swept away. Analysis of the families' views on mental illness has demonstrated that the medicalisation of mental distress clearly has much deeper cultural roots than is provided by the professional needs of psychiatrists.

2) Staff: Working with Ambivalence.

Several studies (besides this one) have noted the poor relationships that families seem to have with professional mental health workers (Creer 1975, Shepherd 1996, Strong 1997). The findings of this thesis suggest that professionals need to develop better understandings of the families' point of view and their experiences. Professionals too consider they are often excluded from decision making processes and previous work has drawn attention to the difficulties of managing change in organisations (for example Menzies Lyth 1988). Perhaps more needs to be done to understand the experiences of mental health professionals (Segal 1991, Ramon 1992). Without this work a too prescriptive approach that offered instructions for 'working with families' would seem unwarranted. A couple of suggestions might be made, however.

Allowing Negative Feelings to be Acknowledged.

Given that it may be important for families to be able to acknowledge and come to terms with having very negative feelings, it may be that professionals can make a contribution by encouraging families to express those feelings in a non-judgemental atmosphere.

It may, however, be difficult for mental health workers themselves to endure the apparent ambivalence of the fact that for relatives acceptance of a more pessimistic prognosis can be more comfortable to live with than continuing to be optimistic. It may run against the grain of their training and outlook, where high priority is given to therapeutic optimism, and encouraging people to higher levels of functioning.

Whilst such thinking is laudable and probably helpful, it would still be important for professionals to be aware of the psychological use of such apparent pessimism to the families. Without awareness of this psychological utility it might be easy to see families simply as being involved in a condemnatory process of labelling.

On a number of occasions I was given a quite hostile response when I turned up on someone's doorstep. In all cases where this happened, it was possible to overcome this hostility. Allowing space within the interview for views to be expressed invariably allowed a more constructive atmosphere to develop. What this suggests is that it is important that professionals who are working with families in similar situations allow space for dialogue about ambivalent and negative feelings to be expressed and acknowledged.

The interview with Penny O'Reilly is one that changed quite dramatically, once the less acknowledged side of her ambivalence had been recognised. Penny O'Reilly had for the first part of the interview been quite dismissive of her brothers and their difficulties. For example:-

I don't think Andrew would benefit from group therapy . He'd bloody bore you to tears! [laughing] They'd all bore you to tears honestly, unless people have emotional [problems], group therapy helps with emotional [problems] or drink problems, not mentally ill people I don't think. 'Cos they start talking, bore you to tears about voices and that sort of stuff . um so I can't see how else they can really help him, apart from medication, he takes drugs I don't know whether he takes them in tablet form, liquid form, injection I haven't a clue.

Clearly a professional hearing this may well conclude that Penny O'Reilly would not make a reliable source of care. However, as I picked up that she was actually more involved than she was letting on (and favourably contrasted this with others), the tone of the interview changed.

DJ: You obviously do feel quite responsible, a couple of times you've used the word 'ought' about visiting . .

PO: I do feel very responsible, they are my responsibility, yep absolutely.

DJ: Where do you think that comes from? Not everyone feels that.

PO: Don't they?

DJ: No, plenty of families eventually give up, cut themselves off.

PO: Oh I think that's . mmmm . . it must be because I'm a nice person [laughing] . I can't. .I just don't understand why . Well I can understand why yes, it depends on the sort of things that they've been up to I mean you can be at the end of your tether and they can be really nasty and . I'm not saying Andrew or Sean in particular, but I would say that er . you know you could get one that would come in and beat you up and smash up the house and take your money. You'd want to wash your hands of somebody like that, but er . I do feel it's my responsibility and a duty as well I mean . they're my flesh and blood it's as simple as that and I like them. It just seems strange that people wouldn't do that or would cut themselves off, it's a pleasure - you know if I actually catch Andrew and he's quite funny sometimes it's, you know, it's nice . I mean obviously some parts of it . if you go into his flat, and you see his flat . it's dreadful and that's another duty to go in there and clean it up . I don't do , I'm surprised actually because I feel quite guilty sometimes because I know that I should do more than I do and I don't. And that people can actually cut themselves off entirely is . you know all credit to them. I wouldn't want to . but when I go to see John sometimes, when I've been admitted into his sanctum- absolute shit-hole of the highest order and I think "God" [sighing] and I look around and I think to myself "I must clear it up" and last time I cleared it up and there were about 12 dust-bin bags full of tut. .oh and the sideboard, and the kitchen and the sink- gunked up. And clothes and shoes, . and people are always giving mentally ill people things, you know people from the church . clothes I just bagged up 12 lots of dustbin bags full of rubbish and I'd been to Marks and Spencer and my mother had come over on holiday and we'd bought about a hundred and fifty pounds worth of really nice stuff, you know trousers, jacket, tee shirts and things like that really nice stuff. And I felt "What a waste!" you know in a months time those things were . . but you have to do it, because you should do it and you feel compelled and obliged to do it and you want to do it, you want them to look nice but you go in there and you know that in six weeks or eight weeks time they'll be worn to death and just dropped on the floor. You buy . I've gone to his flat and spent money on . . oh washing up liquid, bleach , scourers, polish, brooms,

dustbins, toilet cleaners and various things like that . and you know that they're not going to be used but you buy them hoping that he will use them, that he'll snap out of this stupor and some miracle will occur and the next time you go round to the flat it's going to be clean . but er . I do feel that I should do more in fact. What I really feel like I should do and if I was a very good person I would do, I'd go round and clean his flat every week, and it would never get in that state, it's only a small thing to do. Here I am living in luxury and he's in squalor and if I could get access to his flat, which is difficult anyway, but if I really wanted to I'm sure I could- actually go in there and clean every week it would only take an hour or two. But I don't, so I'm not that good. I'm not that good at all. I just do . I suppose in a way I go to see him and to speak to him and, you know, whatever . . I go to see him, speak to him and to be with him but in a way I'm as selfish as everybody else because I'm almost by not committing myself to doing that weekly I'm saying "But I'm not doing too much I'm not getting too involved", so I can understand people cutting themselves off . you know the nature of some people's mental illness makes them really despicable.

