On Rationality, Power and Passion:

A story about a project to improve

co-ordination of services for people

with HIV/AIDS in Lothian

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DECLARATION

I hereby declare that this thesis has been composed by me and (save where acknowledgement is made below) is based on my own work.

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Abstract

The thesis presents an ethnography of an action-research project carried out between 1992 and 1995 to evaluate co-ordination of health and social services for people with HIV/AIDS in Lothian. The study entailed detailed investigations of interactions and contacts between a small number of people with HIV and the professionals who were involved in their care. Interactions and communication among these professionals around the care of individuals as clients and patients were also studied in the context of specific service settings.

The ethnography draws on literary and social science theory on narratives and narrative exchange. A large part of the material collected consists of information passed around for the purpose of service co-ordination, in the course of which people, behaviour and events were evaluated and plotted as stories or narratives addressing dilemmas and ambiguities of service provision. These ambiguities revolved around a central notion of 'control' to which were juxtaposed opposites such as 'manipulation' 'fraud', 'chaos'. Stories were plotted differently according to the narrator's position in the system of services, and they were passionately contested: one person's 'control' is another's 'manipulation'. The ethnography locates the narrative exchange within dynamics of power and authority which differed between settings studied. The social consequence of these dynamics is discussed in a) the way some issues prioritised by service users. e.g. welfare rights, were hidden in service provider discourse and b) in the stereotyping of service users such as 'the chaotic manipulative' drug user and the 'organised gay man'.

The research process became entangled in these dynamics and the ethnography proceeds as a 'story' of the project, the ethnographer's evolving interactions with people, the material produced by research encounters and interpretations of them. The story-line follows (roughly) a sequence of events as they occurred in the time of the project. It carries an argument about rationality and power progressed through critiques of Habermas and Foucault.

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This thesis is to the memory of my father, and to John and Audrey.

Abbreviations

CAST Community AIDS Support Team. A team of community psychiatric nurses offering support to people with HIV in their home.

CDPS Community Drug Problem Service. A tem of counsellors, social workers, doctors and psychiatrists assessing drug users for doses of drugs substituting heroin. Regular follow up and prescribing is then handed over to a general practitioner. CDPS continue to be involved in complex cases.

GUM Genito-Urinary Medicine

HAMT HIV/AIDS Management Team. Committee making recommendations for funding and organisation of HIV/AIDS services in Lothian.

HIV/AIDS Hospital Community Liaison Group. Forum for discussion of co-ordination of services. The project was requested by this group

IDU Infectious Diseases Unit

LHAF Lothian AIDS Forum. Forum bringing together organisations and services for people with HIV/AIDS.

SATA Special Accommodation Team AIDS.

SAM Scottish AIDS Monitor. Voluntary organisation.

SECTION 1

INTRODUCTION

Chapter 1.   Introduction: theory, method and presentation

The story to be told: tensions and potentials

This thesis submitted for a PhD in social anthropology is written as a story of an action research project concerned with service co-ordination for people with HIV and AIDS in Edinburgh and Lothian in the period 1992 - 1995. The project was developed by myself and two colleagues in collaboration with workers in various Edinburgh HIV/AIDS services. The part of the study reported here was carried out by myself with the input of a sociologist with quantitative skills for part of one component.

The study was funded by the Scottish Office Home and Health Department. The main aims of the projects were:

> To study liaison and co-ordination between services in the management of people with HIV/AIDS in Lothian;

> To illuminate the process of decision-making behind care professionals' referral patterns and service provision for people with HIV/AIDS in Lothian;

> To study use and non-use of services by people in Lothian with HIV/AIDS;

> To study service users' and non-users' perceptions of services.

The material produced was to be made relevant to, and available to, service providers and planners on an ongoing basis. (From funding proposal, November 1991)

In order to meet these aims, we carried out four different studies, using different methods which brought myself and at times my colleagues into contact with both users and providers of services for people with HIV in a variety of Edinburgh service settings and contexts. Three of these studies have provided the material for the thesis. The 'service providers' were, for example, doctors and nurses of various specialities and designations working in hospital and primary care settings, social workers and other local authority staff, working in hospital

and local area teams, welfare rights workers and workers in voluntary organisations set up to provide support and assistance to people affected by HIV. This being Edinburgh, the majority of people with HIV who became part of the study had acquired the infection through intravenous drug use or through sexual contact with people infected through drug use. Most were still using drugs of recreation and defined by service providers and others as 'drug users.' The other main group was men who were defined as, and who defined themselves, as 'gay'. These labels mask a variety of lifestyles which cut across the social classification into two distinct groups.

In telling the story of the project, I present an ethnography of my interactions with people with HIV and their service providers. I describe episodes of service use, service provision and service co-ordination which we observed, or which were described to us. I look at how various ideals of service organisation translated into a less than perfect world of day-to-day interactions where people worked to conflicting and unclear obligations and demands and contested the rationality for each others' action. I also try and describe how the research process became entangled in these interactions and discuss some of the reactions among service providers to our research-based explanations of outcomes of their interactions with each other and with their service user clients. Finally, I try to address our own and study participants' experience of service provision for people with HIV.

I have chosen 'the story' as an appropriate frame for the ethnography for two main reasons. First of all, much of the information collected consists of stories about people and encounters passed around as information in the process of service co-ordination. At its most 'proper' and formal, this exchange of information happened by letter, by phone, in meetings and encounters of varying degrees of formality set up explicitly for the purpose of co-ordination of services. However, the informal and casual exchange of information was an intrinsic part of service provision and co-ordination in the settings studied.

Although the express purpose of passing on stories may be to convey information, a lot else is being conveyed with it. The information exchange to which I became witness contained all sorts of information extraneous to the main purpose at hand. This surplus information was revealing of the identities and experiences of the individuals involved. The stories had different functions: Some were 'confessions' and experiences shared for mutual support. This was an important function - work in the settings concerned was stressful and at times distressing. Some were 'gossip', told with varying degrees of intensity to apportion blame and credit, or to comment on moral character of people involved. The distinction between gossip, confessions and the exchange of information is difficult to draw. Most stories contained elements of all and their function was a matter of context: one person's harmless story was another's passionate moral judgement of persons concerned.

In the settings studied, service providers told each other stories about colleagues and clients, service users told each other stories about service providers and about each other and no doubt they all told stories about researchers (of whom there were several). Many stories, as I will go on to describe, became the object of intense inter-professional and inter-personal contest and conflict. Some of the stories were witnessed by me or passed on to me, either unsolicited or in response to my questions. I have used some of them to produce various papers, reports and now this ethnography. The stories have been changed and recreated at every stage in the process, including in my own retelling of them.

There is a question implicit here in separating 'what actually happened' from people's interpretations of it. The stance taken on this question depends largely on one's view of reality. An empiricist would see reality as existing before, and independent of, social interaction. From this perspective, the task of research is to cut through the distortions of subjectivity and opinion to locate and explain the underlying reality and help people adjust their opinions and behaviour accordingly - to become more 'rational.' My own view is that social interaction mediates reality, and that the stories told to me about episodes of service use and provision not only comment on these episodes, they also constitute them

(Good 1994). The distortions, omissions and additions to the stories made by different people in different contexts are therefore taken as the 'social facts' of interest for the purpose of the ethnography (Samuel and Thompson 1990).

I draw on Good's (1994) interpretation of the Russian literary critic Bakhtin's idea of 'heteroglossia'. In literature, a text comes alive in a dialogue between the voices presented in it, between these voices and the reader and also in the play between the reader's imagination and consciousness. In life, 'reality' is likewise seen as constructed, symbolically condensed and objectified through a process of dialogues between socially situated 'voices'. The ethnography aims to build up a description of socially situated dialogues between multiple voices in the service settings I studied. I hope to show how this dialogue constituted what was seen as crucial issues and problems in service provision - problems which were objectified and explained in terms of external factors such as lack of understanding in (other) service providers or character deficiencies in service users. The format for the ethnography is thus 'stories within the story' of the project.

Secondly, the 'story' is an appropriate format because my view of reality as socially constructed implies that the ethnography is 'just another story' - albeit a story which is different from and more illuminating than 'everyday' stories in that it has been constructed on from years of theoretical work, analysis and reflection - about my interactions with people, the material our encounters produced and my interpretations of them. I have structured it as a story around the chronology of the project because as the project evolved and developed, my relationships with study participants changed and deepened and the knowledge we gained from our interactions changed. The storyline follows (roughly) a sequence of events as they occurred in the time of the project, but it is the nature of these relationships and the knowledge they produced about power, rationality and agency which form the subject for the thesis.

Although the ethnography specifically describes service provision and use in the HIV/AIDS field, the substantive issues are general to medical and social service

provision and its research. The study concerned organisations and 'the way they work'. The ethnography therefore draws on a social science tradition of the study of bureaucracies and organisations. This tradition has revolved around debates about 'rationality' of knowledge as the basis for social organisation. Debates about 'rationality', in turn imply a problematic of power and agency. All three areas implicate research and its role in producing and changing knowledge and action.

Theoretically, 'rationality' opens up as the main theme. Current tradition questions the assumption of absolute or objective criteria for the judgement of 'rationality' in human organisation. Rather, systems of knowledge and action are seen as socially constructed in local contexts, and their 'validity' or 'rationality' can only be judged within that context. What then is the relationship of knowledge and the reality to which knowledge refers? On what knowledge basis are organisational decisions made and goals defined? How do goals relate to actions and their outcomes?

Subsumed here is the problematic of 'power' - who makes decisions, on what knowledge basis and to what effect? Social systems and organisations are made up of people in different social positions and operating with different knowledge. What and whose knowledge carries weight and authority as 'rational' and 'true' and why? Whose and what knowledge is seen as 'deluded', 'irrational', wrong? 'Agency' appears as a third issue: are people operating within a (service) system instruments or authors of its logic?

Methodologically, the issues revolve around structure-agency themes: How do we relate individual action and thought to structural contingencies? How do we access experience and the relationship between private experience and the structural factors which condition this experience and produce the language for its expression?

These questions imply issues around the **political** role of research: What is research-based knowledge, and in what ways is it different from other kinds of

knowledge? Does research have a role changing knowledge and the basis upon which decisions are made?

The theoretical, methodological and political issues are all interrelated, and a main aim of the ethnography is to illuminate these interrelationships.

Brooks (1984) suggests that the essence of storytelling is plotting: the dynamic interplay between, on the one hand, the temporal order of events presented in the storyline, and on the other, the order which the narrative discourse imposes on these events. In telling my story of the project as it occurred in time, then, I draw from it and impose upon it a discourse about **power, rationality and agency** in service organisation and research. The way the narrative discourse may throw light on and give meaning to the sequence of events narrated - i.e. any conclusions I may draw from this process - will depend on the specific ways in which I plot the dynamics between the two levels of my story. This has been no mean task. Power, rationality and agency are big and central issues in anthropological theory and research, and the project is ambitious in more than one respect.

The ethnography rides on tensions both in terms of representation, ethics and theory. Writing it has been like walking a very thin line between realising rich theoretical promise, on the one hand, and, on the other, falling into empty and senseless wanderings in a sensational landscape of AIDS, drugs and stigmatised lifestyles. These tensions are rooted in current concerns within anthropological theory, and I can only hope that the tension works to my advantage.

In terms of representation, the material makes for a complex ethnography which presents a multiplicity of voices of people who occupy positions with different degrees of structural power. The way and by whom different views, including the ethnographer's own, are contested take a central place in the ethnography. The material offers an ideal opportunity to explore 'heteroglossia' and the dialogic construction of social settings and individual identities, and the way ethnography contributes to, as well as reflects and describes, this construction.

However, writing these 'dialogues' has been very difficult, because they are so complex. I could have written a less complex ethnography pitched at a more empirical level (and I often wish I had). I could have written an account of 'service use' from the perspective of service users only. I could have focused on 'decisionmaking' in referral from the perspective of service providers only. By throwing the ethnography open to such a range of voices occupying such widely different positions and contesting each other's accounts with such vehemence, I have often felt that any emergent 'reality' I might be trying to catch is at the point of vanishing between all the different points of view - the (postmodern) anthropologist's representational nightmare come true.

This multiplicity of views and perspectives has also made it difficult to handle the material emotionally and morally. HIV/AIDS concerns disease and death (often slow and painful, also for those who watch and empathise) and the social conditions whereby death is distributed. It has been difficult to steer a path between, on the one hand, moral relativism (where the social analyst avoids confronting painful and difficult personal and public questions by hiding behind a detached observer role), and on the other, judgements of views and actions according to personal and unreflected criteria of 'right' and 'wrong'. This is, of course, always the case with ethnographic writing, and when it comes to matters of life and death, perhaps the search for absolutes by which to make sense of it all, or the urge to avoid the questions altogether, become even stronger. An illuminating ethnography does not necessarily preclude the ethnographer from writing from an explicit political and moral stance (Scheper-Hughes 1987). I will go on to argue that it is the only way of writing illuminating ethnographies. However, this involves the ethnographer maintaining a clear, explicit and critical view of her own role in the ethnography. The complexity of the material, the many views reflected and my own relationships to people have made this difficult. It is all too easy to veer from the path of rigorous reflexivity into sentimental and voyeuristic accounts about the untimely and sensational death from AIDS of homosexuals and drug users.

Finally, in terms of anthropological theory, the material offers ample opportunity to address questions central to anthropological research both past and present. Debates about 'power' and 'rationality' have, in various guises and contexts, fuelled development of both theory and practice in many ways. Both terms have been constructed and reconstructed in tune with the history of both anthropology and other disciplines (e.g. Lukes 1974 and Fardon 1985 on 'power' and Wilson 1970, Overing 1985, Tambiah 1990, Good 1994 on 'rationality'). In current (postmodern) theory, both terms are contested to the point where they are deconstructed altogether. The relationship between structure and agency in the response of the powerless to social oppression and control is a live and topical central concern (Abu-Lughod 1990, Tsing 1994). Choosing such central, but unresolved, theoretical concerns and themes as the topic for the thesis carries certain risks because the long history of two of the main analytical and theoretical tools have made them rather unwieldy. It is entirely possible to write this ethnography as senseless personal meanderings around big but empty words.

If the main terms around which the anthropological story revolves are so problematic as to be almost meaningless, why use them? I will argue that the terms have a history of meaning constructed in specific situations and contexts, and that this gives them 'social reality', no matter how thoroughly they have been deconstructed in theory. Bakhtin's views on dialogue as I have understood him in Good (1994) has informed my introduction so far. My discussion of the main theoretical tools and the way I intend to use them draws more explicitly on his views on the role of language in shaping social reality

> 'For the consciousness that lives in it, language is not an abstract system of normative forms, but a concrete heterological opinion on the world. Every word gives off the scent of a profession, a genre, a current, a party, a particular work, a particular man, a generation, an era, a day, an hour. Every word smells of the context and contexts in which it has lived its intense social life; all words and all forms are inhabited by intentions'

> (Bakhtin 1981, quoted in Good 1994 p.173)

Myerson has used Bakhtin's ideas on dialogue in a discussion of precisely the history of 'reason' and 'rationality' in European literary theory and philosophy:

> 'If ideas matter, they should interact like characters in a play, so that their personal qualities can be felt in the drama that follows'

(Myerson, 1990, p4)

On this note, I proceed with a discussion of my three main theoretical tools in an account of contexts in which they have 'lived their intense social life', and the history through which they have acquired their many shades of meaning. This history has created the tensions running through the ethnography to be presented.

Theoretical argument: the main terms used and the context of their deconstruction

'Rationality'

Historically, debates and theories about 'rationality' are tied in with the development of sociology as a tool for the understanding of 'modern' society and the control of its progress and improvement. 'Social' and 'natural' sciences were seen as tools for the expansion of empirical/instrumental knowledge underpinning this progress. 'Rational' knowledge was, in this context, seen as knowledge which corresponded to an external reality. The 'grand thinkers' theorised the transition from 'primitive' 'traditional' and small scale to 'modern' complex society based on 'rational' knowledge in various ways. Underway, the ills of progress and modernity, their causes and sometimes their reparation have been variously explained and diagnosed. Implied in this pursuit of 'truth' through scientific knowledge was the idea of 'rational man' (sic) whose actions were based on the expansion of 'true' knowledge, rather than on scientifically unproved 'tradition'.