What seemed to happen here was that my commenting on her hidden positive feelings of commitment to her brothers, enabled her to talk not only about how committed she did feel, but also her feelings of guilt. I think the quite brusque way she was initially describing her feelings for her brothers was covering up a good deal of guilt about how little she feels she does compared to the affection and commitment that she feels toward them.

There have been many other examples of ambivalence throughout the thesis. The relatives interviewed were able to hold several, parallel beliefs about the cause of mental illness, about diagnosis and treatment. It would be important that professionals should be aware of this and be able live with such feelings of ambivalence themselves.

Encouraging Relative Support Groups.

Professionals might do more to encourage the development of mutual support groups for relatives. This may be a useful way that people are able to experience benefit

from a feeling of group solidarity (as discussed in Chapter 7). Of course there may also be the danger of splitting, with the groups becoming idealised and the outside world denigrated. Support groups can also provide an opportunity for communication and dialogue, through which fresh understandings and solutions can emerge.

IV) Reflecting On Methodological Issues.

i) The Method.

This piece of research might be considered rather unorthodox. It has consisted of very detailed analyses of a relatively small number of quite unstructured interviews with no effort being made to standardise the questioning or quantify people's responses. Yet I hope that it is clear that this study does make a contribution. Whilst much of the thesis has been taken up with the intellectual and methodological justification of the method, I hope the contribution that the findings of the study make also vindicates the use of the method. The study demonstrates that it is viable to use psychoanalytically informed ideas about interviewing and interpretation to explore the experiences of a relatively small number of individuals and that this can generate findings with much wider significance.

ii) The Question of Reliability and Validity.

Reliability: The Self-Selectivity of the Sample.

However much I might believe that the discussions of this study are worthwhile, there will be those who point out that strong claims have been made here about the experiences of the families of people who suffer from mental health problems, based on listening to, essentially, 48 people. It would be entirely correct to question the generalisability of such interpretations.

It may be, for example, that there is a problem with systematic bias in this thesis in

that the people that I was able to talk to were the ones with unusually significant emotional attachments. Perhaps it is only these people who were motivated to speak to me. I was aware that I was talking to the involved members of the families, rather than members of the same families who were hardly involved, or who deliberately avoided involvement. It would clearly be interesting and informative to understand more about the experience of the uninvolved members and why they avoided more contact.

Validity: The Accuracy of the Interpretation.

Many of the 'findings' of this thesis are actually based on my own interpretations of what people have said. What reason is there to believe that these interpretations have any validity? One way of at least attempting to establish validity would be to have fed back my interpretations to the interviewees by allowing them to read and comment on the research findings before publication (Bulmer 1984, Berger Gluck and Patai 1991). However, given the nature of the material and of the interpretations made this would have involved raising some very uncomfortable issues (such as their own aggressive or ambivalent feelings). To have done this in a non-therapeutic context would, I felt, have been potentially damaging.

An answer to this dilemma in any future studies would be to allow therapeutic goals to inform the research design (as I did in a limited way with Mrs Mansell). Whilst such a form of action research may be ethically happier, it may also be that it would actually enhance understanding. If therapeutic goals are acknowledged in the encounter, it may be easier to explore more thoroughly whilst working together to reach an understanding. To allow therapeutic goals into the research encounter may be to encourage the insight of the researched through dialogue as Winnicott (1971:86-87) said:- "I interpret mainly to let the patient know the limits of my understanding."

The Ambivalence of Research: Enlightened Dialogue.

This question of generalisability goes to the heart of the concerns raised in the

Methodology chapter (Chapter 3). Logically I have no way of knowing how applicable the thoughts I have had after listening to this group of people might be to others. What seems difficult to do is to cope with this level of uncertainty.

In Chapter 9 ('Managing Myths'), I talked about how these relatives dealt with the complex losses that they have suffered. That beyond the most obvious losses there are others that are to do with dealing with the loss of expectations, hopes and fantasies - the loss of their place within the discourse of family life they found around them. The question about the generalisability of my own findings leads me to wonder about the hopes and fantasies that are involved in the research process itself. Perhaps there is a considerable proportion of the research process, or indeed of learning itself, which is actually about coming to terms with 'not knowing', with managing ignorance. For any researcher there is perhaps the fantasy of omnipotence to be dealt with: the fantasy of understanding all, explaining all, controlling all. What might be most important to realise is that in doing research, and in talking about or writing up our findings we can only offer an interpretation. In doing this we are, hopefully, opening up communication. Through our interpretations, and what others might make of them, we may make a contribution to understanding. Ultimately, perhaps communication is facilitated more by our not giving definitive answers, the sort of answers that do not open dialogue but close it.

Opening up the Dialogue?

In January 1992 I was involved in organising a conference held at the London School of Economics called "Opening up the dialogue: Informal and Professional Carers in Mental Health." (Jones, Ramon and Tomlinson 1993) I certainly felt afterwards that we had conspicuously failed to open up a dialogue. With hindsight I think now that the reason for this is the lack of a language, or a common ground on which communication can take place between professionals and lay family members⁴. As

⁴It is interesting to observe that at the time we felt that the incorporation of service user's views within this dialogue would have been too ambitious. The findings of this thesis, particularly the relative's scepticism towards professional models suggest that service user and relative views may not be so far apart.

the review of the research models in Chapter 2 highlighted, the models professionals use make few concessions that would enable an understanding of the relatives' experiences. In order for a dialogue to occur there has to be some common language which can be shared by the participants. Perhaps this language is simply not in place to be shared. Whilst there may have been motives for the particular direction of the developments of family research (reviewed in Chapter 2), there are good reasons to see the wider practice of social science as not encouraging dialogue but as attempting to enforce rather partial languages on the social world (Chapter 3).

The explication of the grounds for legitimate communication are central to some of Jurgen Habermas's concerns as he has been attempting to expound a case for the extension of the 'modern' enlightenment project (Habermas 1984). He wishes to do this by unfettering some of, what he sees as, the more desirable aims of the Enlightenment from the iron horse of technologisation (Zweckrationalität) which he regards as having hijacked rationality carrying it far away from 'human interests'. He attempts to point the way to further enlightenment along the path of rational communication.