Central to recent 'rationality' debates is the abandonment of 'grand theory', and with it, the deconstruction of 'classic' European philosophy's 'transcendent

subject' and its close relative, 'rational man' (sic) as the pursuer of knowledge as truth existing outside of, and before, social interaction. This debate goes to the heart of the research enterprise itself and the abandonment of 'grand theory' as unifying and encompassing explanatory schemes in favour of theoretical heterogeneity. Much of this heterogeneity, often loosely termed 'postmodern', rejects a modernist equation between 'reason' 'emancipation' and 'progress' because it masks new forms of domination (Best and Kellner 1991). The critiques of 'rationality' have lead to a consideration of ways in which 'power' produces and underpins certain knowledge as 'rational' and marginalises other knowledge as 'irrational.' In the process of deconstructing the transcendent subject as the active seeker of knowledge and truth, however, agency has become problematic. 'The subject' and 'consciousness' have been dismissed as products of language and discourse, without causal or creative efficacy. Who or what, then, argues about 'rationality' and what is the role of social science in the progression of argument?

The work of Jurgen Habermas and Michel Foucault are central in current debates about 'rationality' and 'power' respectively. Habermas aims explicitly to salvage 'rationality' from current tendencies to deconstruct Enlightenment's philosophical and epistemological edifices. Foucault's work on the archaeology and genealogy of Western Reason and its origins and modulations in specific institutional contexts concerns the role of 'power' in the construction of the individual as 'subject' in dominant European discourse. I develop my theoretical argument through critiques of these two thinkers. A consideration of Habermas leaves questions about 'power' unanswered in ways which suggest Foucault. Foucault's work, in turn, raises questions about 'agency' which ultimately are addressed through styles of ethnographic writing. These critiques are incorporated in the ethnography to follow. In this introduction, I will set out positions in the debate about 'power and rationality' which will lead up to a more detailed consideration of the work of Habermas and Foucault.

Habermas and the salvaging of 'Rationality'

Habermas has been called 'the last modernist'. He is concerned with salvaging the benefits of modernity, and this can, for him, only be achieved through its critique. He acknowledges that 'reality' and 'truth' are cultural and social constructions, and that we cannot therefore determine the 'rationality' of a system of knowledge by its relationship to an external 'reality'. He shifts the focus of 'rationality' from 'consciousness' (of knowledge) to 'language' and communication. The criteria for 'rationality' exist for Habermas in the conditions whereby this communication is organised. 'Rationality' is for him a communal product, decided through communication which is democratic and where everybody has been given equal opportunity to speak. He develops a view on 'argument' as a basis for integrating reason with dialogue.

With this shift in perspective, Habermas raises a range of issues around power. According to Myerson (1990) 'argument' has a several shades of meaning: it can be both 'reasoned argument' and 'disruptive struggle', or a ritual exchange of views where no positions change. Argument and communication are for Habermas 'rational' if they lead to agreement, but this view precludes from 'reason' a history of arguments and conflict which has created new ideas or perspectives and moved the debates on, without necessarily 'harmonising action orientation'. Arguments about 'rationality' have unintended consequences, in the process of which 'reason' itself, and criteria for 'reasoned' argument evolve. According to Myerson, because Habermas fails to fully explore the ambiguity inherent in the term 'argument' he does not adequately deal with the issues he raises.

According to Doyle and Gough (1991), Habermas' view of 'harmonising action orientation' begs further questions about how knowledge is produced. Knowledge is a product of situated practice, and the institutional arrangements of relationships of production and communication will determine what we 'know' and put forward as arguments in a political debate. 'Reason' is thus not an epiphenomenon of dialogues and arguments, but rooted in structural dynamics and modulated by 'power'. So what, then, is 'power'?

The problematic of power and agency- looking to Foucault

'Power' as an analytical and theoretical concept is highly contested and elusive. In anthropology, theories about 'power' have changed with the dissolution of 'political anthropology' and its replacement by the politics of anthropology (Fardon 1985 a,b). According to Foucault (1982) 'power' is no longer a repressive force exercised by institutions superimposed on social relationships, but part of the social nexus and inherent as a potential and a productive force in all relationships. The dynamics of power (whatever power is) produce discourses which constitute the world and its 'truths'. Discourse creates the objects, identities and events, and also the 'true' and 'rational' significance, meaning and affect which we attach to these.

The thing about 'power', in terms of structural constraints on action and thought, is that it is so obviously important in all aspects of social life and its study. Yet, power as an analytical tool is a slippery concept, derived from metaphors whose sense lie elsewhere: in physics, law. It is not immediately visible and manifest, but has to be 'read off', and this reading off leads into potentially unending epistemological tangles (Fardon 1985a).

To the interpretivist, 'power' is a 'different thing to different people'. Ritches (1985) discusses power as a preoccupation of Western intellectuals. He sees it as a 'representation' used mistakenly by us as a tool of social analysis. 'Power' is conceptualised and experienced differently in different settings, and unless part of the language and perceptions of people studied, power cannot be used to explain their actions. According to Ritches, the analyst's task is translation and explanation of native terms and the context in which they are constructed and given meaning. The problem here is that what is to be translated is a function of the question asked. This imports the analyst's meaning to what is to be translated and positions the analyst as an agent in the social field where 'power' is defined (Fardon 1985a).

To the analyst of social structure, determining the locus of power is problematic. Who has power? A category of privileged people who manipulate the less

privileges' concepts of true self interest and deny them the knowledge and opportunity to reflect on their destiny? Or are privileged and unprivileged all dancing to the tune of some mystifying set of ideas, and, if so, from where do they come? Analysis of power is potentially endlessly regressive, and the cut off point becomes a matter of the analyst's decision (Fardon 1985a).

Ritches (1985) suggests that 'power' is our evaluation of the effects of actions - a handy tool for the evaluation of unintended consequences. The idea of unintended consequences makes it possible, with recourse to ideas about the subconscious, to see native conscious conceptualisations about goals, intentions as explanations for action as irrelevant surface phenomena, while the forces of history work on a subconscious level and drive development of social form according to their own logic visible only to the analyst. Analysis of power thus becomes analysis of destiny. Weber saw bureaucratic instrumental rationality encroaching upon the domain of value rationality and producing an 'unenchanted world'. Foucault analysed 'surveillance' as an unavoidable result of the exponential development of the mechanisms of control by the state.

This position produces a problematic of the privileged position of the author/social analyst as the only 'free' agent capable of grasping 'the truth' about destiny by rational means. The ghosts of Enlightenment are resurrected in ways which suggest the perpetuation of domination, for possibilities of subjects as agents in any way affecting the logics of power and their subjection to it are effectively foreclosed..

With Myerson (1990) I believe in and suggest the possibility of democratic argument which integrates 'reason' with dialogue and progresses to new understandings and new knowledge. He suggests the idea of 'double arguability': argument is 'rational' when it connects with different lived experiences, changing these in ways which leads to development and refinement of 'reason'.

This raises the question of whether and how people can learn other knowledge than that which is produced in the relationships which structure their everyday life and work? Can we communicate effectively across structural and experiential divides? If not (as Lyotard 1988, might claim) then the multiplicity of voices will talk past each other into thin air, and argument, whether 'reasoned' or 'unreasonable', becomes impossible. This ethnography would be only one voice among many, wandering around the different points of view and demonstrating the lack of argument.

On this question, I go with Myerson, who cites Putnam (1981) to the effect that since the argument is about reason itself, reason cannot therefore be the final arbiter of the argument. This does not mean that absolute criteria cannot be postulated for a 'reasoned argument'. Some ways of defending premises and claims to 'truth' are better than others:

> 'Truth must be conceivable, otherwise how would we know there is an argument going on! Truth is a 'limit' verdict, it makes the difference between a journey with wrong turnings and many routes, and just wandering around.

> (Putnam 1981, cited in Myerson 1990 p. 59, my emphasis)

Still according to Putnam, a 'rational proposition' has wide appeal, the consistency to withstand critique and it is morally liveable. Most importantly, it is connected to lived experience and thus rooted in more than rules of logic. David Parkin (1985) suggests that we all, researchers and researched alike, empiricists are able to check out the 'truth' value of a proposition.

I see ethnography as the written product of knowledge gained through the ethnographer's interactions with people under study. Whatever 'power' and 'rationality' is, the anthropologist is clearly not an outsider and an objective observer of the way 'power' structures social life and its 'rationalities'. She is implicated because she forms relationships and uses them to produce new knowledge. This has implications for 'anthropological rationality', something which is brought out in a comparison suggested by Good (1994) between Evans-

Pritchard's 1937 study of witchcraft in the Sudan and Favret-Saada's 1987 study
of witchcraft in France.

An anthropological rationality: EP and Favret-Saada on witchcraft.
The starting point for many anthropologists' discussions on 'rationality' seems
to be Evans-Pritchard's work 'Witchcraft, Oracles and Magic among the Azande'
(1937). He provides a detailed and complex ethnography of the Zande tradition
of witchcraft, the oracles and other methods through which witchcraft is
diagnosed, and the knowledge upon which this system rests. He portrays this
system as totally 'false' in terms of Western 'scientific' knowledge, and also
internally illogical in that it contains self-contradictory elements. However, it
'fits' with empirical evidence in a way which supports the theories and utilises
its contradictions to maintain a self-perpetuating system of knowledge which is
'closed' to challenges of empirical data. Evans-Pritchard concludes that other,
'non-scientific' ways of thinking may be entirely logical within the social context
in which they operate, but they may be totally 'false'.

Good (1994) has termed Evans-Pritchard's study the 'modernist' account of
witchcraft. Importantly, his role as a representative of the colonial power within
the field placed him outside, or above, the relationships within which witchcraft
beliefs and accusations flowed. He was given the title 'Prince without Portfolio'
by the Azande and was able, or perhaps forced, to maintain the social distance
necessary to pose an 'objective' account of its working.

Not so for Favret-Saada (1980) 'Deadly Words. Witchcraft in the Bocage'
(France). Good (1994) has called her book the 'post-modern' account of
witchcraft. Since the 1930's, the role of anthropologists in the field has changed.
Favret-Saada did not enter the field under the protection of an official power.
She had to negotiate her relationships on a personal basis and became part of
events where witchcraft and accusations of witchcraft were a salient factor. A
position as an outside collector of stories about witchcraft automatically brought

forth an academic discourse about the 'irrationality' of witchcraft beliefs in assurances that witchcraft was a thing of the past or more remote and unsophisticated regions or villages. She discovered that her interest in witchcraft, in the eyes of the local population, implicated her as a potential ally in their attempts to fight off its effects. Moreover, until she demonstrated her readiness to become involved, people could not talk to her about witchcraft because there was no language with which to speak about the topic to people who did not occupy a position in a witchcraft drama. From her position, the 'rationality' or the 'truth' of the witchcraft theories were less important than the intense (and deadly) fight against evil in which her informants were engaged and into which she herself was drawn.

She reminds us that all theory has been abstracted from specific encounters between individuals - anthropologists and specific members of host communities, and yet, these individuals appear as shadow members of social categories in the finished monographs while the analyst hides behind theoretical abstractions. This PhD project has its roots in the history of anthropological theory about 'power' and 'rationality', and making them 'work' on the story of the research project is a matter of situating their use and meaning in the here and now of the research encounters and their interpretations. This is largely a matter of the way I tell the story.

Method of presentation: The narrative in sociology and anthropology

The personal and the social in narrative.
An anthropological answer to the problematic of power and rationality is ethnography which relates my use of the terms to specific contexts of behaviour and its observation, statements of experience and their interpretation. In choosing the 'story' of the research project as a frame for the presentation of my ethnography I slot into a current trend in medical sociology and anthropology

and now also increasingly in medical disciplines, where 'illness narratives' are used to gain insight into illness as lived experience, and the (social) dynamics of diagnosis, help seeking and therapy (e.g. Kleinman 1988). In particular, I draw from Good's (1994) theories about 'the narrative' and narrative exchange as a medium for communication whereby personal experience becomes social facts and acquires value as social currency. Good's field is medical anthropology, and he discusses illness narratives.

Good suggests a way of analysing illness narratives which draws explicitly and extensively on literary theory of the social act of telling and listening to stories. He claims that, perhaps paradoxically, literary theory gives improved insights into the dynamic relationships between the personal and the structural in accounts of illness and help-seeking, and, by implication, its research.

Experience is directly accessible to neither the persons recounting experience nor their audience but is poured into the narrative as a social 'form' which shapes it and brings it vividly into the 'here and now'. Stories are thus cultural artefacts. They are crafted from a cultural repertoire of idioms and their connections and linkages in culturally specific semiotic fields or 'semantic networks' constituting social worlds and their mediation of the natural. These are culturally 'deep' in that they are not merely explanatory schemes and models, but also generative of practice and interpretation. Stories are, furthermore, structured according to cultural and social conventions of plot, time sequencing, characterisation and dramatic tension.

In recapturing experience, stories give it **meaning**. Stories are crafted in order to wrest meaning and significance from the accidental, confusing and unexplicable temporal order of the everyday. The stories into which experience is poured shape the everyday flow of events, behaviours and emotions into patterns and themes which entail explanations of cause and effect rooted in different more stable, timeless moral and natural orders. For Good, not only the stories we tell, but life itself, or rather our living of it, is analysable in terms of theories of storytelling.

He emphasises theories of 'reader response' in understanding narration as part of life. A text is brought to life as it is read, and the literary aesthetic product emerges in ongoing interaction between text and reader. In a similar manner, we live our (illness) narratives in dialogue with other people and ourselves, as audience. We are in the middle of the narrative's unfolding and thus both the performers and audience of its telling. We 'read' the narratives like we would read a final text: we anticipate plots, points of view of different characters and we create dramatic tension and build into the reading of our own narratives a 'subjunctivizing element' which deals in the 'potentialities' of life, rather than fixed conclusions and outcomes.

The narrative changes course and potential according to new experiences, new knowledge, new hopes and fears. Narratives about illness, particularly about chronic or present illness are thus 'open' in the sense that their end is not yet written or told. The narratives have alternative plots and potential endings, which are often contradictory.

> 'They have indeterminacy and openness; therapeutic actions, motives of participants, the efficacy of interventions and events are open to reinterpretation as life goes on, revealing hidden aspects unavailable to the blindness of the present'

> (Good, 1994, p164)

The indeterminacy and openness increases with the intersection of the social with the personal. (Illness) narratives, once told, become public in that they are 'entextualised' and removed from the original situation and performative setting. Like an author's text, they take on a 'life of their own' largely outside the control of their author and as several people are involved in one story, the telling of it changes with the motives, point of view and social position of the narrator. As social practice, narratives are products of, and reflect, the structural dynamics in which its narrator(s) are caught. They are

> 'configurations that conceal dynamic relations as well as representing a coherent ordering of experience' (p. 161).

There is room for agency here. Mahoney and Yngvesson discuss the problem of feminist theory and history of

> 'documenting women's position as victims of their culturally constructed subordinate status while also celebrating women's strength and creativity in resisting that subordination.'

<div align="right">(Mahoney and Yngvession, 1992, p. 45)</div>

They use Lacanian psychology as a starting point and take it further to explain individual's reactions to the exercise of power. Briefly, they suggest that the intersection of multiple and sometimes contradictory identities leaves gaps in discourse and these 'gaps' leave room for the individual to create an alternative discourse as to their motives, interests, identities. The people taking part in the study reported here, whether providers or users of services, met in a variety of contexts and circumstances, where they acted out, tried out and contested, different stories, with different ordering of events giving rise to different interpretations and different outcomes. The research encounters provided one more forum in this respect.

The ethnographic narrative to follow is presented as the 'story' or an 'argument' framing the stories about 'arguments' told me during fieldwork. It has the potential of relating the social/structural tensions inherent in the relationships between the narrators and recipients of the stories to the experiential 'here and nows' of the encounters and to progress another story about power, rationality and agency. This is a matter of plot.

Plotting the story

According to Lewis (1982, cited in Good 1994, p. 165) stories need to be organised in terms of a sequence of events in order to be recognised as stories, but this sequence is 'only a net whereby to catch something else. The real theme may be, and perhaps usually is, something that has no sequence in it'. Plot according to Brooks, is the logic of a narrative 'analogous to the syntax of meanings that are temporally unfolded and recovered, meanings that cannot

otherwise be created or understood' (Brooks 1984 p. 21). Plotting, or creating the dynamic interplay between, on the one hand, the storyline as a sequence of events and on the other, that something else which this storyline tries to catch, is an activity central both to the act of telling and listening to stories. Good suggests that plotting is a central activity of life. He cites Lewis (1982):

> 'If Story fails in that way, does not Life itself commit the same blunder? If the author's plot is only a net, and usually an imperfect one, a net of time and event for catching what is not really process at all, is life much more? ..In life and art both, as it seems to me, we are always trying to catch in our net of successive moments something that is not successive'

> (Good, 1994, p. 165).

Transposing oral narratives into the ethnography as written texts involves a particular process of 'distortions' in storytelling. The oral medium is fluid, flexible and short-term, while the written medium is fixed in time. Reflections on the art of writing stories are thus a necessary precursor to the presentation of my own, and European literary traditions presents an appropriate history of convention in which to root my own attempt because ethnographic writing also draws on this convention. Current debates concern precisely the need for, or form of, plots in modern storytelling.

The act and art of storytelling worldwide has produced a variety of plots around which to structure a story. All plots are, however, constricted by certain conditions of human communication and meaning-making. Indeed, it has been suggested that the narrative is a basic medium of communication whose structure is a natural given, on a par with languages. Until the 'modernist' novel of the 20th Century, most plots are, according to Brooks, variations on a theme of beginning - middle - end. The beginning poses the problem in the form of a collapsed metaphor where the event, the person or the mystery together with their potential for meaning lies embedded, and hence unrealised, at a point in a temporal sequence. The middle 'works' the metaphor by repetition, reflection and return by transposing it through time and place in a metonymic landscape towards the end which reflects back on the storyline and confers the final

meaning, as the solution of a mystery in a Sherlock Holmes detective story or the explanations of a neurosis in one of Freud's (early) case studies. It is particularly the finality of the ending in the way it forecloses meaning, which has become the object of debate spurring the experimentation with plot in the 20th century novel and ethnographic writings. Joseph Conrad comments on the conventional novelistic endings at the time (turn of the century):

> 'These solutions are legitimate inasmuch as they satisfy the desire for finality, for which our hearts yearn, with a longing greater than the longing for the loaves and the fishes of this earth. Perhaps the only true desire of mankind, coming thus to light in its hour of leisure, is to be set at rest'

> (Conrad, 1924, in Brooks 1984, p262)

The task of the writer has become to refuse the reader this rest. Rather than building a storyline with an ending which reveals final meaning, the modern narrative derives a multiplicity of meanings from the progression of the story. It avoids endings which conclude, but ends in ways which create the possibility of more and other meanings. The final story is never told, there is always the need to go over old stories, to retell and reinvent meaning.

The debate about literary form has entered ethnographic writing. In this context, it concerns particularly the authority of the author in representing as 'real' the people and characters studied and the information they offered in response to the ethnographer's questions. (Boon 1982, Geertz 1988, Clifford and Marcus 1986). With the demise in authority, the author can no longer present connections and links created through the ethnographic text as authoritative facts, only as probabilistic constructions whose relationships to 'what really happened' and hence whose epistemological status is uncertain.

Both anthropology and sociology have been thrown into a 'crisis of representation'. Epistemologically, the idea that we can access the social or individual 'reality' of our research participants is being critically examined, and it has been suggested that the only thing we can say anything about is our own experience of the people among whom we carry out research (Rabinow 1977,

Crapanzano 1980, Dwyer 1982). Ethnography has been used as a way to 'the comprehension of the self by the detour of the comprehension of the other' (Rabinow 1977 p. 5 quoting Ricoeur 1969). We grapple with issues around how to accurately represent others' view of themselves and the world. We also confront political and ethical considerations in determining our right, as researchers, to do so. In the process, reality and experience may be deconstructed in textual critiques.

These debates concern precisely the form of, indeed the need for, plot in storytelling, in the way the temporal sequencing of the storyline anchors and restricts the creation of meaning and interpretations. In order to avoid the finality of an ending, plots become ever more complex and convoluted as authors experiment with temporality in narration. Plots work increasingly on the level of narration itself, making transparent and questioning their own mechanism of meaning making and inviting the reader to engage in the process (Brooks 1984). Texts become an interplay of ideas with an indeterminate relationship to action in time and place. Ethnographies become a 'dialogue of voices', where the structural contingency of the dialogue often recedes into the background (Spencer 1989).

Time is, of course, not done away with and as Brooks contends, these debates, while questioning existing form of plots, and demonstrating the limits of storytelling 'nevertheless insist that stories must be told.'

> If plot has become an object of suspicion, it remains no less necessary: telling the self's story remains our indispensable thread in the labyrinth of temporality'
>
> (Brooks, 1984, p. 285).

I see the research encounters which produced ethnographic material and their interpretations as 'real' in the sense that they have taken place in time and place. 'No matter how much the anthropologist is part of the reality studied, it is still real' (Hastrup and Hervik 1993, p.3). The conditions around the encounters and

their interpretation are similarly located and researcheable. The researcher's and the respondent's experience of the setting may well be different, but the setting is real. The research process is one form of social interaction where this reality is negotiated and shared and the argument about reality progressed. Experience, however, is lived, not verbalised, and epistemological issues arise around the researcher's translation of their own and informants' experience into text.

I address this issue by using passion to plot the story.

Plot and passion

Although the specific form stories take are cultural products and therefore vary worldwide, the need to tell and to hear stories is, suggests Brooks, (1984, quoting Barthes, 1982) universal because rooted in human quest for meaning. Brooks (1984) compares the telling of stories to Freud's model of psychoanalysis, where repressed material is liberated from the past and incorporated into present existence.

Stories may liberate experience from the obscurity of easily forgotten details of the everyday, but experience is not entirely recaptured, for, in Lacan's terms (Brooks 1984 quoting Lacan 1977), there is always slippage between on the one hand, (past) experience as signified and, on the other, the story or narrative as signifier bringing the experience back. Hence the universal passion for stories, the quest for the word or the saying that will articulate experience, making it whole and real, but never quite succeeding, always leaving something unsaid. And if the ultimate meaning were captured and desire satisfied, passion for life dies with the story, because it is the tension between desire and its unobtainable object - the ultimate meaning - which drives life itself (Brooks 1984 drawing on Freud 1920).

The stories I collected during my field work were delivered and contested with considerable passion. A secretary who helped with the transcription of tapes once said about an interview with a social worker: 'this is not an interview - it is a confession! Do these people have nobody to talk to about their work?' The passion was not necessarily that of repressed feeling, however, for in many settings people did talk about their work, endlessly and passionately, and difficulties were shared, as much as they were hidden. This passion and intensity was public and shared, it was acknowledged as an important feature of the settings I studied. As such, it should be reflected in the ethnography. However, I cannot do this by quoting what people said because the passion was beyond words. It came through in the tone of voice, in the sudden intake of breath between clenched teeth, in the pauses and silences and in facial expressions. And as the project proceeded, the passion came to be my own.

Our passion was not merely the result of a personal distress of knowing and losing very young people through a slow and untimely death, although this no doubt affected us all to different degrees. The passion was public inasmuch as we all, my informants and myself, were engaged in making meaning out of a central cultural drama about social, moral reasons why people were affected by death and disease in certain ways.

The 'drama' can be compared to a Greek tragedy, with the study participants in the roles of the main characters, or protagonists. The protagonists argued from very different perspectives and experience, and they were all 'right' or 'rational' on their own terms. I took the role of the 'chorus' in observing the tragedy unfold, summing up the different points of view and explaining why interactions took the course they did. My summaries and explanations were generally appreciated, and occasionally my voice would lead to changes in positions and action. However, more often I stood by watching events take their course because the arguments presented were rooted in structural contingencies which I was powerless to change. And at times I was drawn into the drama as a character in my own right. Our arguments were driven by our attempts to understand why people behaved, lived and died as they did, in

such seemingly senseless and irrational ways. We very rarely found our own individual answers, and we never agreed on them, hence our passion.

If we accept Freud's and Lacan's views, passion is the urge for meaning which drives all narrativisation and dies when it is spoken. Therefore, rather than looking for words which will adequately describe the atmosphere of the settings I studied and the experience of people interacting in them, I have tried to use our shared passion as a dynamic element driving my own narrative. It is the passion in the intense contest between characters about whose plot is the right and true which anchors my narrative in lived and socially situated experience.

I intend this use of passion to work on the story in two respects. In a sense, it is a technique of presentation which conveys the message that 'I experienced this'. It thus lends authority to my account. Ethnographies written on the basis of long-term fieldwork in alien societies far away from the author's own often contain scenes and descriptions which carry the message 'I was there, therefore my account has authority'. Often, this message is wrapped up in scenes of arrival on foreign shores (Firth 1936 in Geerz 1988). I did not have to travel in space to acquire the experience upon which I base this ethnography. I only had to step outside my front door to meet the people who came to be participants in my research. Sometimes not even that was necessary. My husband is an Edinburgh general practitioner who cares for both drug users and people with HIV/AIDS and the experience seeks me out as I try to be a source of support to him in a difficult area of his job. The relationships we establish as ethnographers are different from those we form in other capacities: as a friend, spouse, colleague. Thus, I need to show that there was a special quality of my relationships to the people in the field whereby I participated in their experience in a particular way. The use of 'passion' is on one level a matter of technique which I freely admit and willingly make transparent because it links into a more substantial, theoretical level of representation.

My use of 'passion' as a representational ploy anchors my ethnography in lived experience. It therefore makes the difference between a narrative of wanderings

among unconnected voices and an argument which evolves an understanding of 'rationality' and 'power'. I hope it makes a story worth telling.

Structure of the story

In order to guide the reader through the ethnography I describe here briefly my intention and design for the story to follow.

The main movement of the story is from the general to the particular and inter-personal, and it is within this dynamic that the theoretical discussion gathers momentum: from considerations of 'rationality' and 'power' on the level of social structure to consideration of 'agency' on the level of individual behaviour and experience. Intertwined with this general theme are a number of subsidiary stories. In terms of empirical description, I move from service provision to service use. In terms of method, I move from structured, pre- planned survey methods to open-ended enquiry in order to demonstrate the power of ethnography and reflexivity as tools of understanding and insight. Finally, I demonstrate and discuss the main findings we made in the course of the study and integrate this discussion with the progression of the theoretical argument.

I have structured the story into three sections. The first section, of which this introduction is the first chapter, introduces the story and sets the scene. The approach to theory, methods and presentation which has guided my presentation of the story has been outlined. The next chapter consists of a description of the settings where I did my fieldwork, and gives a brief historical account of the HIV epidemic in Lothian and the reactions it elicited in terms of development of services. This description explains the various political interests and interest groups which emerged in the local HIV/AIDS field, and the arguments and contests which were conducted between them. A central ideal for the Lothian development of HIV services was to create an innovative, because democratic, system of service delivery and development which included, in co-operation, services and service sectors which do not normally work together. In

particular, the ideal of giving service users a voice was emphasised. The project was a part of this experiment in innovation. This description heralds the ethnography as both an empirical description and a theoretical discussion of ways in which the reality diverged from this ideal. This chapter also describes the history of the project as a product of contests and arguments in the field. The project came into being as a compromise between myself and my colleagues both in terms of focus and methods of investigation. The assumption behind the study was that the main problem in service co-ordination was lack of integration of primary care services in a hospital-centered system of services.

Section two, which consists of chapters three to six, moves into the theoretical argument. It concerns the task of service provision and the ways in which this work is experienced by various workers. This section has three functions. First of all, it aims to build up the reader's understanding of the concepts and terms by which service provision and service use was experienced and articulated in the settings I studied. I aim to demonstrate the central role of the notions of 'control' or 'self reliance' to which were juxtaposed apparent opposites such as 'manipulation' 'chaos' and 'fraud'. I also describe some of the ways in which these terms were contested in that a person's behaviour was variously interpreted as 'control' or 'manipulation' depending on the interpreter's point of view and structural position. Secondly, I aim to build up an understanding of the structural dynamics which sustain these contests. Finally, I progress the theoretical argument through critiques of Habermas and Foucault. These discussions are anchored in the history of the project and the findings we made as the study progressed.

In chapter three I describe the ethnographer's first tentative steps in the field and her encounter with complexity. I describe how we embarked on a quantitative study of discharges from hospital into the care of primary care, social work, voluntary agencies and family and friends. I outline how the abandonment of quantitative and structured methods in favour of open-ended ethnography yielded the beginning of an understanding of the structural dynamics which produced complexity and feelings of lack of control both in people working in

the system and in myself and my colleague who were studying it. I also describe how we were forced to change our focus of study from the relationships between hospital and 'community' based services and look instead at the 'invisibility' of material need and welfare benefits and housing services in the medical settings we studied. Chapter four describes in more detail the system of welfare benefits and ways in which it relates to the system of medical services. It raises the question of why the importance of good welfare benefit services was 'invisible' to the workers in the medical settings. Chapter five addresses this question through a description of an instance where I became caught up in the very dynamics which blot out and brush aside welfare rights services and strategies to obtain benefits as 'fraud'. This chapter ends in a critique of Habermas and looks to Foucault's 'Birth of the Clinic' and his concept of 'the gaze' which is discussed in detail in chapter six.

Chapter six bridges the transition from discussions of 'power' and the experience of service provision to the consideration of 'agency' and the experience of service use. I contrast two hospital units where communication and co-operation among workers are organised differently. In one unit, drug users form the majority of patients seen, whereas the other is used mainly by gay men. The different ways in which service users are defined and 'seen' differently in the two units leads into a discussion of ways in which 'drug users' and 'gay men' are stereotyped as 'chaotic and manipulative' and 'organised and articulate' respectively.

Section three concerns agency and resistance. It consists of chapters seven and eight. This section draws on the understanding of 'manipulation' and 'control' as central terms in which service provision is experienced, the power dynamics which sustain these terms, and the critiques of Habermas and Foucault. Central to the discussion is a problematic posed by Foucault's refusal to clarify the distinction between 'subject and object' of discourse.

Chapter seven brings back narrative as a medium of representation in ethnographic writing. Two service users are described. One is a 'typical' gay

man', the other is a woman and a 'typical' drug user. Ways in which they were 'told' and thereby defined differently in interactions among their service providers and researcher are described, and their reactions to these definitions is discussed. This discussion revolves around the concept of 'marginality' as a social site from where the service users engaged with and manipulated powerful definitions about their social identity and personal qualities. 'Marginality' is also used to mean an analytical placement from where the analyst engages with theories about power.

Chapter eight combines a summary of the argument put forward in the previous chapters with a critique of studies of users' satisfaction with services. Studying service users' experience of services was one of the main aims of the project, and it is also a growing area in health services research. User satisfaction studies are often based on assumptions that users' opinions about services exist in clearly articulated form for researchers to take away in short interviews or questionnaires. However, it cannot be assumed that (even qualitative) research can elicit people's 'true' opinions of services because private experience is articulated in language and conventions which are public. Ethnography illuminates the social and structural conditions in which statements about experience are elicited and makes explicit the role of the ethnographer in coaxing and eliciting certain stories about private selves at certain times. Ethnography treads a balance between liberating experience and suppressing it in the discourse of the times. Chapter eight ends the story with a discussion of the power of silence as the space where the private engages with the public and where new stories will emerge told by different voices.

The thesis concludes with brief reflections on the use of ethnography and social research in policy and practice. The relationships between (intellectual) understanding on the one hand, and experiential knowledge and behaviour on the other are complex. I will suggest that ethnography, like other forms of research, has limited effects in terms of changing knowledge and behaviour. Such change is dependent on structural conditions of thought and action, and as researchers we do not always have the power of influence on this level. Neither

might we want it, for good ethnography depends on the ethnographer's position of marginality both in a social and analytical sense. In conclusion I suggest that it is this tension between detachment and involvement, theory and action, which makes practice- and policy-oriented research a potential rich avenue for theory development.

Chapter 2 Setting the Scene: an experiment and innovation in service development

The ethnography to be presented concerns arguments among care professionals of various sectors and services about issues in service provision for people with HIV. The arguments which I witnessed and which I make the object of analysis took place in Edinburgh service settings, in a limited time period and under specific circumstances created by HIV infection and local reactions to this event. Arguments among care professionals about whose definitions of a problem and its solution are the 'right' ones are of course, nothing new. They existed before HIV became a public concern and continue now funding and development of HIV services are no longer given priority. The arguments are constantly changing because they are constructed and contested within local contexts affected by events and shifts in policy and perceptions on more global levels. The local contexts in which the arguments are conducted affect their content, the structural dynamics through which arguments are contested, and also the outcomes of this contest both on a structural level (in terms of policy and practice) and in terms of individual service users' and service providers' experience. To understand the arguments and contests described and analysed here it is necessary to understand something of the particular history and context of HIV infection and its management in Edinburgh and Lothian. The arrival of HIV infection in Edinburgh in the 1970's is therefore an appropriate point at which to enter the story and present in some detail the main characters and settings which will figure in the ethnography.