What Habermas seems to be searching for are some solid foundations on which to build understanding. Perhaps more properly put, he wishes to construct some transcendental balcony above the confusing urban melee of post-modern relativism. His wish is for communication without distortion. The chief source of distortion being the ideological forces acting on the speakers. Whilst being a doubtlessly desirable goal, it is difficult to imagine such conditions. Foucault's persuasive formulation of the ubiquity, and positive fashioning, of power renders the uncoupling of power from knowledge seem unlikely.

What I find to be a more convincing retort to some of the pessimistic refrains of post-modern relativism is the plea by Richard Rorty (1980) for continuing conversations, and it is in this tradition that I would want this study to be understood. Rorty agrees with the post-modernist position that absolute knowledge is simply not possible. The best we can hope for, he argues, is that we continue to have conversations that help

us to live. Such relativism stands accused of neoconservatism by Habermas and others. It appears as being conservative because it seems to offer little hope of progress, there is no vision of a better future, there is no road to freedom being sign-posted.

However, reconsideration of the description of the Kleinian understanding of the desire for knowledge given in the Methodology section, can throw light on this problem. From Kleinian analysis comes the idea that the most we can hope for in terms of psychological health and creativity is an oscillation, or equilibrium (Steiner 1992), between depression and mania, between despair and hope.

Melanie Klein and Ambivalence.

Alford (1989) has argued that the psychoanalytic constructs of Melanie Klein can rescue the Frankfurt school of critical theorists from utopianism. He argues that the Frankfurt school have failed "to integrate aggression" within their theories. To Klein it is aggression and anxiety which lie beneath the desire for knowledge. It is therefore a deep-rooted anxiety which underpins Foucault's power-knowledge double act.

From Kleinian theory comes the notion that for creative mental health there must be a paradoxical willingness to engage with the reality of the world (including one's own aggression) coupled with a certain amount of self-aggrandising delusion.

Hanna Segal (1952) uses Klein's theorisation of the 'depressive position' to understand creativity. For mental health and development to occur there has to be the capacity to tolerate sadness (the depressive position) if a person is to be able to take in new information (since new information inevitably involves loss and change). However, this might simply lead to despair were it not balanced by more defensive manoeuvres (of the paranoid-schizoid position) which allow someone to feel omnipotent, to feel that they can create and find solutions to the problems that they face.

Thus for creative development to occur there must be a capacity for both despair and hope. There must be a 'healthy' oscillation between mania and depression, between feelings of impotence and omnipotence (Steiner 1992). Thus to do research, to indulge the desire for knowledge is fraught with ambivalence. It is a desire that is underpinned by anxiety and aggression. It is the anxiety that leads to the need to control and even to destroy. Complete inattention to these aggressive motives has perhaps led to the more triumphant methods of quantification and positivism; studies that have chopped up people's experiences so that they will fit into the categories of the researcher. This is the prerogative of instrumental reason, where people do indeed become simply objects of study. On the other hand too much awareness, and fear, of the aggression perhaps leads to too little analysis; an unwillingness to look beneath the surface, to disturb that which they study. Jane Flax (1990:11) argues psychoanalysis highlights the unwillingness to address contentious issues:

According to analytic theory, ambivalence is an appropriate response to an inherently conflictual situation. The problem lies not in the ambivalence, but in premature attempts to resolve or deny conflicts. The lack of coherence or closure in a situation and the existence of contradictory wishes or ideas too often generate anxiety so intense that aspects of the ambivalence and its sources are repressed. It is equally important to examine why, when lacking absolute certainty, the will becomes paralysed.

A pertinent example of ambivalence is found within Michel Foucault's vision of the world, which has been so influential on epistemological debates of the past 10 to 15 years. Richard Rorty writing about Foucault's contribution puzzles over the contradiction within Foucault's work which has allowed for an 'American' and a 'French' Foucault to emerge. The American Foucault can be read as being of "the standard liberal's attempt to alleviate unnecessary suffering" and could view liberal democracies as "promising social experiments" (Rorty 1991:194). Yet the Foucault the French seem most enamoured with is the one who relentlessly berates the social developments of the last 300 hundred years for their cruelty and inhumanity. This upsets the American liberals, like Rorty, for ignoring the fact that "during that period suffering had decreased considerably, [and] that people's chances of choosing their own styles of life increased considerably." (1991:195). Rorty explains the apparent

schism within Foucault by arguing that Foucault is actually trying to do two things at once. On the one hand he was trying to be a social analyst and good citizen working to improve the world around him. On the other, he was also involved in a Nietzschean (poetic) search for personal autonomy, to which end a frank disregard for those around was essential. Rorty gently scolds Foucault for not separating his public life from his personal quest:- "The Romantic intellectual's goal of self-overcoming and self-invention seems to me a good model (one among many other good models) for an individual human being, but a very bad model for a society." (p196) Rorty is undoubtedly accurate in his description of Foucault as being politically rather ambivalent (Simmons 1995), but that he was also "a useful citizen of a democratic country - one who did his best to make that country's institutions fairer and more decent" (p198). However, perhaps these positions are not really paradoxical. Perhaps it would not have been desirable to separate Foucault's destructive, anarchistic and distinctly illiberal impulses from his apparently more positive social vision. If Foucault is ultimately constructive perhaps it is precisely because he was able hold two visions of the world - one gloomy, even cynical, the other hopeful and struggling together. The social developments of the last 300 years in many ways have to be considered as progress. Nonetheless, there is surely a down side to this progress. Firstly, it is progress for only a minority of the world. It is progress fuelled by the exploitation and emiserisation of large tracts of the world population. In Europe itself most of us are now in better health, have more choices, are better educated, housed and fed than ever before. However, there have been, in this century alone, two world wars and one holocaust all featuring slaughter on a virtually unprecedented scale. There *is* painful contradiction and paradox here (Bauman 1989).

As Klein suggests, perhaps psychological development occurs through the working through of the depressive position. As some of the interviewed relatives found, real love only became possible again when they were able to allow their son, daughter or sibling to be both ill and a person, to be both good and bad. Relationships could develop when they had given up the hope in their omnipotence to fully control the world and remove that ambivalence. Likewise in carrying out research, our work may

be all the stronger for appreciating the contribution we can make to understanding (our own and others) through opening dialogue rather than in supplying authoritative answers.

iii) The Ethics of Research.