This description is written with hindsight and does not claim to represent my own state of mind and understanding at the time when I started my fieldwork and the sequence of events which I have made my storyline, begins. It feeds on the analytical and theoretical work I have undertaken in order to write the ethnography. Neither does it pretend to be a factual and objective description of events and developments. It includes my own interpretations of these in order

to set the scene for the arguments to be described and analysed and the process of my own deepening involvement.

In Edinburgh and Lothian, HIV infection during the mid and late 1980's appeared dramatically and suddenly as a major public health hazard associated with intravenous heroin use. During this period, Edinburgh earned the dubious reputation as 'the AIDS Capital of Europe'. By the time of my fieldwork in the early and mid 1990's the panic had died down. It was by then fairly certain that the probability of HIV spreading much beyond specific groups such as homosexual men and drug users had been exaggerated. The history of Edinburgh's response to AIDS thus parallels in some ways that of Britain generally outlined by Berridge (1996). The discovery of AIDS in the early 1980's set off ground-level activist reaction, particularly among gay men, but also elicited a state of shock and disbelief combined with inactivity on a political level. This was followed by a period between 1986 and 1987 of 'war time emergency' when AIDS became a political agenda item and politicians intervened. From the late 1980's, AIDS has become 'normalised' as a chronic disease rather than an epidemic.

In Lothian, the legacy of the panic and the 'war time emergency' lived on in important respects. By 1990, a system of HIV services had been created which was somewhat different from and apart from, mainstream services. These developments had been fuelled by generous funding and a pioneering spirit of innovation and social experiment (Bennet and Pettigrew 1991). There were real aspirations and hopes of creating a service which was different in that it was user-centered and democratic. The users of the service, many of whom belonged to groups which were marginalised and stigmatised, i.e drug users and gay men, were to be given a voice. For a while, there were enough resources put into HIV/AIDS work to make these aspirations and hopes realistic. These circumstances have affected both the kinds of arguments being constructed and also the way in which and the structural conditions under which they were contested. This experiment in innovation explicitly concerned the inclusion of a number of disparate groups and factions with diverging interests in the

structures of service development. Contest and arguments were therefore
expected, even valued, as a part of the experiment.

The research which has provided material for my ethnography was
commissioned to facilitate communication and co-operation between various
service sectors, and one explicit aim was to elicit the opinions and experiences of
people using the service so that these opinions could feed into service
developments. The project was thus a part of the experiment in co-operation and
co-ordination of services, and we were inevitably drawn into the contests and
affected by their intensity. We participated in dialogues among groups with
different points of view and different degrees of power to impose these. This
participation has provided an ideal opportunity to apply anthropological tools of
reflexivity and theorise about the discrepancies between ideals and realities in
the experiment in co-operation

The Edinburgh and Lothian HIV epidemic

The early stages of the history of HIV in Lothian were inconspicuous and
undramatic. The infection arrived sometime in the 1970's and affected a slowly
increasing, and until diagnosis and knowledge about the disease were
developed, an unknown number of gay men. Service provision for gay men was
traditionally centered in a Department of Genito-Urinary Medicine (the GUM) in
Edinburgh's Royal Infirmary. This department provided a high quality and,
most importantly, confidential, acute and long-term clinical service for gay men
and those infected with HIV continued to attend this department for treatment
of the infection. The GUM department developed expertise in the clinical
management of HIV within existing staff and without major changes in internal
department organisation and relationships to other services such as primary care
teams, social work services, voluntary organisations.

Somewhat later, 32 haemophiliacs who were cared for in the Department of
Haematology in the Royal Infirmary of Edinburgh were infected by a batch of

infected blood products. These haemophiliacs continued to receive care for their HIV infection in the Department of Haematology and its out-patient clinic, the Centre for Haemostasis. Like the GUM, this department developed skills and expertise in the management of HIV within existing organisation and staff, and like the GUM, these developments were low profile and attracted little public attention.

During the early 1980's an HIV epidemic among intravenous drug users was gaining momentum which was to have more far-reaching consequences. During this time Edinburgh became a major centre of the European distribution network of heroin. Cheap heroin from Iran was dumped on Edinburgh markets at a time when unemployment among young people in the economically and socially marginalised housing estates was depriving many of any prospect of a future beyond minimum income support (Brettle 1990). Heroin provided both psychotropic escape, employment and income for this generation and intravenous heroin use and heroin dealing became a way of life for large groups of young people. According to local drug squads' estimate, there were 40 - 50 heroin users in Lothian during the 1970's. Most of these lived in central Edinburgh. By 1983 the number had risen to 2000, and the centre of drug trade and use were now in the council housing estates (Robertson et al 1988).

This fact did not go unnoticed neither among the agencies of law enforcement nor among health and social services. This new form of drug culture demanded a response and there was disagreement and contest between politicians and some 'on the ground' services such as GPs over what this response should be. Police and the courts adopted a policy of increased surveillance and severe sentencing. In 1984 the Solicitor General for Scotland made drug trafficking a High Court offence with increased sentencing. Heroin was injected, and the Pharmaceutical Society and the police also decided on a policy of restricting the number of needles in circulation as a way of demonstrating public refusal to accept and condone heroin use. The assumption was also made that lack of needles would stop or prevent people from injecting. Pharmacists were instructed not to supply needles to customers who could not demonstrate a

legitimate clinical need for them. Needles and syringes for heroin use came from one supply only, a surgical supply shop whose owner was concerned that young people used dirty needles and broken syringes to inject. However, he was boycotted by Edinburgh doctors and persuaded by police to abandon his trade in injecting equipment. The 'Bread Street shop' closed down in 1982 (Robertson et al, 1988, Brettle 1996).

The combination of a growing number of people addicted to heroin and a reduced number of works available resulted in widespread needle sharing. Dealers in heroin provided works for injecting the drug 'on site', with up to 60 people sharing two or three 'works'. The situation was rife for spread of blood born infections, and between 1978 and 1983 the number of cases of Hepatitis B infections, skin infections and also heroin overdoses among drug users rose markedly (Robertson et. al. 1988, Brettle 1996). Dr Roy Robertson, a general practitioners in one of the housing estates where heroin use had become established warned against the danger of blood-born epidemics. As early as 1982 he started a policy in his own practice of 'harm minimisation' on models provided by Amsterdam. Rather than adhering to the policy of restriction and criminalisation of drug use he provided clean needles, advice, information and medical care to patients injecting drugs. Dr George Bath, a specialist in public health, advocated making clean needles and syringes available to drug users as a way of preventing public health hazards. However, such warnings went unheeded until the discovery of an HIV epidemic among drug users (Brettle 1996).

Randi Shilts in 'And the Band Played on' (1987) describes how the origin of the HIV epidemic into American gay communities was traced back to one man (an airline steward whose geographical mobility combined with sexual promiscuity introduced the virus in several places during a limited time span). There is a similar story about the Edinburgh epidemic among drug users. Allegedly, it has one named source who arrived on the scene in 1982, when needlesharing was firmly established standard practice. From this infected person the virus spread unchecked, with alarming rapidity and unnoticed for two years until 1984, when

a reliable test for HIV antibodies came on the market and was first put to use. The first to do so was Dr C. Ludlam, a consultant haematologist in Edinburgh who tested his patients and found a number of the patients to be infected. This finding suggested a Scottish epidemic, because these haemophiliacs received blood products from Scottish donors only. One year later, Dr Peutherer and colleagues tested blood taken from drug users and other patients attending different Edinburgh hospitals in order to compare the rate of infection with HIV among haemophiliacs with that of a group of controls. The intravenous drug users among the controls were infected at a high rate. (Peutherer et al 1985).

Further research on the infection rate among drug users was made possible by the work of Dr Roy Robertson who during 1983 had collected blood specimens and information from a cohort of drug users visiting his practice in order to investigate the spread of Hepatitis B. These blood samples had been stored, and in 1985 it was decided to run HIV antibody tests on them. The tests ran overnight. In the morning Dr Robertson and his colleagues came in to what seemed a major public health epidemic. Results showed an infection rate of over 50 % in the group of drug users tested (Robertson et al 1986).

The drama of this discovery must be understood against the then lack of knowledge of transmission, clinical management and infection risks to people in contact with HIV infected people on a daily basis. The fear and stigma surrounding HIV was much more prominent than it is today. HIV positive people in hospital were virtually quarantined and isolated by health care staff who donned protective suits before entering their rooms or touching them. HIV positive women giving birth during this time suffered particular denigration and poor care. Home helps refused to work with HIV positive clients. Care professionals who admitted to working with HIV positive people were often shunned by family and friends (Vachon and Dennis 1989).

These findings had several alarming implications. First of all, they meant that a generation of younger people in a number of Edinburgh localities might be decimated through AIDS. A link between HIV infection and fatal AIDS related

disease was not firmly established, but enough was known to make this a strong likelihood. Moreover, these families were poor and living in economically and socially marginalised housing estates where provision of health care was difficult and costly because living conditions were already detrimental to health. At the time, it was estimated that people who contracted HIV had an average life span of 10 years. These drug users had caught HIV during a two year period and they were expected to die around the same time. This meant that a large number of very 'needy' people - perhaps over 1000 - might become seriously and terminally ill in the early 1990's and need both medical care and social/emotional support which were beyond the capacity of services at the time.

Secondly, there was real anxiety and fear about the possible trajectory of the epidemic because patterns of sexual contacts within the larger population were not known. Many people infected through drug use in the early 1980's were assumed to have stopped taking drugs and to have established sexual relationships outside of the drug taking social networks. If this was the case, then the infection might already be spreading to 'the general population' and if the rate of infection was only a fraction of that of the epidemic caused by needle sharing, this would be happening with an alarming speed. Moreover, many infected through heterosexual intercourse would probably not come forward for testing because they might not think of themselves as at risk. This possible 'heterosexual' epidemic was likely to go unnoticed for several years until people infected began to show clinical symptoms of immunodeficiency. Cynics may say that the danger of HIV spreading to the 'normal' population caused a change in response to local cries for both changes in policies on drug use to prevent HIV and resources for the care of people already affected (Hart 1989).

The Lothian response to HIV

Introducing the City Hospital Infectious Diseases Unit (IDU) and the history of my own involvement

The shock of a possible epidemic spreading from groups of drug users elicited a swift local response. This response caught the imagination of 'on the ground' workers in various services and service sectors, funders of services and policy makers. The combination unleashed 'a pioneering spirit' (D. Taylor, 1996) and there followed a remarkable period of innovation, creativity and above all, co-operation in service development to which people in the Edinburgh AIDS field today look back with both nostalgia and fondness. The response concerned both prevention and management of HIV. To a large extent, the response also revolved around the Regional Infectious Diseases Department (the IDU) at Edinburgh City Hospital. Following the report by a committee chaired by the then general manager of Lothian Health Board, this Unit became one of the three main centres of management of HIV in Scotland (Scottish Home and Health Department 1987). The gay men infected with HIV were already attending the Royal Infirmary GUM. The new and more dramatic epidemic among drug users became the concern of the City Hospital IDU. In contrast to the GUM Department, the Infectious Diseases Department expanded both in terms of staff and services linked into the department. A range of new services was drawn in or created anew.

In April 1991 I took on the job of documenting the history of these developments and assessing its effects in terms of co-ordination of services linking in to the City Hospital IDU. In particular, I was looking at ways in which the hospital-based services organised their links with non-hospital services, for example general practitioners and primary care teams, social work and voluntary organisations. I spent three months interviewing representatives of various services. I also sat in on interdisciplinary co-ordinating meetings where staff discussed patients, their problems and the management of these. This study was a pilot project which fed into the main project upon which the PhD is based. It

gave me a privileged insight into the history of the service settings which I was later to study in detail (Huby, Porter and Bury, 1992).

The pilot project and its development into a larger study had its origins in an initiative by a small number of Lothian general practitioners who worked in areas of high drug use and were acquiring expertise and experience in the management of HIV. They felt that the hospitals, in particular the City Hospital IDU, were taking both resources and patients away from 'community' services, particularly primary care. According to these general practitioners, the emphasis in HIV care should be 'in the community' i.e. in services located out of hospital. In their view, HIV infection is a chronic disease where the infected person spends most of his or her time at home, and treatment and follow-up should be provided as far as possible in the patient's home environment by professionals who know them in that context, namely general practitioners and other primary care staff. There was also the possibility that the expected wave of terminally ill people with HIV would exceed the capacity of hospital specialist services and that some of this work would be 'offloaded' onto primary care services. These services needed to be adequately resourced and trained for this eventuality.

The term 'community' as used in this context merits explanation and comment. In policy discourse, 'community' carries a range of meanings and connotations, few of which are critically explored. According to Higgins (1989), in community care policy, 'community' is distinguished from 'professional' 'institutional' settings as a social field which has an innate capacity to provide care and protection for its needy members. As such, it has acquired an almost mythical status as a resource which can be activated by playing down the importance of institutional care settings. The resource implications of this view fits neatly into community care policies, the aim of which is to reduce the cost of long-term care for the elderly and chronically ill (Higgins 1989). In the context of this project, 'community' was a 'native term' used to denote services which are located outside of hospital centres. With this location are linked a number of assumptions which define professional positions on either side of a political

divide. For example, 'community' based workers see themselves as distinguished from 'hospital based' specialists in that they see clients in their home context and therefore provide holistic care which is aimed at the whole person, not just the disease. Reversely, hospital-based clinical specialists see 'community' professionals as lacking in knowledge and expertise in the intricacies of HIV management.

The Lothian general practitioners with a special interest in HIV/AIDS work campaigned for a primary care HIV/AIDS and drugs facilitator employed by Lothian Health. This facilitator was appointed in 1987 in order to encourage and support general practitioners and other primary care workers in the management of HIV. Her brief was also to facilitate the move of HIV care out of hospital into 'the 'community'. She established the 'Hospital/Community HIV Liaison Group' which included members from both hospital-based services and services located out of hospital. This group is still in existence. The role of this forum is to enable the exchange of information and opinions among hospital and non-hospital services about the care for people with HIV. This group commissioned the pilot study and the larger study which followed, and the primary care facilitator was one of my two co-grantholders.

The prominence of the City Hospital IDU compared to the Royal Infirmary GUM department and other non-hospital services is a strong feature of the Lothian response to HIV. It structured the history of this research project and is therefore reflected in the ethnography to be presented. The reason why the pilot project was commissioned was twofold: first of all, there was a concern that the relationship between hospital specialist units, in particular the IDU, and non-hospital services worked to exclude the latter from involvement in HIV management. Secondly, and as I became increasingly aware as the pilot study progressed, there was a concern that co-ordination of services within the IDU environment was a problem.

Service development in the City Hospital Infectious Diseases Unit

The City Hospital IDU expanded their services for people with HIV around the existing and traditional structure of a hospital specialist unit. Usually, this structure is based on 'firms' of doctors, each led by a consultant who supervises doctors in junior training grades. The most junior of these rotate between jobs every six months in order to aquire training and experience in a range of specialities. Four of the consultants in the IDU took on HIV work. One of them took the lead in developing research, clinical management and a service system which would be able to cope with the large numbers of people ill with HIV related disease. The environment which was built up around his leadership was clearly affected by his energy, enthusiasm and commitment. A close colleague said about him:

> *"He is so conscientious and hard-working. He is just so involved! His style has set a pattern for the rest of us. There is no way we could sit back while he was rushing around, getting involved". (Fieldnotes November 1994)*[1]

The new services and the activity around them created a centre of gravity around the IDU, towards which patients and their management was drawn. In Lothian, as in other parts of Britain, the pioneering HIV work of hospital specialist units created an imbalance in expertise and experience between on the one hand, hospital specialist services and on the other, primary care, generalist services who look after people in their home environment, for example general practitioners and community nurses. It was obvious that the expertise developed in the IDU could not be matched by general practitioners and there was concern that these doctors might be excluded from the care of people with HIV. The GUM Department had always provided a comprehensive service which in many cases bypassed or excluded GPs and primary care services and there was a

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[1] In my presentation of data I distinguish between (a) extracts from fieldnotes which may contain quotations from conversations; (b) extracts from interviews (untaped); and (c) extracts from taped interviews. The status of data is indicated in bracketed notes at the end of each extract.

strong likelihood that this pattern would continue in the case of patients with HIV.

In order to support primary care staff to work with HIV, various models of hospital-based outreach services have been tried out (Smits, Mansfield and Singh 1990, Higginson and George 1991, Butters, Higgonson, Wade et al. 1991). In Lothian, a service of 'community liaison nurses' was established. Two nurses were based in the City Hospital IDU and employed by the community services division of the Health Board (i.e. they were not hospital employees) to make sure that nursing support was organised for patients with HIV discharged from hospital while still needing day-to-day care. These nurses also offer a service to GUM patients with HIV. They contact community nurses linked to these patients' general practitioner and primary care teams and they also provide training, advice and back-up support to generalist workers with little specialist experience in HIV management.

In the IDU, back-up for general practitioners was organised through junior doctors in the out-patient clinics whose explicit job description included advice and support for GPs. Whereas normally junior doctors would man both the out-patient clinics (where patients attend appointments for follow-up care or specialist one-off investigations or investigations) and the in-patient wards (where people are admitted for residential treatment), in the IDU special money was used to fund permanent junior doctor posts in the out-patient clinic. There was thus some continuity for both patients and general practitioners in their dealings with the IDU. No equivalent service for general practitioners was on offer in the GUM. However, many doctors return to the Department after they have completed their training grades, and there is continuity in personnel.

In the IDU, a range of dedicated AIDS services were set up around these core clinical services (Brettle 1990). A Lothian HIV Psychology Team was established with the senior psychologist based at the City Hospital. She organised and supervised a regional service for the emotional support for people with HIV. One team member works in the Royal Infirmary GUM and offers counselling

and therapy for HIV positive patients here who want help coming to terms with their illness. A psychologist was appointed with a 'community HIV brief' to help primary care teams and community groups provide out of hospital support for people infected and affected by HIV. A liaison consultant psychiatrist post was created between the City Hospital IDU and the Western Hospital. In her job at the IDU the psychiatrist provides advice and decisionmaking in the management of patients with HIV classed as psychiatrically ill, (as distinguished from emotionally affected by external circumstances such as HIV infection). She assesses in-patients with AIDS in terms of psychiatric illness and management. As a 'liaison' consultant psychiatrist, she has no team of junior doctors who work under her, and she has no beds where she has sole decision-making power when it comes to admission and discharge. She works in a supervisory capacity with the other services who in one way or another provide emotional support.

A counselling service was created at the IDU whose staff counsel people who come to be tested for HIV. The team is staffed by a psychiatrist and several counsellors. In addition to short-term advice concerning tests and the results of tests, these workers also provide long-term follow up for people who have tested positive. A specialist HIV occupational therapy post was created in the IDU, to help patients rehabilitate after episodes of illness and organise special aids to help them cope with disabilities on returning home from hospital. This post emphasised the hospital-centered nature of the service system for HIV, for occupational therapists are normally part of local social work teams and thus classed as belonging to 'community' services. A specialist HIV physiotherapy post and a dietitian post were also created. Finally, a specialist HIV social work post was created in the City Hospital social work team. Hospital social workers advise and help patients adapt to possible decreased mobility and health and help them prepare to manage at home after a hospital admission.

In 1991, Milestone House, a hospice for terminal and respite care for people with HIV was opened within City Hospital grounds. The hospice is a voluntary sector effort with some health board and local authority funding, but because of the

close proximity to the IDU, communication and contact between the two services are close and frequent in comparison to for example the GUM.

Development of services around the IDU was rapid and decisions made to establish new services were made often with little thought about the management and functioning of the service as a whole. There was a considerable 'slack' in the system, with a large number of service providers offering help to a limited number of people with HIV. In September 1990, the official number was 1117, many of whom seemed reluctant to come forward because they were not yet ill. At that time, 500 patients with HIV were registered as users of the city Hospital IDU, but 20% of these were not using the service (R. Brettle, personal communication 1991). The expression 'chasing patients at the City (Hospital IDU) ' was coined in order to describe specialist workers looking for clients in order to justify their existence and fill their time. There was also considerable blurring of roles and responsibilities, with a number of workers offering emotional support to help people cope with HIV. Counselling and emotional support was stressed at the expense of more practical assistance such as welfare benefit advice and housing, a pattern which was found in other British sites of care (Silverman 1990). For example, the specialist HIV occupational therapist, whose main responsibility is to help patients with disabilities or reduced physical functions aquire practical aids which help them lead independent lives in their own homes told me she had received special training in 'anxiety management'. This is a counselling technique aimed to help people identify anxieties and develop ways of controlling their reactions to them. Many workers would say that anxiety might be both a reasonable and sound reaction in somebody who has just realised (s)he is infected with HIV, and that offers of anxiety therapy might not always or necessarily be the best response. However, when employed to help, workers have got to do something.

An example of a swift decision concerning a new service and the implications of this for management and relationships between services is provided by the history of CAST, or Community AIDS Support Team. CAST figures prominently in the ethnography. CAST is a team of community psychiatric nurses (CPNs).

CPNs offer ongoing contact and support to people with mental health problems which are not severe enough or not suitable for hospital treatment. They are employed by health boards' community services division and thus have the same status as a community or district nurse. CAST was established in 1987 in order to provide a 'troubleshooter' service for ward staff both in the City Hospital IDU and other hospital departments caring for people with HIV. A few cases of very disturbed and violent in-patients with HIV caused concern that as the epidemic progressed, large numbers of difficult patients would pose impossible demands on hospital services. CAST was hastily established in order to provide a 24 hour emergency service. The plan was that hospital staff who were faced with unmanageable patients would be able to call the team to come on the ward and sort the problem out. This plan did not quite work out for two main reasons. There was not enough money to establish 24 hour cover, and the CAST team was unhappy with a brief they felt was unrealistic. Rather than intervening after the damage was done, they preferred to see themselves as preventing crisis by working with people long term to build self esteem and self reliance

The CAST team thus added to the number of workers who provided long term emotional support to people both in hospital and in people's home settings. There was tension between the CAST team and the counselling clinic, who felt the CAST CPNs were taking clients and work away from them. One opinion was that CAST team members should find their clients 'in the community', i.e. outside of the City IDU. However, people with HIV were not necessarily willing to identify themselves as positive in generic settings outside of hospitals, and those identified were more than likely to be attending hospital anyway. CAST members joined the many other services 'chasing patients at the City'.

Many workers I spoke to during the pilot study and the subsequent project expressed their experience of the IDU environment as stressful, emotionally charged and 'full of hype'. This is perhaps to be expected, considering their job consisted of caring for young terminally ill people. However, the content of AIDS work has been suggested as a lesser source of stress than the

organisational context and the professional relationships through which the work is carried out. The rapid development of new services which did not fit into traditional and familiar patterns of inter-professional relationships caused extra work and uncertainty contributed to the difficulties of organisation (Barbour 1993).

A feeling emerged that there were too many people involved in the care of people with HIV and that as a result, co-ordination was poor. While anecdotal evidence suggested that some people received far too much attention, there might well be others who received no help at all.

Several meetings were organised to share information about patients and facilitate co-ordination of their care. The primary purpose of these meetings was disputed. Some said they were started to control patients' use of drugs and prevent them obtaining prescriptions from several people at once. Whatever the reason for their instigation, these meetings also helped workers decide on the appropriate involvement of services so that gaps in provision were closed and overlaps avoided. There were four such weekly meetings at the time of my pilot study, three of which are still in existence. Two are concerned with clinical care. One meeting is held to discuss clinical care of patients attending the out-patient clinics the previous week, while another is held to discuss clinical management of people in hospital. These meetings are chaired by consultants and modelled on 'wardrounds' where junior doctors describe the patients they have seen and their seniors quiz them on their diagnosis and management skills. However, other staff, such as the CPNs, counsellors, the psychiatrist and psychologist also attend and are given space to speak. A third meeting is a 'psycho-social' meeting chaired by the consultant psychiatrist to discuss the social and emotional support of people in hospital, both while in hospital and on returning home. A 'discharge meeting', now ceased, was convened by the junior doctors in charge of liaison with primary care services. During this meeting, the home-care of patients about to be discharged was discussed and information collected about the people involved in their care. The idea was that general practitioners and

others could phone up the hospital and find out what services were involved in the care of a patient, but this service was rarely or never used.

While these meetings improved co-ordination, they also created their own complexities. Information and decisions were not always communicated between meetings, and decisions made in one meeting were often undone in other fora. The number of meetings - four per week - is a large number considering the total number of patients using the IDU at that time. During one week there were perhaps 20 in-patients and 40 or 50 out-patients in the Unit. The meetings created extra work and activity, and I occasionally noted nurses lifting their eyes to heaven in dismay as yet another entourage trooped into their ward to ask them information they had given to somebody else the day before.

No patients were present at any of these meetings. The information exchange which took place in the meetings included gossip and evaluations of patients' home circumstances, criminal activity and life styles which were not strictly necessary for service co-ordination. The meetings were also scenes of professional contest and performance, where people showed off their understanding and knowledge of patients' circumstances and challenged each other's perceptions of them. In particular, the opinions of clinical senior staff was privileged over contributions from 'community-based' workers with a brief of general psycho-social support, for example members of the CAST team. The meetings thus added to tensions and unease in interprofessional relationships where competition, rivalry and uncertainty about roles and demarcation of responsibility were already factors.

With hindsight, it is easy to see that the large number of services in relation to the number of service users would cause difficulties. It is also now clear that the sometimes unorthodox forms of service organisation caused problems of communication and co-ordination because workers had to invent patterns of work and co-operation (Barbour 1993). The large number of meetings is an example. It was said that the psycho-social meeting was established by the psychiatrist to give her a visible role and a function, and the discharge meeting

was similarly a way for the junior liaison doctors to fulfil a task which was ill defined and ambiguous.

At the time, however, the large number of services made sense. These were extraordinary circumstances which required an extraordinary response. Planning and development was done on the assumption that in a few years' time a deluge of very ill patients would flood the system and test the services to capacity. The consultant who had taken the lead in developing HIV services told me in early 1991:

> *"I have to remain two steps ahead of the epidemic". (Fieldnotes February 1991)*

He felt it was important that services were in place before people became very ill. He wanted the patients to feel at home with the service system and at ease with the people who cared for them by the time they needed intensive and terminal care.

In the early 1990's, the first panic about the large scale HIV epidemic had somewhat abated. In 1991, it was realised that the number of known cases of HIV infection, (1117 by the end of September 1991) , was significantly inflated due to duplicate test results (Huby, Porter and Bury 1991). Secondly, the number of new positive HIV antibody tests was stabilising at a moderate rate. In 1985, 194 people had tested positive and in 1986 the number rose to 283. However, from 1987 onwards the number of new positive tests fell each year to 63 in 1991. From that year, the number of new identified infections has risen, mainly due to a rise in cases of sexual transmissions. It seemed that behaviour among drug users had changed away from sharing of injecting equipment and injecting, to safer forms of drug taking. In 1986, around 80 % of identified cases of HIV infection was due to intravenous drug use. In 1990, the proportion had fallen to around 30 %. The nature of the epidemic changed to resemble that of other places in the UK, with sexual contact the most important source of infection. Some of these are recent infections, which suggest that the health education

campaigns to promote safer sex, both among the homosexually and heterosexually active, is losing effect (Lothian Health and Centre for HIV/AIDS and Drug Studies 1995).

Among the workers in the City Hospital, however, these figures, although reassuring, did not allay their chief concern. The services had been expanded to provide care for a large number of HIV positive people, perhaps 1000, who had become ill around the same time and therefore were likely to become terminally ill and die around the same time. The senior psychologist in the regional HIV/AIDS team told me in 1991 that there was a feeling among the staff that they were bracing themselves for a time when they would be required to care for an overwhelming number of seriously ill and dying people:

> *"Each year people ask themselves: is this the year the epidemic is going to hit us?" (Fieldnotes June 1991)*

The epidemic never did 'hit them' in that way. Although the number of deaths increased in the mid 1990's they were never overwhelming. The prevention measures worked, and the epidemic among drug users abated. Advances in clinical management have improved both the quality and quantity of infected people's lives and also staggered the onset of terminal illness in groups of infected people. However, the organisation of services which had been built up around the IDU in the mid and late 1980's had taken on a momentum of its own. The dynamics were complex and not to be undone by the provision of mere epidemiological information. For example, the fear of overwhelming numbers was replaced by anxieties over too few numbers to justify levels of service. The workers continued to experience their working environment as stressful. 'Hype' continued to be a word often used to describe the experience of working in the IDU setting.

Harm reduction policies

The most drastic and innovative measures where Lothian has provided models for other parts of Britain occurred in the field of prevention and management of drug use. The earlier policies of restriction of injecting equipment was abandoned in order to prevent spread of HIV through needlesharing. In 1986, the Pharmaceutical Society changed their stance on sale of needles. The same year a committee set up by the Scottish Minister John Mackay and the Scottish Office Chief Medical Officer to report on drug abuse and HIV, recommended that a service of exchange of used needles for new be made available to intravenous drug users (Scottish Home and Health Department 1986 'The McClelland Report'). A central government experimental needle exchange clinic was set up in Leith in 1987 (Greenwood 1992).

Other ways of preventing infection through needlesharing existed in the form of oral substitutes for injectable heroin. In 1986, the IDU began to prescribe oral methadone to patients who were using heroin because heroin use was proved to affect the progression of immunodeficiency in patients with HIV. From then, the IDU included management of drug use in treatment for HIV in HIV infected drug users. (Brettle 1990). The City IDU could only prescribe methadone to their patients, i.e. people already infected with HIV. HIV negative drug users who attended the Leith needle exchange scheme requested drug treatment or threatened to become HIV positive in order to obtain methadone on prescription. In 1987, the Community Drug Problem Service (CDPS) was set up which offered prescribed drugs to users not diagnosed but at risk of infection by needle sharing. The CDPS involved general practitioners in routine prescribing of substitute drugs. Widespread distribution of substitute drugs to a population of more than 2000 drug users was beyond the capacity of one agency, and generic services had to be involved (Greenwood 1992).

Using general practitioners as the main source of substitute drugs for drug users was both innovative and risky. In the 1960's, when illegal drug abuse became noticed and defined as a medical problem, management of drug use was in many places seen as a specialist service offered the few drug users who were

motivated to come off drugs altogether. With the advent of HIV in the 1980's, prevention of harm from drug use, notably HIV infection, in whole populations of drug users became the primary goal. Total abstinence from drugs was no longer the purpose of management, but substitution of risky drugs such as injectable heroin by more harmless drugs such as oral methadone (Hart 1989). This shift in policy was beyond the capacity of specialist agencies.

In Lothian, specialist drug services, such as psychiatric units, had never emerged and general practitioners had always had a role in drug abuse management (Berridge 1996). Nevertheless, the role of general practitioners in distribution and prescription of substitute drugs has been a topic of controversy from the beginning of Lothian's harm reduction programme. The question is often asked whether a doctor should give away drugs which are known to harm rather than heal. Substitute prescribing has also added significantly to doctors' workload and a small number of violent drug users disrupt surgeries both for patients and staff. Persuading general practitioners to prescribe for drug users has been both difficult and time consuming. (Greenwood 1992). More importantly, giving a large number of general practitioners responsibility for distribution of recreational drugs raises questions of control. Lax prescribing behaviour by some doctors would lead to large amounts of drugs being released. Many people, particularly young people who would have no access to drugs under the old system of illegal dealing could now obtain drugs legally from their general practitioners with comparatively few difficulties. This has complicated people's relationships to the GPs and the policy has elicited some resistance among patients, particularly parents of drug users (Foster forthcoming). In the early days, this fear seemed to be justified (Greenwood 1992), but after 10 years of substitute prescribing by doctors the question of control is being addressed.

The substitute prescribing policy has had several benefits. In a study carried out in 1992, drug users on substitute prescriptions reported that they were less involved in crime, that their life was more stable and that family relationships therefore worked better after they received substitute drugs from their doctors. They also reported a better access to other services (Haw 1993). The question

still remains, however, whether substitute prescribing has outlived its role now intravenous drug use is no longer a main source of HIV infection although it remains a potential one. Large-scale distribution of drugs to poor people without social and economic prospects may well help stabilise their lives and prevent infectious diseases such as HIV in the short term. It is also a form of social control which is cheaper and easier than addressing the economic and political issues around marginality and poverty or the global production and sale of illegal drugs.

The issues and controversies around substitute prescribing are of particular importance to the ethnography because management of drug use provides such rich material for arguments and contest among professionals involved in one client, and between client and professional. Medical treatment of addiction affects in fundamental ways the relationships between doctor and patients because neither party can assume that they share a common goal for the interactions (Strong 1980). When the doctor is the supplier of the drug of addiction the situation becomes more complicated still (McKeganey and Boddy 1988). The doctor's assumption is often that the drug user will lie and deceive in order to obtain as generous a prescription as possible, while the drug user often assumes that the doctor's main aim of the consultation is to restrict the prescription. In the process, there is ample scope for diverging opinions about what constitutes a 'lie' and what 'the truth' about a particular situation is.