In carrying out these interviews I was purposively seeking out the more emotional aspects of people's experiences. Many interviews were thus inevitably upsetting experiences. They were upsetting for me to sit through but they also often left me with feelings of guilt. I felt guilty because it seemed to me that I was entering people's lives, stirring up things that were distressing for people, getting my material and then leaving. Some of this might well be (as would be suggested by the Kleinian formulation of knowledge seeking, given above) a problem created by my own guilt feelings (provoked by the aggression and vicarious pleasure that might be involved in doing interviews that encourage people to 'expose' themselves). It might also be that the same reparative feelings of wanting to rescue people, to make things better in the world that had led me to do this sort of work, would inevitably leave me feeling that I should have done more. People doing research in this kind of area may need to be sure that they are sufficiently well supported and are able to reflect on some of these issues.

Despite the qualification that my own guilt might have made me more anxious than necessary, I still feel concerned that there are dangers in doing this sort of interview with people. If Melanie Klein is right about the desire for knowledge as having such primitive aggressive roots, anybody doing research on people would need to be careful. I am certainly aware that it is possible that I had encouraged people to think in ways that they had not done before. I had, for example, perhaps exposed some of their more ambivalent feelings towards the ill relative. It may have been unfortunate in some cases that people were then simply left to get on with things. Of course there may also have been times that it was of benefit for people to talk to someone. Undoubtedly this kind of interviewing may help people to make sense of what were otherwise confusing and distressing experiences and feelings. Certainly people often

told me that it had been helpful to talk. But even in these cases I would wonder whether there they had been left with tangled feelings exposed which they may have had to deal with over the following days, or even weeks. Mrs Mansell was someone who I returned to several times, and my encounters with her were the ones that bordered most on the therapeutic. She was able to report how she had felt quite euphoric just after my initial visit, but had the following day felt "over-exposed" (to use her phrase). She worked as a counsellor herself, yet she had very strong feelings of guilt that made it difficult to accept such help for herself. She quite openly used my visits to talk through this. In this case we were able to discuss this in terms that I believe were helpful to her, but only because of the particular circumstances, and I was quite aware of stepping outside a strictly research role.

In spite of these doubts, I do think it is important there is more of this kind of research. It is becoming increasingly believed that it is important for social scientists to be able to apprehend the emotional lives of social actors and to be able to incorporate them into their understanding of social processes.

Envoi.

The relatives talked to were involved in a painful struggle not only with their own feelings and experiences, but also with the discourses they found around them. They struggled with difficult and conflicting feelings, with ideas and hopes about what 'family' should mean. An important aspect of their understanding, the discourse which provided most useful meaning to them, was that their relatives were suffering from an illness. Whilst there may be dangers in such a construction leading to the devaluation of the person deemed ill, what is notable are the lack of alternative models. Indeed it is striking that these relatives themselves found the discourses of psychiatry often to be inadequate. Yet they still had powerful investment in forms of medical model. Such needs and investments will undoubtedly survive and form a crucial component of the post-Asylum age. Those concerned with finding solutions to the problems of mental illness would benefit from entering discussion with those who, like these relatives, are close to and continue to enter dialogue with mental

illness. It is surely through dialogue that new perhaps more hopeful and emancipatory meanings and discourses can be created.

Appendix (A)

Mr M *** ****
19 ***** Road
London

15 July 1992

Dear Mr .,

As you may know there are considerable changes occurring in the National Health Service at the moment, particularly in Mental Health Services.

I know that you have had some involvement with your son ***** who has had cause to have considerable contact with the psychiatric services in *****. I am involved in a study of the experiences of relatives of people who have been in contact with psychiatric services. I think that an important part of the planning process ought to be a consideration of the views and opinions of the people who use the services, and of their relatives.

I would therefore be interested to listen to what you have to say about the service that Bernard has received, and of experiences you may have had of coping.

I would like to come and talk to you at your home on **WEDNESDAY 22nd JULY at 10-00 AM**. Clearly this may not be convenient for you. If this is not convenient, perhaps you could leave a message on this telephone number, - ***-***-**** and maybe we could arrange another time.

Yours sincerely

David Jones

Research officer

Appendix B.

2 people only had family in the W. Indies, according to the notes. I made no contact them.

2 people's parents were dead. One had a daughter apparently in occasional contact. The other had a brother involved, but for neither was there an address in the notes.

1 man's parents had moved back to the W. Indies, there was an address for his sister which I visited but she was not there, it appeared to be temporary B. & B. accommodation.

1 man's mother's address was in the notes, but she could not be contacted (possibly moved to Nigeria).

2 men had family in different parts of the country, who I wrote to but got no response.

2 people had family elsewhere (Ireland and Northern England) who I contacted by letter and received responses.

1 man's mother was around but was apparently in an old people's home and there was no address given.

1 man's sisters were very involved, and I spoke to them on the phone and arranged to visit but they were never in.

1 woman's brother was apparently involved but he did not want the hospital or his sister to have his address because of upsetting experiences with his sister in the past.

2 men's families were local and were very involved but were never there to be interviewed, these probably constitute refusals.

1 man's father was mentioned in the notes, but was never in when I visited the address that was mentioned in the notes.

1 man's mother's address was in the notes, but she had moved on from this temporary accommodation.

1 woman's parents address was in the file but I got no response from them when I visited.

I visited 1 man's parents address but was told by a neighbour that they had moved years ago.

1 man's brother had moved on from the address in the notes.

1 woman's father lived most of the time in Nigeria, had quite a lot to do with his daughter judging by the correspondence on file.

1 man's sister was apparently involved, but their address was a B&B hotel, she had moved on leaving no forwarding address.

1 women's parents seemed to be around but there was no address in the notes.

Appendix (C)

FAMILY NAME	RELATION INTERVIEWED	ACCOMMODATION CATEGORY	SEX	MARITAL STATUS	AGE
Ajani	F	3	M	Single	19
Blacksmith	M	4.i	M	Single	32
Bryant	F	2.ii	M	Single	23
Christodoulou	B / S-L	1	M	Single	27
Christian	M	2.i	M	Single	42
Cook	(F/M/B)	4.ii	M	Divorced	42
Daley	S	4.i	F	Single	40
Dear	M	3	M	Single	21
Doors	F	3	F	Single	27
Galton	M/S	4.i	F	Single	29
Gazza	(M/A)	3	M	Single	39
Gouella	A		M	Single	22
Gyradogc	B	2.ii	F	Single	33
Harris	B	3	F	Single ⁵	45
Jenkins	F	2.ii	M	Single	29
Karajac	M/B	1 / 2.ii	F	Single	26
Land	M	2.iii	M	Single	33
Light	M	3	M	Single	47
Lord	M	3	M	Single	33
Mansell	W	3	M	Divorced	46
Manula	B	4.i	M	Single	31
Mason	M/S/B	4.i	M	Single	36
Murray	M	1	F	Single	27
O'Reilly	S	4.i	M	Single	37
Peters	(M/S)	4.i	M	Single	35
Pickles	D	1	F	Single	38
Quinn	S	4.i	F	Single	38

⁵ In long term partnership with an ex-long stay patient.

Reece	F/S	3	M	Single	28
Regan	(S/B-L)	3	F	Single	38
Rivers	(M/F)	1	F	Single	29
Snellman	C	3	M	Single	33
Sole	M/F	3 /2.iv	M	Single	40
Sutherland	W	3	M	Divorced	36
Teague	M	3	M	Single	37

Abbreviations.

M - mother F - father B - brother S - sister

W- wife A - aunt C - cousin S-L - sister-in-law

B-L - brother-in-law. ()- only interviewed together.

Accommodation Categories.

1) At home with family.

2) Hospital at time of interview.

- i) long-stay ward.
- ii) usually at home with family.
- iii) previously homeless.
- iv) usually in hostel accommodation.

3) Hostel/supported accommodation.

4) Independent Accommodation.

- i) Council flat/housing association.
- ii) DSS Funded Bread and Breakfast accommodation.

Summary of Initial (Identified Patient) Group.

Average age=33. 11 Women
23 Men

Summary of Interview Group.

15 Mothers 8 Fathers

8 Brothers 8 Sisters

Total: 17 Men 30 Women

Appendix (D) Typical Scenarios.

1) Those living at home with family.

George Christodoulou was living alone with his mother. I did not interview her as she spoke no English but I interviewed the brother and his wife who lived around the corner. For George to continue living at home was not regarded as a satisfactory situation by them.

Mr and Mrs Rivers cared at home for their daughter. Indeed the fact that they had coped with her at home was the source of some pride, I was told that they had never had her admitted. She had actually been admitted once for two days back in 1978, according to the hospital notes the father had signed her out as he felt nothing was being done for her. This episode was not referred to and her parents seemed quite content with the situation, although Diane did appear to be quite disabled.

Janice Karajac was still living at home when I interviewed her mother. However by the time I interviewed her brother Jean Karajac, a few weeks later, she had been admitted.

Jane Murray lived at home with her mother. This seemed to be a reasonably contented situation. Jane had a manic-depressive diagnosis and was considered to be stable most of the time. She was the only person in this sample to be in full time employment (with the Civil service although her mother thought this was too stressful and was not likely to continue).

The other person in this group was Helen Pickles. I obtained her name from the Community Psychiatric sample, she had been diagnosed as suffering from schizophrenia. On reading the notes it seemed that she was rather well, the main reason for her referral to the Community Psychiatrist appeared to be that her mother had suffered from schizophrenia for a number of years and had been hospitalised many times and was quite disabled. Helen seemed to be the carer, in this situation,

so I interviewed her, assuming that she might have an interesting perspective.

2) Those in hospital.

Six people fitted into this category. Only one person, Peter Christian, had during the study period become a long-term resident of a large psychiatric hospital. I was deliberately excluding people who were part of the hospital reprovision programme. Peter Christian was unusual in that he seemed by the last time I saw his mother to have 'broken the rules' of the reprovision programme and had become recognised as a long-stay patient.

Chris Sole had been placed in a hostel but this had broken down and he had been on an acute psychiatric ward for many months. There was some doubt about where he would be placed on discharge, but it was likely to be the same hostel. This was a constantly traumatic situation, the parents lurching from one crisis with their son to another. They lived close to the hospital where he was admitted, and a short journey from the hostel where he was placed. They therefore saw him pretty well every day. I met with Mr Sole on a weekly or fortnightly basis for more than 12 months. The way that their lives were taken over by what was happening to their son was astonishing, and the unhappiness Mr Sole suffered barely imaginable.

Fred Bryant was perhaps the most extreme example of a commitment to caring in this whole sample. He was from Leeds, his son, John, had been put into care in Leeds when he was 14. Following the break up of his marriage he had gone to his mother but she had her own difficulties and John went into care in York, becoming delinquent. He began 'bunking off', coming down to London getting into trouble. He eventually became involved in a quite well publicised scandal at the time (this episode was not directly talked about at interview, but I did have to reassure Mr Bryant that I was not from "The Sun"). John was also convicted for assault, but he was sent to Friern on account of his mental state. Mr Bryant then moved from Northern England to London to look after his son. This has been very difficult, although formerly running his own business he was 60 years old and unemployed at the time of

interview. He was living in a council flat, with no carpets on the floor and barely any furniture. He had lived in a squat with John before that. He gave over a considerable proportion of his social security money as pocket money to John. John would be admitted when his aggressive behaviour became intolerable, he was in Friern when I interviewed Mr Bryant. He was doubtful whether he could cope with him again.

Brian Land was living rough as a vagrant prior to his admission to the acute ward. He lived by scavenging for food, evaded contact with other people and refused any offers of help. He was admitted on a Section 136 by local police when his clothes fell to bits to the extent that they no longer covered much of his body and he became "indecent". Eventually in hospital enough was found out about him to contact his mother. She began to see him regularly.

3) Those Living In Hostels - Supported Accommodation.

This group consisted of 14 people. Mrs Teague had not seen her son for six months, she could not face seeing her son after traumatic times. She felt she would try and get in touch. She was emotionally much affected by what had happened to him.