Response by non-medical services

The expansion in specialist clinical services was matched by a response in both local authority and voluntary sector development and organisation of services for people affected by HIV. I will describe these developments in some detail because they parallel those I have described in clinical services, both in terms of the speed of service development and its consequence. Underlying these similarities were the conditions of funding for HIV work at the time. The clinical services described were funded by the local Health Board. The local authority

and voluntary organisations were funded by both the Health Board and the local authority. Both the Health Board (health district in England) and the local authority had access to 'ring-fenced' money from Central Government which was not only earmarked for HIV work, they were also generous compared to the reduced grants given to other areas of health and social care (Bennet and Pettigrew 1991).

Lothian Department of Social Work responded with a programme of training in which dedicated 'AIDS' posts were rotating among staff. Several members of staff thus had the opportunity to develop skills and understanding of care for people with HIV, and they were able to support colleagues who had not had training (this system was replaced in 1987 by a more traditional hierarchical model of social work organisation. Responsibility for HIV work was vested in one senior officer). A large scale training programme for home helps was also instigated, and negative attitudes among home care staff in working with infected people were successfully addressed. A Supported Accommodation Team for people with AIDS (SATA) was established in 1987 in response to documented need for protected housing for infected people. SATA is part of a wider accommodation team offering protected housing to a range of groups, for example older people and people with learning difficulties. A SATA tenancy comes with a support worker who visits the tenant regularly and makes sure he or she is coping. Finally, the Social Work Department funded Pilton Drugs Project, an out-reach and support service for people in Pilton affected by drugs.

The expansion of voluntary sector activity started in 1983 with the Scottish AIDS Monitor (SAM). SAM was set up to meet the need of Scotland's gay communities in preventing HIV and providing information and support to people affected. After 1985 a number of projects were started, many of which explicitly addressed the material needs associated with HIV/AIDS among most drug users. For example, SAFE (Support on Addiction for Families in Edinburgh) started in 1987 as a parents' support group to 'look for a solution to some of the problems created by drug addiction, HIV and AIDS'. The initiative for the organisation was taken by a Catholic Father in one of the affected

housing estates, Pilton. SAFE ran a second hand furniture service and provided training for young people in the furniture workshop. The organisation also organised a volunteer befriending service. It closed down in 1996 because of lack of funding and misunderstandings in contracting negotiations between SAFE and the health board/local authority. Similarly, Positive Help, started in 1988 by initiative of the Episcopal Church Diocese, organised a volunteer driver service which offers transport. This service is particularly important and valued as the trip from outlying housing estates such as Pilton, Muirhouse and Wester Hailes to the City Hospital is difficult by public transport and prohibitively expensive by taxi. Volunteers also provide babysitting, house decorating, gardening and children's outings. Positive Help is still in existence. ACET (AIDS Care, Education and Training) trained and organised volunteers to offer practical home support for people with HIV. ACET was the only voluntary organisation to offer a night sitting service for people who were ill and wanted to stay at home rather than go into hospital. It closed down in 1992 due to lack of funding.

Body Positive, the only self help group for HIV positive people, was established in 1986 and received funding for a co-ordinator, a project worker and an administrator in 1990. The staff offers welfare rights services, alternative therapies, children's outings, and it supports and houses groups. SOLAS, around the corner from Body Positive, opened in 1991 as a centre aiming to enhance the quality of life for people affected by HIV/AIDS. SOLAS runs a cafe with cheap and very good food. The cafe is a popular meeting place. SOLAS also offers alternative therapies, art therapy and social events. A creche for under five's runs during opening hours, and there is a weekly club for 5 - 11 year olds. A welfare rights officer from the Regional Advice Shop runs weekly sessions from SOLAS premises.

Two projects for sex workers are in existence. These offer advice, medical treatment, protection and support for sex workers working the street, from saunas and from home.

In addition to HIV/AIDS projects set up anew, a number of voluntary drugs projects, many of which had been in existence since the early 1980's, expanded and some new were set up.

The voluntary sector development of HIV projects mirrors in many respects the development of clinical services. The rapidity and urgency created overlap, with several projects offering very similar services. There was competition and tension between some, which increased in the mid-1990's when funding became scarce. There was also a sense that the development lacked direction and strategy, and that services would be more effective in meeting needs if the system was more integrated and there was co-operation between different sectors and agencies.

Integration and strategic planning: an experiment in co-operation

In 1986, David Taylor, a member of the Lothian Region Social Work Department, was seconded to the Regional Headquarters to develop a policy for Lothian Regional Council on HIV/AIDS. A Regional AIDS Support Group was set up in order to facilitate this work. The AIDS Support Group consisted of representatives from Lothian Regional Council's Departments of Social work, Education and Management and Information Services, together with Lothian Health Board, Lothian and Borders Police and the district councils. After the Regional Policy was launched and accepted in March 1987, the Support Group continued as a decision-making and monitoring body for the implementation of the policy. Its membership grew to include members from voluntary organisations and prisons and it was renamed HIV/AIDS Management Team (HAMT).

Another offshoot of the Regional Council policy was a regional HIV/AIDS Forum for organisations and agencies involved in HIV work. In 1987, this forum was constituted as Lothian HIV/AIDS Forum (LHAF) with a membership of organisations and services from both voluntary and statutory sectors, social

services, local authority and health board. LHAF was divided up into five 'functional groups': a Community Services Group (including community nursing, CAST, Positive Help, ACET, SAFE, welfare rights, SOLAS) a group for self help (Body Positive, service user representatives, sex worker project), a group for accommodation and housing (SATA and local authority housing) , a group for drug problems (drug projects) and a group for prevention and education. These groups met regularly to monitor developments in their field and feed suggestions and information into LHAF and HAMT meetings. LHAF met to discuss developments, proposals and ideas for presentation to the Management Team. HAMT makes recommendations about priorities in funding and development of services. The decision-making power now lies with local authority and health board purchasing teams which include service provider advisors.

Early in 1992 the Regional HAMT and LHAF worked together to produce a Regional Strategy for HIV/AIDS. The Strategy was launched on world AIDS Day 1992. The Strategy has also provided input into Lothian Regional Community Care Plan.

The LHAF and HAMT were remarkable and rare in that they included in one forum representatives of services and service sectors which are traditionally at loggerheads and which do not as a rule work together, for example social work and health, voluntary and statutory organisations. The organisation and integration of services in the Lothian AIDS field were thus an innovative venture and a source of pride and enthusiasm. Debates and contests between individuals and services with diverging interests and points of view were acknowledged as a necessary part of this innovation. In particular, there was an emphasis on letting representatives of service users have a say. The debates were often heated and protracted, but I suggest that as long as there was enough money to fund innovation and the planning structures were familiar and stable, the contests paradoxically had an integrating effect because they were part of the experiment in planning in which everybody in the AIDS field were involved. The open contests did not take place elsewhere, and it was precisely the open contest and

the battles which set the AIDS services apart from other examples of service organisation.

The situation has now changed, as AIDS money is no longer ring-fenced and AIDS services have to compete with other services and with each other for scarce resources. The establishment of the internal market in the NHS has had a divisive effect. With the reorganisation of the local authorities in 1996 Lothian Region has vanished and its functions been taken over by four unitary authorities. Local authority planning structures have become fragmented. As the financial cut-backs begin to bite and ritual contest is replaced by real competition, the hope that something new and special in service development might be created has somewhat faded.

The leadership and initiative for joint working has vanished. This was largely down to the local authority worker David Taylor who developed HAMT and LHAF, and a public health physician, Dr George Bath. As the HIV/AIDS co-ordinator for Lothian he had a prominent part in the prevention and treatment models which were developed in the region. One of his many qualities was the ability to consider and accommodate different points of view. I have watched him preside over meetings at the brink of dissolution because of political battles and seen him bring the meeting around to agreement through great patience, sensitivity and good humour.

David Taylor retired in 1995. Dr Bath developed cancer in 1992, but continued in his role as co-ordinator until his death in May 1995. The man who devoted his energies to addressing the problems of AIDS himself died of cancer, the disease which a few years ago held similar symbolic properties in terms of exclusion and stigma (Sontag 1989). This point has not gone unnoticed. This particular story does not end with him, for another of the leaders in the Lothian AIDS HIV field has since been diagnosed with cancer. It is perhaps a peculiar twist of fate that activists on the 'safe' side of the us/them divide created by AIDS should now be asking themselves the same question that gay men and drug users were asking themselves in the early 1980's: 'who's next?'

The AIDS field in Edinburgh was thus seen and experienced as a special example of service organisation characterised by a spirit of openness and access between different services and service sectors, and between service providers and service users with various and often stigmatised lifestyles. This spirit was not only seen in the LHAF and HAMT structures, it was also experienced in the everyday work of service provision in various settings.

In 1993, a lesbian who is involved in both provision and management of HIV services told me that HIV/AIDS work has attracted a disproportionate number of gay men and lesbians, who have personal experience of discrimination and stigma. They have seen an opportunity to use this experience constructively to create new forms of service provision which are non-discriminatory and therefore empowering. She said:

> *"I feel I have something special to offer. For example, from my own experience of 'coming out' I can advise HIV positive people how to manage information about their status. I tell them to think carefully about whom to tell, and in what order - not to let the whole world know at once."*
> *(Fieldnotes November 1993).*

In 1992 a voluntary organisation worker spoke of the relationships between her organisation and the hospital departments where her clients went for treatment. She described the relationships as open and constructive, and pointed out that this was a new and welcome development. She explained this in terms of the new role doctors in these departments had developed for themselves:

> *These departments (where care for people with HIV is a major concern) are pioneers when it comes to practising medicine in a way which takes account of the person carrying the disease. The doctors here do not hide behind a formal doctor-patient relationship . (Interview April 1992, quoted in Huby, van Teijlingen, Bury and Porter 1993)*

In 1995 I discussed with the head of the HIV psychology unit the advantages and disadvantages of working in the AIDS field. We both agreed that 'burn-out' was a real risk because of the intensity of involvement, and that too many people were working in this area anyway. She said she had considered leaving, but that she would miss the possibilities of creating real working relationships with a range of professional colleagues that only the AIDS field offered. She is still in post. Like her, many workers in the field tend to stay on. They may change jobs within the field or leave and come back, but many have been around for a long time.

The Project as a product of contests in the HIV/AIDS field

The Lothian HIV/AIDS field is a thus a small world characterised by close-knit networks of people who have known each other for a long time. They are united by a sense of mission and common purpose, and they are, or they were at the time of my field-work, in a sense 'united in contest'. The divides across which arguments and contest take place are many and various and some go deep. The project was a part of these contests from the very start. The discourse of co-operation only goes so far in creating unity, and the purpose of the ethnography is to demonstrate and reflect on the limits of its ideals.

There is an argument between the City Hospital IDU and the Royal Infirmary GUM which concerns resources, profile and authority. The GUM developed an expert and high quality service long before the City Hospital IDU acquired its reputation and status as a centre of excellence, but it has done so quietly and the GUM has a low visibility compared to the IDU. This is sometimes the cause of tension. In a meeting of the HIV/AIDS Hospital-Community Liaison Group to discuss the pilot study at the IDU and its possible expansion into a long term project, a GUM consultant was present. Midway in the meeting he threw down his papers, exclaimed that he was fed up with all this talk of the City (IDU) and reminded us that the GUM also saw patients with HIV infection. He then stormed out of the meeting. His display had the desired effect in that I went to

see him shortly after to assure him of the GUM's inclusion in the study. The low visibility of the GUM compared to the City (IDU) is one of the themes of the ethnography.

Associated to the argument between the GUM and the City is the contest between drug users and gay men. Gay men do not use services frequented by significant numbers of drug users and vice versa. For example, gay men find it difficult to stay in Milestone because of the impact drug users have on the atmosphere. Drug users do not go to SOLAS because it is dominated by gay men. Divisions between the two populations run deep and come from class differences where notions and behaviour around gender is profoundly different and mutually challenging. Gay men feel that drug users take resources and attention away from their needs, while drug users see gay men as middle class 'snobs' and morally, because sexually, deviant. Because the argument between drug users and gay men is so dominant, women who do not take drugs and who have been infected with HIV through heterosexual contact, together with their children, tend to become less visible. The needs of women and children as a separate issue has been a long-standing argument in LHAF and HAMT. Some organisations have campaigned for a special interest group for women, while the HAMT opinion was that their interests were implicitly served by the structure as it existed.

Other arguments were conducted over the divide between statutory and voluntary organisations, and between the health services and social services. The project upon which this thesis is based emerged out of the particular argument, referred to earlier, between hospital specialist services and 'the community', in particularly primary medical care services. In this argument, the hospital-centered nature of the systems of services for people with HIV, together with general practitioners' failure to take an active role in this field is seen as a problem. This is a concern both in England and Scotland, not just locally to Lothian. The assumptions upon which this argument rests have a history where research is involved, and the project linked into this history.

General practitioners and the care for people with HIV infection

The assumption that lack of primary care generic involvement in management of HIV infection is a major problem has generated a body of literature about the role of general practitioners in HIV care. This literature revolves around the image of general practitioners as far as their involvement in HIV work is concerned. Perceptions in the 1980's were that general practitioners were unfit and unwilling to take on the care of people with HIV, due to lack of skills and knowledge, and due to prejudice against people with HIV/AIDS and the category of people who predominate in infected populations: homosexuals and drug users. There is also a literature on the perception among people with HIV about their GPs which goes some way to supporting this. Concerns about confidentiality, lack of sympathy and understanding are main reasons for not using GPs. (King, 1988, Mansfield and Singh 1989, Wadsworth and McCann 1992, Fitzpatrick, Dawson, Bolton et al 1994).

According to Clarke (1993), the literature about general practitioner involvement on HIV care is in large measure a response to the 1987 House of Commons Select Social Services Committee's report 'Problems Associated with AIDS' (House of Commons Social Services Committee 1987). This report was being produced during the period in 1986-87 when political activity around AIDS was at its most intense and visible. According to Berridge (1996, p. 143) the Committee hearings were a kind of:

> public drama in which the various policy options facing government were examined, criticised, legitimated or undermined.

The report was also influential in setting the political and public agendas around service response.

The report not only failed to mention any possible contribution from GPs, but cited one incident where a GP refused to enter the room of a person with AIDS who had died (House of Commons Social Services Committee 1987, cited in Journal of the Royal College of General Practitioners 1987). A Working Party was set up by the Royal College of General Practitioners partly in response to this. The report from this Party's work suggests that, unless GPs convince both

patients and government of their contribution to care for people with HIV, their role in the evolving new community care arrangements would be threatened. The House of Commons Select Committee report suggested that models of care in the community for people with HIV may be applied to other patient groups, and that there was a danger that these models leaves out the GP altogether. What was at stake, therefore, was the role of GPs in the 1990's (Working Party of the Royal College of General Practitioners 1988).

Studies about GP involvement in the care of people with HIV were being set up in the mid-80's partly in reaction to these damaging reports (Clarke 1993). It was also of practical importance to undertake this kind of work at the time, because it was assumed that the number of people with HIV would increase beyond the capacity of specialist hospital services, and the GP might have to take on a large share of the care. Information had to be collected quickly about their level of knowledge, insight and involvement so that training/resources could be targeted appropriately. These studies of GP involvement went some way to correcting and investigating the negative image of the GP as far as commitment to and involvement in HIV work was concerned. A Department of Health funded survey of one in five general practitioners in England and Wales was conducted in 1988 to establish general practitioners' workload and contact with patients (Gallagher et al, 1990). This was run parallel with a study of general practitioners in Scotland (Naji et al, 1989, a,b,). This survey found that HIV-related consultations formed a substantial part of GPs' workload at that time. Involvement by GPs in HIV care was confirmed by studies carried out in Oxford (Anderson and Mayon-White, 1988), London (King, 1989, Boyton and Scambler 1988,) and Northern Ireland (Boyd, Kerr, Maw et. al. 1990). These studies also uncovered lack of knowledge and training needs for GPs.