Mrs Mansell saw her husband regularly but only because he is the father to her son. Otherwise she would rather not see him and she was not involved in providing care or involved in any decision making. Never the less the impact of his illness on her life was still great.

Liz Regan for the time being could not cope with seeing her sister due to a series of traumatic incidents.

Mr and Mrs Snellman were cousins to Erik who lived in a social services run hostel. They saw him every week or so, and kept an eye on his progress. If anything went wrong they would be the ones to become involved. They had previously been more intensely involved.

Marjorie Harris lived at the other end of London from her brother Mike. However he kept in regular contact, saw her regularly, always had her stay with him for Christmas and regarded himself as being responsible for her.

4) Those Living Independently.

This group consisted of eight people, 12 separate interviews were carried out, three of those with more than one family member present.

All those interviewed were emotionally highly involved with their relative and what had happened to them. The impact on their lives was great. Penny O'Reilly only saw her brother irregularly (this seemed to be his choice as she saw another brother who was also diagnosed as suffering from schizophrenia and was in Broadmoor, on a weekly basis).

All the others in this group saw the ill person very regularly certainly several times a week, often daily. Molly Quinn for example had a sister over every Sunday and spoke to her most days on the telephone. Terry Blacksmith lived around the corner from his mother and saw him everyday. Charlie Mason lived in a housing association flat in the same area as his mother, brother and sisters. He visited and had meals with his mother regularly. His brother tried to visit him regularly, often sorting out practical and financial matters for him.

Appendix (E) Example of an interview.

Interview with Mike Harris.

Although this is a witness who was particularly direct, the themes raised by the interview are typical. It is one of the later interviews I did, so I think I was particularly well primed to hear some issues which had been raised by earlier interviews.

I obtained Mike's name and address from his sister's psychiatric file. He has been in correspondence with the hospital, trying to arrange to take Marjorie on holiday. Otherwise he is not really mentioned in the notes. Such lack was typical. He does not live with Marjorie, in fact he only lived with her for a few years when he was a teenager, and he now lives on the other side of London, sees her irregularly but as we shall see the involvement has depth.

I meet Mike at his nice house in Barnes on a hot summers afternoon. He is a man in his late fifties, but looking younger. The time has been arranged and I am welcomed in and given a cup of tea. After a few pleasantries and explanation about the project, the tape recorder is switched on and straight away we are introduced to the breadth of the influence of Mike's sister on his life. His sister's illness became apparent around 30 years ago, and immediately I am taken back there. This material was very much immediately 'alive', there is no doubt that Mike feels a very considerable degree of concern about his sister. It is notable that other major family events, like Mike's marriage and his father becoming ill are now thoroughly entwined.

It is apparent from this opening that Marjorie's difficulties are seen as being due to illness, that had a specific temporal onset (1). It is also clear that the idea of 'family' is significant, it permeates this first passage. Marjorie's illness is associated with Mike's own marriage (2). His father becomes infirm at the same time (3). Mike first becomes aware of Marjorie's odd behaviour when visiting, as he puts it- "my family

with my wife" (4).

Marjorie had been seeing things, behaving in ways totally foreign to Mike's father and mother. They didn't know what to do (5). However, apparently unproblematically the situation is seen as being a medical problem. It is the "family doctor" who refers to Friern Barnet (6). I am also introduced to some rather sad and guilty images of violence and sectioning (7).

(TAPE SWITCHED ON)

DJ: . . OK . you were saying you had quite a lot to do with Marjorie.

MH: Well I . Marjorie was taken ill when she was 18 (1), she's now . um 43 or 46 one of the two . she was born just after the war . anyway there were . I got married around about 1960 (2), and that's when she was 17, 18. And my father was rather infirm (3) and when I went to see Marjorie one night, or when I went to see my family with my wife one night (4) . . . We lived in a flat, . . M. said she'd been seeing things and you know . . it was totally foreign to my father and my mother. They didn't know what to do (5), so they then had to take her to the family doctor who referred her to Friern Barnet (6). Of course that ultimately led to her, well, . . residence there. Erm . she used to be allowed, well not allowed . she was sectioned at the beginning and then my father would go up there and bring her back home at weekends and she got . she was very, very violent (7). She would in fact, at one time . . I lived away from London I used to invariably get the phone-call to take her back. Bringing her home was OK, taking her back wasn't.

In asking for clarification about Marjorie's reluctance to return to the hospital I encourage him to elaborate (1). Mike jumps from the beginning to some way ahead to a time when Marjorie has been in hospital, has been treated for some time. Explanations are proffered for Mike's involvement in sectioning. She is described as "young and strong" (2) (perhaps the medication has affected her, making her put on weight). Mike is having to step in for his father who is physically infirm and cannot cope with her (1). Then there is the startling description of a "liaison". To Mike, Marjorie has been taken advantage of sexually (3). He intervenes, physically, to stop this occurring. So it would seem that an important justification for physical restraint and involvement in compulsory hospitalisation is protection from sexual exploitation. The anger is palpable, 30 years on it is very much alive:-

DJ: She didn't want to go (1)?

MH: No. So therefore I used to have to come down, my father just couldn't handle Marjorie (2). She was young and strong (3), she put on a lot of weight, whether it was the treatment or what- Because she was quite a slim girl, my whole family were. At one time they'd stop her from going out. She'd gone out and had a liaison with somebody in the street, (4) you know . . . it was very difficult . and at that time I'd gone out looking for her, caught up with her, found her, . . explained the matter to the person she was with and that led to some considerable fracas . . .

Within the first minute of 'formal interview' a great deal of emotion has been shown. This is not the first time during an interview I have been struck by the significance angrily accorded to actual or feared sexual exploitation. I ask for clarification. Mike moves on to further 'shameful' description. Mike's father has locked his daughter into a room in their home (to protect her from the exploitation outside), she kicks the door to pieces.

DJ: You felt she was being taken advantage of?

MH: Well she was. . Yes she was . . mmm . . [Mike looks angry, and tearful, he collects himself and continues] . One other time I went to take her back to the hospital, my father had had to lock her into a room, it was in Islington, downstairs basement-cum-living room you know these old tenement houses and she had kicked all the panels out of the doors to get out. . .Um

I then ask the first question of the interview, a very open question leaving Mike to tell me in his own words about his construction of events (1). I try to find out what his understanding was of the way that Marjorie was behaving at this time. His response is an admittance of confusion (of the family's confusion). Apparently straightforwardly, however, the problem is seen as being to do with "mental illness" (2), which has involved a great change. There is then a description of contrast, of what Marjorie had been like, of what has been lost to Mike. I am presented with memories of Marjorie as she was before. She was intellectually capable, she was coping with finding work (3). She was pretty and there is an optimistic note as she had found "a nice young guy", his leaving is associated with her deterioration (4). There is then the memory of the intrusive psychiatric interview (5):-

DJ: What did you think was going on originally? (1)

MH: Er I didn't know. It was my first experience of mental illness (2), my family didn't know, we were all taken aback it was completely unknown to us. She'd . Marjorie had been reasonably bright, a reasonably bright girl. She'd gone to work in the civil service department (3), Import/Export division of the civil service. She'd

done . stumbled through the Pitmans short-hand exams and stuff like that. You know she'd done reasonably well and um . and then the turning point was as I said when she was 18, or late 17, 18 . She had . she lived a fairly sheltered life, um . .she was pretty girl, she'd not had boyfriends as such, just prior to having the breakdown she embarked on a relationship which was . . or a friendship with a chap which was nice. Because he was a nice young guy, and then this thing blew up and of course he dropped her (4). She was saying strange things to him, . . So the outcome was that she went to Friern Barnet, and of course we were called- my father and myself to the psychiatrist who was a lady, the psychiatrist I can't remember her name. And she asked me a series of questions, some of them quite outrageous questions- how the hell would I know if she masturbated! (5) You know . um . and she seemed to have a lot of things which were obviously painful, she had was it ECG?

Within ten minutes of meeting this man, and just a minute or so into the interview, some strong feelings have been communicated. His feelings about his sister are strong and very much alive, and have come across very strongly. I cannot ignore the sexual references, all appearing so very early on in the interview: 1) The tearful anger shown at the memory of the sexual exploitation. 2) The hope of her meeting a "nice young guy". 3) The amused/angry recall of the intrusive psychiatric interviewer asking about masturbation. It will be seen below that these sexual references cannot be understood to be about prudery or possessiveness; Mike later expresses delight at Marjorie having found a long-term partner.

I will allow Mike to continue the story. In telling it he gives a flavour of his involvement and his concerns over the years. Mike goes on to give a summary of around a ten year period. That his sister found a partner clearly means a lot to Mike. He is respectful of their relationship. To Mike it was the "best thing that ever happened" that she could find a companion, a relationship that he assumed to be sexual (there is the association to contraception). I am introduced to a sense of his alienation from the psychiatric service, which builds on the description of Friern as 'ghastly'. Again there is further mention and palpable distress at being involved in the sectioning process. There is also animated comment on his feelings about the lack of communication from professionals, in particular the way he was not informed when Marjorie discharged herself. This was a common complaint in other interviews and raises the important issue of responsibility. The contrast in Mike's involvement with his sister compared to that of his brother seems also to be interesting:-

The interview continues:-

DJ: ECT?

MH: mmm. Er she wasn't very keen on that. I don't know whether treatments, .
. I suppose they've improved - you're looking at the early sixties now.

DJ: What did you think of Friern?

MH: Well . I didn't , ha! . . A ghastly place and it still is. it still is, but I hadn't anything else to compare it with, so I mean . apart from other normal hospitals and of course it doesn't resemble a normal hospital one little bit. . . The er . [edit] . she met a young chap, or chap up there [at Friern], roughly her own age. They formed a friendship, that's Ken Burton who . I believe would be roughly of the same dimension of illness that Marjorie had. They both showed the same signs that all was not right. And in fact it turned into a relationship, because in . er let's see, going back um, times got a habit of marching on, . . . They made an effort to rehabilitate Marjorie- the authorities - . . and she was taken, . . she was given a flatlet in a house in Finsbury Park, it was a Housing Association residence. And Ken Burton at the same time, he was also given the chance to have a place in Tottenham. He lived there for quite a while. Marjorie was in the Housing Association house for possibly five months, and she just couldn't settle: she would keep the residents up, she would sleep all day, stay awake all night. And it was very unsettling to the others, they weren't all . . I do believe, or I think that they weren't all suffering from the same illness, it was a variety of things, perhaps one had had a nervous breakdown. Whether or not Marjorie was one of the worst affected there I don't know, it had a very unsettling effect on the rest. Eventually they said "Look", they phoned me at work and said "Look, we can't have Marjorie here any longer". I mean I used to visit her there of course, she just -the Housing Association it was a good . . it was a nice sort of location, it was an old building that had been completely renovated. They were nice little rooms. Apart from the unsettling effect she had on everybody, she was really a fire hazard as well, because she would go into Oxfam shops and spend all her money on old clothes and stuff and you'd go into her room and it was piled high with clothes, teddy bears and this, that and the other. and it was a real junk, it was an absolute mess. And she just wouldn't listen. I would say to her "Look you will get thrown out if you don't keep the room tidy". And she would say "Oh yes, yes". I would say "Let's have a tidy up" and I would bag some much stuff up and put it outside, for the dustmen to take it away. When I would go back, say a month later- it was just the same. Anyway they phoned me up at work, and said "Look, this won't do, we've got to put Marjorie back into care, into a more caring environment, and its going to be the hospital, would you sanction it?" I said "Well I'll have a word with my mother", and my mother said, you know "Will you?" so I said "Yes". So I had to go with a doctor and they, . . I think the doctor had to section her for seventy-two hours. It was very difficult I didn't know what . .

DJ: You had to sign as well?