In the eight years or so which have passed since these early studies general practitioners have been taking on provision of a range of services. For example, a survey of GPs undertaken by this project suggests a marked increase in GP involvement in both care for people with HIV and, importantly for Lothian, care for drug users in the years between 1988 and 1993 (Bury et al 1996). The negative

image of GPs as being less than adequately involved in care for people with HIV, has nevertheless persisted. The National Audit Office published a report in 1991 which 'lamented the role played by the general practitioners in the overall care of patients with HIV infection' (National Audit Office 1991, p.3). A new Working Party of the Royal College of General Practitioners was convened in 1993, in order to 'counteract the continuing perception that general practitioners have little specific role in the care of patients with HIV infection' (Singh, Mansfield and King 1993).

The body of literature about GPs' involvement in HIV care has been produced predominantly through survey work. Issues around methodology emerge from this literature which are pertinent to my ethnography. The questions posed in surveys undertaken concern general practitioners' and patients' individual attitudes, knowledge and experience. The questions are based on assumptions that GPs' lack of involvement is a main issue, and responses tend to reinforce these assumptions because the narrow range of questions do not allow any alternative to emerge. These individual responses are then aggregated and the sum taken to represent in some way one 'social reality' rather than a set of individual perceptions of a reality. Moreover, survey questions of the kind used in these studies tend to tap what GPs and patients think, rather than examining behaviour and the results of interactions between GPs, other service providers and patients. Attitudes and knowledge are used to predict the outcome of interaction and its outcome in patterns of service arrangements on macro levels.

An exception is an article by Mansfield and Singh (1993) which looks at the continuing lack of involvement of primary care workers in HIV care and termed this a 'care gap'. The authors explain the difficulties of providing care in the community for people with HIV as resulting from a series of interactions between the hospital services, patients and GPs. The pattern of service use is explained as the result of the 'pull' of a highly resourced and skilled specialist hospital sector, and not just a function of lack of knowledge, skills and the right attitudes in GPs and lack of trust in patients. However, this article is based on the findings from survey work, and like many others, these authors frame their

questions in terms of assumptions about GPs' role in the set-up of services: that they **should** take on a share in clinical management, and that they **should** be key players in organisation of services.

Students of social systems have long worked on the premiss that 'the system is more than the sum of its parts'. Interactions between individuals may have effects on a systems level which go unnoticed on an individual level. To address this possibility a methodology is needed which grasps the wider social context in which individuals operate - in short, what is needed is ethnography.

The literature on general practitioner involvement provides an example of how assumptions are made in political contexts which are then underpinned and reinforced by research. The argument that GPs lack involvement, and that this is a problem, is perpetuated when researchers continue to frame their questions and methods in terms of the assumptions around which this argument revolves.

When it started out, the project which has produced material for this thesis was no exception. The pilot study was instigated and funded on the assumption that the lack of primary care and other 'community' involvement in relationship to the (City) Hospital was a major issue in service organisation. The continuation of the study was formulated to investigate the extent to which general practitioners and other 'community' based services were excluded from the care of people with HIV in Lothian, and to make this information available to redress the imbalance. At this point, however, a contest between the main grantholders took place which set an alternative course for the project.

Quality of Care for People with HIV/AIDS in Lothian: an argument over methods and approach

The pilot study of City Hospital and services linking into this unit suggested that the hospital provided a good outreach service which compensated for the lack of primary care and general practitioner involvement. The prospect of an

excessive workload in hospitals which would lead hospitals to 'shed' significant numbers of patients with HIV into general practitioner care seemed unlikely, but could not be disregarded. The report stressed issues in co-ordination of care generally.

Based on these findings, I submitted, together with the primary care facilitator and a senior lecturer in the Department of General Practice, University of Edinburgh, a proposal to the Scottish Office for funding for a major project. The proposal was developed in consultation with services and the Hospital/ Community HIV Liaison Group. The final proposal was submitted in November 1991 and funding was granted. The project started in April 1992.

The proposal was for a project structured in four components, each component building on the findings of the previous study and allowing frequent feed-back and discussion with users of the research about the kinds of data to be collected and the interpretation of information collected. The four components were:

A descriptive study of services for people with HIV which were not covered in the pilot study. This included a description of the GUM Department but stressed non-hospital services.

A survey of GPs' involvement in and confidence in work with people with HIV. This was to repeat a study carried out by Dr George Bath in 1988 and would measure changes in GPs involvement since then.

A study of discharges from the IDU, the GUM and the Department of Haemophilia of people with HIV into care by family carers, general practitioners, social work, voluntary organisations. This was planned as a quantitative study of contacts between patients and services in a four week period after discharge, and also counting and recording of contacts among each patient's service providers to establish patterns of co-ordination between services at the point of discharge.

A longitudinal prospective and in-depth qualitative study of a small group of service users and their service providers. This would document and explain the process and context of decisions among both service users and providers which lead to the statistical patterns uncovered by the discharge study. This component was my idea and design, and I intended it to provide me with material for a PhD thesis.

Behind this successful application and seemingly well thought out proposal was a brief power struggle among the project grantholders which was to profoundly affect the development of the project.

In the months leading up to the submission of the research proposal to the funding body, I was developing my proposal for a longitudinal and prospective study of a small group of people with HIV infection and their service providers - what in effect ended up as the 'longitudinal study'. However, shortly before the proposal was to be submitted, a dispute arose between myself and one of the grantholders, the HIV/AIDS primary care facilitator, as to the main focus of the study. She objected to my proposal on the grounds that it did not address the issues as perceived by the main instigators of the project, namely The Hospital-Community HIV Liaison Group.

What they would want, according to the primary care facilitator, was a study of discharges from hospital into the community modelled on a project then running in the Orthopaedic Directorate of the Royal Infirmary of Edinburgh. This was a collaborative scheme between orthopaedic surgeons, geriatricians, occupational therapists and a liaison nurse. The aim of the project was to identify elderly patients admitted for orthopaedic surgery (mainly for hip fractures) who would be able to return to their homes, without undergoing rehabilitation in a specialist unit, so long as support in the form of community nursing and home help was provided. Specialist staff, namely an occupational therapist and a community liaison nurse, were appointed to support and facilitate the discharge of these patients. Evaluation of the project suggested that almost half of all patients aged 70 or over who were admitted from their homes

(as opposed to from residential homes) were discharged directly home after surgery (Currie 1993a).

Two main advantages of the improved co-ordination of discharge for these patients were identified for the purpose of our own study: First of all, patients were found to cope well and appreciate the early return to familiar surroundings after hospital admission and surgery. Secondly, links between the hospital unit and community staff were strengthened (Currie 1993b). This model seemed highly appropriate to a perceived task of relocating care for people with HIV away from the hospital and out to services based in people's home surroundings, thus helping people reduce unnecessary and perhaps unwanted time spent in hospital. Strengthening the working links between hospital- and community based staff was clearly vital in this relocation of emphasis, for community-based, generic staff needed the support and advice of hospital specialists in providing appropriate and up-to-date care.

The primary care facilitator argued for a quick, quantitative study of hospital discharge in order to identify gaps in co-ordination. A mechanism for filling these gaps would be introduced, and the discharge study was to be repeated after 6 months to measure any changes or improvements in the system.

It was obvious that this model fitted ill with my own plans for the project as then stated and discussed with several of the people who would take part in the project. However, I suddenly found myself confronting my two co-grantholders on this issue. It was even suggested that I give up my own plans (including plans for a PhD) and consider the job as a research assistant on a study of discharges. In the event, I argued successfully for a combination of the discharge study and the long-term study in order to achieve a one-off quantitative picture of service use through the discharge study and to deepen this picture by the qualitative study of the dynamics of the service system over time. However, this discussion took place less than one week before the proposal deadline, and there was little time to think through ways in which the two components would link together logistically and conceptually. As a result, the

project became at times unwieldy. Nevertheless, it is highly probable that the inclusion of a quantitative component in the project was one reason why the proposal was accepted and funded.

The power dynamics within the small group of grantholders thus adds another dimension to the narrative about power and rationality which I develop in the thesis. The initial findings which set the scene for the rest of the project in many respects ride on the methodological tension introduced into the project by the contest which took place at its inception. The way in which we arrived at these findings is the topic for the next chapter.

SECTION 2

RATIONALITY SUBSUMING POWER

Chapter 3   Power and complexity:
Studying hospital discharge

Discovering complexity

When the project started, it already had a history which was intimately bound up with debates and contests in the field we were to study. First of all, it grew out of one particular debate within the field of HIV/AIDS service provision and incorporated a number of assumptions upon which this debate rested. Important among these was the assumption that a major issue was the hospital-centered nature of provision at the expense of involvement from 'community' services, such as social work, voluntary organisations and particularly primary medical care services. In policy jargon, the problem was in 'the hospital-community interface' and we even added a subtitle to our project: 'studying the hospital-community interface'. Many of these assumptions were not critically examined, and much of the research that had aimed to test and explore the (lack of) involvement by primary care services had been carried out with a limited range of research strategies, mostly surveys. Secondly, our final project design was a product of an argument and a contest between myself and my grantholder colleagues, and this argument was structured by the debate concerning the lack of primary care involvement in organisation of services. The project proposal was a hastily assembled compromise, like so many service developments which were to be the object of our study. When the project started, we had become a part of the problem which we were to clarify, and we were implicated in the debates and contests which structured our field of enquiry. The topic of the present chapter is the long and arduous process by which we started to disentangle ourselves conceptually from these restrictions and the findings our strategies produced. It was the adoption of an open-ended methodology which allowed us to go beyond a reproduction of the assumptions underpinning the debates we had been called in to help resolve.

Of course, I write this with hindsight. At the time the project started we were immersed in the practicalities of getting the project off the ground and responding to the demands and hopes of the many people who had supported the application and indicated their willingness to take part in the study. Chief among these were the staff in the City Hospital IDU and Royal Infirmary GUM, general practitioners, the Social Work Department, the community liaison nurses and CAST, the Community AIDS Support Team.

My major concern was to protect 'my' part of the project. One of my aims with the project was to demonstrate the use and power of an ethnographic approach and I wanted to maintain the status as a grantholder with decisionmaking powers. I did not want to be relegated to the position of a mere research assistant. There was more than my vanity at stake, for I needed to collect material for a PhD. I was worried that the issue and the study of discharges would come to dominate the project. The planned quantitative methodology for the discharge study was unlikely to produce the kind of qualitative material I needed. I also anticipated the frustration of spending vast amounts of time and energy to arrive at figures, the meaning of which we could only guess at because we did not sufficiently know the context in which they had been produced.

At least our research problem was clear. We were to study discharge from hospital of a group of people with HIV into the care of primary care teams and other 'community-based' services such as social work, home help, community psychiatric nurses and voluntary organisations. We were looking for a breakdown in communication between on the one hand, 'hospital-based' and on the other, 'community-based' services and expected that these gaps in communication would translate into gaps in service. Our task was to locate and explain these gaps so that they might be closed.

The methodology was equally neatly defined. We intended to chart the system of hospital discharge by counting the number of contacts and acts of communication between service users and providers, and among providers at the time of and for some time after discharge. We were to accomplish this at a

distance, by sending out questionnaires for people to complete at home or at work and send back to us. It was certainly an administrative challenge, but it hardly amounted to anthropological field work.

I need not have worried. Quantifying a system in this manner presupposes knowledge of what to count, and this, in its turn, requires some understanding of the principles by which the system works (Leach 1967). This principle constantly eluded us. Our search for it led us into an in-depth and open-ended study of the nature and content of relationships between people, their relationship to the system of services as a whole and the way this system worked to produce unintended complexities which rebound on the task of both service provision and research. In the process, our neat research design unravelled and ethnographic fieldwork revealed a number of dimensions and issues which had been hidden in the, as it turned out, rather naive discourse around the 'hospital- community interface'.

Complexity, power and methodology: the problem of discharge in the literature.

Issues of contest, power and methodology around which the history of the project came to revolve are mirrored in the literature on hospital discharge, although these issues are largely implicit and remain untheorised. Hospital discharge has, until now, not been a separate management task (Marks 1994) but part of nurses' work to ensure that patients' progress through the hospital system goes smoothly. This work involves both managerial and administrative tasks which have been 'hidden and unmeasured' because they do not accord with nurses' status within the medical hierarchies as handmaidens to staff with explicit decisionmaking powers, i.e. doctors (McWilliam and Wong, 1994). Not surprisingly, since nurses are key players in the organisation of discharge, nursing studies have taken a lead role in the study of hospital discharge.

This literature raises several questions. First of all, what are the criteria for 'rational' discharge planning, and by whom and how are they decided? Are there absolute standards, or is the political process whereby they are decided the crucial point? Closely related is the issue around the methods whereby discharge is studied and evaluated. How do we best capture the complexity of discharge arrangements, and how do we measure and evaluate their outcome in terms of both patient and staff experience?

A brief glance through this body of literature suggests that the emerging interest in the topic parallels the increasing formalisation and standardisation of health services. 'Discharge planning' as a discrete topic culminates in the Community Care legislation and the vital role discharge procedures have in relocating care from hospital into 'the community'. National and regional guidelines for good practice in discharge planning have been produced as an important part of preparations for Community Care. In Scotland, the Scottish Home and Health Department and, in Lothian, the Department of Social Services and Lothian health have produced such documents (The National Health Service in Scotland 1993 and Lothian Regional Council/Lothian Health Board 1993 and 1996). However, as I will go on to argue, the production and implementation of such guidelines are unlikely to be effective unless the structural context in which they are to be introduced is explicitly taken into account.

Lack of co-ordination of services on hospital discharge was identified as a problem in the 70's with Muriel Skeet's report 'From Hospital to Home' (Skeet 1970). She identified lack of patient/carer involvement in discharge planning, little awareness among patients and their carers of services available to help them in the period after discharge and poor co-ordination of services that were in place. The resulting lack of support for people on return home from hospital resulted in poor prognosis and frequent readmission for many patients. Skeet was the first to coin the phrase 'discharge planning' as a way of systematising the procedures of communication and organisation around patient transfer from hospital to after-care at home. She produced forms and written checklists for

nurses to help them ensure that the appropriate and necessary information has been transferred and the mechanism of care are in place.

In the 20 + years since Skeet's study, research has continued to paint a picture of poor service co-ordination and lack of patient participation in discharge. For my purpose, I want to emphasise two aspects of the process as discerned in this literature: firstly, that the participants in discharge procedures, i.e. patients, doctors and nurses experience the process differently, and secondly, that discharge procedures are embedded in local organisation of hospital specialities and wards.

Tierney and colleagues (1994) studied discharge planning for older patients going home from an Edinburgh hospital. The study was carried out in eight acute wards, four medical and four surgical. Different perspectives and experience of the discharge process among staff and patients were identified. Thus, nurses saw themselves, and were seen by doctors, as the main organisers of discharge and providers of information to patients, whereas patients saw the doctors as the main providers of information and organisers of care. Ward staff considered the information given to patients comprehensive and adequate, whereas patient recall of information given was poor.

Tierney and colleagues also carried out a Scotland-wide study of discharge of patients from hospital to home, and findings from this study suggest differences in discharge organisation between wards and specialities. Thus, geriatric assessment units were more likely to have a written discharge policy and explicit and formalised systems of co-ordination of discharge planning where responsibility was vested in primary nurses, and also procedures for multidisciplinary co-operation and information sharing as part of discharge procedures. Surgical wards were the least likely to have in place procedures of multidisciplinary co-operation and co-ordination in discharge planning (Nursing Research Unit, 1993). The organisation of hospital discharge thus seems embedded in the specific histories of the ward and speciality and the way this history structures relationships between and among staff and patients.

Issues of professional authority and identity play an important part in this history. McWilliam and Wong (1994) write about the work of nurses in discharge planning and organisation and suggest a contradiction between, on the one hand, the explicit aim of nursing as patient contact and care, and, on the other, the large amount of 'hidden' administrative and managerial work they undertake to ensure that communication and co-ordination around patient care takes place. This 'hidden and unmeasured' work takes place within, and is a product of, the structural context within which nurses work.

Clearly, then, the establishment of efficient and smooth procedures for discharge is a matter of teamwork and requires sometimes thorny issues of power and authority in professional relationships to be addressed. The idea of 'efficient' and 'smooth' procedures for discharge merits further exploration. Defining 'efficiency' is also a matter of interprofessional contest, for what is 'efficient' and 'smooth' to for example a consultant, may be highly problematic for a patient or a nurse and vice versa. Measuring or describing 'outcome' of discharge arrangements also leaves room for contest between research disciplines and involves fundamental debates about methodology and epistemology, as illustrated in the early stages of our own project .