MH: Yes .[there is a slightly tearful pause] . . So she went back to hospital. She was there probably another five years I suppose. Ken was, at this time Ken used to visit daily, on a daily basis and during this time if it was summer time, Marjorie and Ken would stay out all night or all week even. I was never informed by the hospital if she had absconded . or not absconded because she wasn't there under any sort of duress. There was never any . even now there's very much or never has been much communication. They've . . I'll go onto that . erm . . where was I . . Yes Ken used to visit Marjorie and if it was summertime they'd go off and sleep

in a park somewhere for maybe days on end or . you know . . If I was ever going up to the hospital I would always have to ring first and say "I'm coming up", and they did use to attempt to keep her in. And of course she did stay in, because it was always, . . obviously when I went up there was always goodies at the end of it- some pocket money, stuff like that, some cigarettes what-have-you. At Christmas time we used . . I used to bring Marjorie here for Christmas, I was married . well I've been married twice my first marriage failed and my . er my second wife died. . er The . er We used to bring them here for Christmas, I say used to, I still do. She came here last christmas, and . .

DJ: She and Ken?

MH: Yes she and Ken, oh yes yes, cos, they're virtually inseparable. I mean it's the best thing that ever happened to Marjorie, absolutely . he is her absolute companion. So . er . the . where were we? I'm trying to go through different, trying to assess different years . it's difficult I should have written it all down. Um Anyway as I say, he went back from Finsbury Park and . . it was difficult to persuade her, obviously to go back, but she, you know jumped, into my car with Ken and went back to hospital. . Er Ken continued to live outside the hospital, Marjorie lived in Friern, as I say he visited near enough every day. Now, Ken . ooh two years ago, his mother died and . three years ago . Both mothers- my mother died three years ago and Ken's mother died. . . I had three deaths in one year, my wife, my mother and my mother-in-law . .

DJ: God.

MH: Ken's mother died, the same year and she left him 16,000 pounds, fortunately she left it in a bank, with a bank manager. The bank manager couldn't control the finances, Ken withdrew it and near enough blew it, within fourteen months. And the first thing he did of course was to say to Marjorie "Discharge yourself", which she did. And the hospital, never, ever told me. She, . they literally just discharged themselves . when I queried it and they said "Well she is an adult person, she is a voluntary patient"- this I disagreed with because she wasn't a responsible person, she may've been an adult she may have been here under her own volition, but that . . for next-of-kin not to have been notified was diabolical and . .

DJ: Presumably you just found out when you tried to visit?

MH: Yes. Yes. Yes, so then I had to search for them both and I mean I eventually found them because they're very parochial, they don't wander too far. They lived in a hotel, and of course he got ripped of the chap, . . sixteen thousand pounds in the hands of someone, I'll say loosely is of 'diminished responsibility', because he is a very bright guy, he's far brighter than I am - academically. But there's no worldliness about him, they're taken for a ride.

DJ: How did you find them?

MH: Um . . there was an address that someone had said . that someone had given me that wasn't right. But it had been an address that they'd stayed at formerly, and the person at that hotel, I mean they all knew Marjorie and Ken, I suppose they'd all had a go at ripping them off, or them off, him off . . I did in fact eventually find them. I was annoyed because a) Marjorie had discharged herself from the hospital, I knew 16,000 pounds wouldn't last very long. I was also worried that having discharged herself that she wouldn't be allowed back. Anyway, Ken was rather you know . said . 'Oh we won't want to go back, or need to go

back'. I was worried about other things, the medication part of it . I mean heavens above they've lived together for so many years, its amazed me, . I don't know whether or not they've ever, she's ever been . I know she . at the onset of her stay outside hospital she was given contraceptive pills, you'd find packets of the things lying about, I don't think she ever took them! And there was never any, she never fell with child, obviously they were and still are on those sort of terms, and still are I assume on those sort of terms. Anyway . . . getting away from the point . . Yes the medication bit, especially the fortnightly, or the monthly jab, the largactil or whatever it is. Is it largactil? Whatever it is, I wondered how she was going to get that, and it turned out that it was a very, it seemed a very vague affair that she had to go along to her GP, register with a GP outside of the hospital. Er . And of course I believe that she had to do that anyway in order to collect DHSS payments . . I'm not very au fait with it all, and they aren't! Anyway . . they lasted about, just over a year I suppose, and I was . . . in somewhat in a bit of a turmoil myself then, my wife had died. She died under very difficulty circumstances, she died very suddenly . . .And things slid rather with Marjorie and Ken . Um and one day . . and my mother had died . .Oh I have got a brother, he lives in, he emigrated to Leeds his daughter was in the Uni' there. He sold up here, bought a place in Leeds and then bought a place in Majorca and took early retirement . . he never had a great deal to do with Marjorie, .

DJ: Why do you think that was?

MH: . . Don't know. He's a smashing bloke . I think he might have been secretly ashamed of her . . of her illness.

DJ: Was that something you ever felt? . . people often do.

MH: No, . no, no never did, never worried me. Oooh no, I mean I . . None of my . I mean obviously both wives would go and visit Marjorie and it didn't bother them, it just didn't . No I was never ashamed of her. It's become, it happened . people were very understanding even in the early days, but they're even more understanding now, because it seems to be more prevalent . Or it's become more accepted, its become accepted . . Anyway, I had a call from work . let's see it must have been early summer of last year, from the police in Peckham saying they've picked up someone called Marjorie Harris and Ken Burton, and we'd like to know if you're the nearest relative. I said 'Yes I am', they said "Well she's at the Maudsley now and she is seeing" . a um . , you see I'm getting this wrong. No, that's . I've got it in reverse, what had happened is that at the end of Ken's money running out they had been befriended by a man who had a flat in Hackney with a room and he was charging them 90 pounds a week for it . with no food. The money started running out, it did run out. Ken had got no more liquid funds left. And the chap said "Right off you go", and he threatened Ken with violence, but they didn't know where to go, um . I never did get to the bottom of why they never went to social services or whatever . perhaps they weren't aware of the various things that were available, but . . it got . .And he, the Scotsman . he was a Scotsman the chap with this place, came here to see me. Marjorie had given him my address. Ken had gone, sleeping rough I suppose, it was summertime, early summer.. . And he came here and he said to me "Look you've got to get Marjorie out, because . . you know I can't live there with Marjorie", so . there was a bit of an argument about where the money had gone, ha! . and er, so I went up to Marjorie . Oh and in the meantime, Marjorie who is also . she is under the court of protection . my mother left her some money and the court of protection look after it . [phone rings] .

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