The nursing theorist and researcher Donabedian (1969) has devised a model for discharge procedures conceptualised in terms of structure, process and outcome components. 'Structure' here refers to the structural context such as ward size, number of patients, staffing levels and composition and geography of the ward. 'Process' refers to the procedures of communication and organisation, and 'outcome' refers to the result of these procedures in terms particularly of patient satisfaction and prognosis. In health services research, the outcome component has been emphasised and attempts have been made to devise quantitative and 'objective' measures of outcome. The conceptual and methodological issues in isolating, measuring and relating elements of the three components is outlined by Closs and Tierney (1993), where they suggest that the definition of activities and events as structure, process or outcome is dependent on context.

Quantitative methods alone cannot capture context, and the value of qualitative methods suggests itself. Moreover, and more fundamentally, an emphasis on a 'standard' of outcome, no matter whether this is described quantitatively or qualitatively, ignores the complexity of the power dynamics which has produced the definition in the first place and also hides the role of research in these dynamics. 'Standards' of care have undoubted value as a guide to decisionmaking in individual cases, but they make little sense without a consideration and understanding of the process which has gone into their production.

Interprofessional contest in discharge organisation and issues of methodology in its research converge in the setting of local 'standards' of care with reference to nationally agreed 'guidelines'. This is increasingly seen as a solution to problems not only in discharge planning but in organisation and delivery of health care generally. This is neatly summed up in the slogan: 'national guidance, local possibilities'. This trend is tied up with 'formalisation' of health care, (Jackson 1994) and also with an almost mythical trust in 'multidisciplinary work and co-operation' as the cure of all organisational ills. The effects of this formalisation of discharge procedures and the increased co-operation and communication between professionals are to be captured by research and audit. However, the research evidence about the extent to which formalisation of discharge organisation care improves patient outcome and reduces costs is inconclusive, partly because the instruments vary and the results are not comparable (Jackson 1994).

In Lothian, guidelines such as those produced by the Lothian Social Work Department/Lothian Health Board (1993) and the Scottish Office Home and Health Department (The National Health Service in Scotland 1993) have been used locally to develop standards for discharge planning in all regional hospitals. 'Standards' refer to measurable and researcheable aspects of organisation such as the existence of 'checklists' of tasks to remind staff what to do when organising discharge and the existence of named staff as key co-ordinators of a patient's care. This work was carried out in 1994 and 1995 by a

'Joint Lothian Health and Lothian Region Social Work Department Discharge
Standards Settings Group'. If the cumbersome nature of a committee name says
anything about the nature of deliberations which have gone on, this committee
must have been the scene of some complex negotiations ideeed. This was indeed
suggested by its chairman who described the committees work in a meeting in
Edinburgh on hospital discharge in spring 1995. These standards are now
published and have to be implemented by all Lothian hospitals by the end of
June 1996 (Lothian Regional Council Social Work Department and Lothian
Health 1996).

These guidelines contain and perpetuate, rather than resolve, some inherent
tensions and incompatibilities in the systems of discharge planning. Thus, the
Scottish Office guidelines state three principles for good practice in discharge
planning. The first two state:

> 1) discharge should take place, on the decision of the doctors
> concerned, as early as is consistent with clinical need, and
>
> 2) discharge should not take place until any arrangements for post-
> discharge support that may be requested are in place'.
>
> (National Health Service In Scotland 1993 p. 6)

Thus, potential disagreements between patients, who may have their own
reasons for either staying in hospital beyond the point of clinical need, or leave
at short notice, doctors (consultants) who balance clinical responsibility and
accountability with patients' demands and contingencies of ward organisation
(e.g. shortage of beds) and community staff's concern with adequate and
working arrangements for patient's home support, are left for local players to
resolve.

In the following, the attempts of the research project to unravel the
incompatibilities and harness the potentials of professional relationships in
organising discharge for people with HIV in Lothian are described.

The Discharge Study

Expectations of and preparations for the discharge study.

During the first three months of the project I invited potential respondents and users of the research material to participate in a Project Advisory Group in order to give 'ownership' of the project to its participants. We wanted help in deciding the details of data collection procedures so that these were ethically sound and practically feasible. We also wanted help in making sure we collected material which would be of use and relevance for service delivery and development. The Project Advisory Group included representatives from the Royal Infirmary GUM, City Hospital IDU, community nursing, Community AIDS Support Team (CAST), voluntary organisations, Department of Haematology (although only briefly) and general practice. Two service user representatives were also invited, of whom one attended regularly. The extra salary to employ, on a part time basis, a social scientist with quantitative skills to help in the discharge study had been included in the budget. Edwin, a sociologist, was in post by August 1992.

The methods for the discharge study were briefly outlined in the research proposal as follows:

> 'Every person with HIV disease who is discharged from the Infectious Diseases Unit at the City Hospital and the Departments of Genito-Urinary Medicine and Haematology at the Royal Infirmary will be contacted by a researcher personally and invited to take part in the survey. Those who agree will be sent a short questionnaire and a stamped addressed envelope 4 weeks after discharge. The questionnaire will ask for information about the extent of community care services' involvement post discharge, the degree of co-ordination and integration of community and hospital services, the involvement of the individual user in the decisions taken, the users' perception of the appropriateness of the services and their perceptions of omissions and overlaps. A researcher will personally follow up those who do not reply'
>
> The person arranging the discharge will also complete a short form giving details about the community care arrangements that have been made for the patients.' (p. 5, proposal).

Meetings in the Project Advisory Group in June through to October 1992 were used to develop the questionnaires and discuss the practicalities of the study in the light of Advisory Group members' knowledge and experience of the system.

Our hopes and fears for the study are recorded in minutes from the Group's meetings during that period. A summary of these discussions is included here to indicate the painstaking preparations and planning which preceded the study, preparations which were to be undone by the realities of the fieldwork.

There was a concern among all of us about the response rate among service users. Were people really going to fill in diary questionnaires about their service use during periods of four weeks after returning from hospital, and then return them to us by post? Various changes and elaborations were made to the original plans in order to ease the work involved in participating in the study, and also to make this an attractive proposition.

It was suggested that four weeks was too long for people to remember, and to maintain the motivation, to keep a diary. It was therefore decided to send people weekly diaries to fill in and weekly reminders to return the diaries by post.

The voluntary organisation representative emphasised that we needed to make the respondents feel valued. The diaries had to look attractive and to be fun and easy to use. Edwin designed a striking and friendly front cover for the diaries, and much work went into the lay-out of the diaries to make them easy to fill in. For example, most of the information could be provided by simply ticking boxes, rather than writing full answers, although there was ample space for people to do so if they wanted. Considerable time was spent in tuning complex questions about co-ordination down to a 'yes/no' format. For example, the main question became:

> Could you tell us your opinion about the mix of services last week?
> (Was there) *too much help from services * too little help * the right
> amount of help

> (Diary, last page).

The role of service users in the study was discussed at some length. Group discussions emphasised the perspective set out in the research proposal that this

was a study of service providers and the way the systems of communication and co-ordination affected service users. We were not attempting to explain the service systems in terms of service user characteristics and 'needs'. Thus, the information we would ask from service users about their private lives and circumstances was to be limited. For example, we would avoid categorising people in terms of route of transmission of HIV infection and decided not to use labels such as 'homosexual' 'drug user' and 'heterosexual' as a variable in a quantitative analysis of patterns of service use. This is interesting in view of the significance of service user stereotypes such as 'gay man' and 'drug user' in explaining the nature of service provision in different settings. I will discuss this in more detail in chapter 8.

We discussed how to introduce the study to prospective service user participants. We had to provide people with adequate information about the study and give them the space to consider whether they wanted to take part or not without confidentiality being breached. We designed leaflets explaining the study. These were to be given to nurses who would give them to the relevant patients. The service user could tell the nurses whether or not they wanted to take part and we need never know the identity of people who refused.

Finally, some form of incentive to complete and return the diaries was discussed. The question of payment or incentives for participation in research projects is rather sensitive. Participation in research might be said to be a service and a duty rendered to society. Payment or incentives, monetary or other, for people to take part in a study might force the cost of research up to unacceptable levels for other than commercially motivated research. However, the population of people with HIV in Lothian is overresearched and exposed to a number of projects. We expected a certain research fatigue to prevent people from taking part in our study. We also expected difficulties in making people understand the difference between this study and the numerous others to which they might have been exposed. We felt we needed something to make our study stand out in the minds of participants, without blatantly offering to pay for this participation. In the end, a compromise was reached, thanks to the enterprising project secretary,

Lindsey. She wrote to the manager of Odeon Cinemas and asked if they be willing to donate two tickets for each of the eight weeks during which the survey was expected to run. She received a positive reply, and these tickets were entered in a weekly 'raffle' where those who had returned their diaries for that week were entered.

The City Hospital Infectious Diseases Unit: Anticipating complexity

At an early stage, the City Hospital Infectious Diseases Unit took centre stage in the discussions about the study. First of all, the Department of Haematology appeared reluctant to take full part in the study. Very few haemophilia patients with HIV are in hospital at any one time. We asked the consultant and the sister of the Department of Haematology if we could distribute our leaflets and recruit patients in the Haemophilia Centre, where all haemophiliacs attend for out-patient care and follow up, and whose staff is also involved in in-patient treatment of patients. The consultant appeared willing, but referred us on to the sister. She stated clearly that she was opposed to exposing 'her' patients to the project. She felt that confidentiality for haemophiliacs with HIV was a particular issue. She did not want to distribute our leaflets to all patients with HIV using the Haemophilia Centre. Instead, the Haemophilia Centre staff would approach people on our behalf whom they thought were suitable and willing to take part. As a result, we recruited only two people from the Haematology Department to the study, and one had never been in hospital. The number of patients with HIV using this service is very small (only 23 at the time of the study), and the number of people recruited might well have reflected the proportion of people with HIV who were patients here. However, we gained no real understanding of the way the system of services centered around the Haematology Department worked from these two participants.

The number of people recruited from the Royal Infirmary Genito-Urinary Medicine Department was also very small, namely four out of 49. Because of the small number of patients recruited from the Royal Infirmary Genito-Urinary

Department and Department of Haematology compared to the City Infectious Diseases Unit, the discharge study became in important respects a study about the latter. The remainder of this chapter therefore concerns the City Hospital Infectious Diseases Unit.

Response rates among the service providers were not anticipated as a problem. However, finding out what arrangements had been made for each patient from the City Hospital Infectious Diseases Unit and thus identifying the right people to approach for information about these arrangements, was raised as a possible problem. Whereas in the Royal Infirmary wards discharge and continuing care in the community is arranged by the ward sister, who would be able to provide this information to the study, in the City Hospital IDU the system is more complex.

In the City Hospital Infectious Diseases Unit, there is a large number of staff involved in each patient's discharge. Last minute changes are made to formal recorded arrangements. These last minute informal arrangements are difficult to get hold of and, according to Advisory Group members, it is here that communication and liaison often breaks down.

Decisions about care in the community are also made in multidisciplinary team meetings in the IDU , and it was suggested that participation in these meetings would provide information about the workers involved in the care of each patient discharged. As I explained in the previous chapter, there were four such weekly meetings in the Unit at the time of our study: one 'sit down wardround' where the clinical care of patients with HIV in hospital is discussed, one meeting where clinical care of people with HIV attending out-patient clinics are discussed, one 'psycho-social' meeting where the non-clinical care both in and out of hospital of patients currently in the ward is discussed and, finally, one 'discharge meeting' which was started to discuss the clinical care of patients after they had left hospital for home (this has since been discontinued).

It was decided that the researchers would identify the people involved in each discharge by obtaining the help of the ward sister in locating the nurse who had made the arrangements in each case. This information would be supplemented by information obtained through participation in the psycho-social meetings. Admission to the sit down ward round, or 'the in-patient meeting', was denied us by the consultant because of the large number of non-clinical staff already attending these meetings. All service providers thus identified as a service user respondent's professional carer would be sent postal questionnaires asking for information about their involvement in organisation of discharge and care after the event.

The manager of CAST, the team of community psychiatric nurses for HIV which link into the City Hospital, asked why discharge was discussed in two separate meetings. The community liaison nurse said it was because the psycho-social meeting did not deal with physical care, and that the discharge meeting was started to fill this gap. The CAST team leader suggested that one member of the psycho-social meeting might attend the discharge meeting to link the social and psychological support with the clinical care provided after people left hospital. We, that is myself and the two other grantholders, were excited and encouraged. We had not even started doing the study, and here we were bridging gaps and tightening communication already. *'It's all happening before our eyes, Guro,'* one of my colleagues said after this particular meeting.

In these Advisory Group meetings, it was stressed that although the system of discharge might be unclear and complex, the value, purpose and outcome of the discharge study would be precisely to provide systematic information about liaison between professionals in discharge organisation. The areas where communication breaks down would be identified so that they could be tightened up. The uncertainties would be reduced, the unclarities made clear. We would help towards a manageable system, where people know what is happening to whom, where, and when, and what their own role is. A system where people are in some degree of control.

As it turned out, this expectation was extremely difficult to meet. Edwin and I, on leaving the safe confines of the Advisory Group and entering the reality of the field, were soon seized by events as we became victims of the very uncertainties and unclarities that our research user group wanted us to clarify, systematise and thereby control.

The reality of researching discharge from hospital for people with HIV infection in Edinburgh: a tale of the anthropologist fumbling in the dark.

The discharge study was piloted in late September 1992. The study proper started mid-October, when Edwin and I started recruiting patients with HIV infection on the three wards in the City Hospital IDU and the medical ward of the Royal Infirmary where GUM patients were admitted. Any hopes we might have harboured of carrying out a quick, neat and tidy quantitative study of the process were quickly dashed.

As soon as field-work started, control, or rather lack of control, over the research process became an issue. The setting we were to study was to all intents and purposes a familiar one to us, and we knew the people and their position well. However, the research strategy so carefully worked out in collaboration with our study participants turned out to be highly unrealistic. Importantly, what we set out to study, namely the system of discharge organisation, was an elusive entity and we found ourselves searching for an order which constantly evaded us. This is, of course, a situation which faces all anthropologists who enter settings which are totally unfamiliar and the open-ended methodology we adopted has been developed by ethnographers working in these situations. However, while an anthropologist working in a foreign language and alien settings can play on her status as an innocent and incompetent guest, we had less scope to do so. We were experts, people were looking to us for answers and in order to retain credibility we could not appear completely without understanding of what was going on. The tale of this stage of the research reads as a tale of the naive (if not idiot!) anthropologist desperately seeking a foothold and an angle on the

material as the deadline of data feed-back loomed ever nearer. Now I can say that this period of confusion was extremely fruitful in terms of data collected and insights gained. We came to share the staff's experience of stress and uncertainty and this proved a vital clue to understanding the system of discharge. At the time, however, there was only the stress without the satisfaction of an understanding that only reflection and analysis can provide.

Service Users

Firstly, the number of people discharged from hospital was smaller than anticipated. We had been told that around 50 people per month were likely to be discharged from the three City Hospital Infectious Diseases wards and Royal Infirmary ward 29, used by the Genito-Urinary Medicine Department for in-patient treatment. By the 6th January, the total number of people discharged from the Royal Infirmary ward 29 and the three City Hospital wards was 84.

Although recruitment to the study was relatively easy, our fears that service users who agreed to take part in the study would not return the diaries were entirely justified. At the end of November we were set for a response rate of less than 20 %. As a consequence, The Scottish Office was approached and asked for funds with which to employ Edwin on a full time basis for two months in order to collect the information on service use and service user perceptions of care by personal, retrospective interviews. The study was also extended by three months with a new end date of March 1993. This request was granted, and in the beginning of December Edwin invested in puncture free tyres for his bike and set out to contact people in their homes. When the study ended in April 1993, 49 out of 102 service users recorded as having been in-patients in the relevant wards or out-patients in the Haematology Centre were part of the study. Although still low, this response rate was quite an achievement considering the nature of the study. We were congratulated by the Project Advisory Group members to this effect.

Extracts from Edwin's first week's entry in a fieldwork diary suggests the frustrations and rewards of the follow-up of service users: (Reproduced with permission)

> *A total of sixteen visits were made to respondents in Edinburgh. One person was visited three times before we found out from a family member that he had been admitted to Milestone House for a five day period. He was subsequently visited by Edwin in Milestone.*
>
> *One respondent had moved house which Edwin found out from a neighbour. His address was obtained from the GUM out-patient department.*
>
> *One respondent has been visited twice on different days, but he was not in.*
>
> *Two respondents told the researcher that the time he knocked on their door was inconvenient. One died the next day, the other suggested a better time to visit him.*
>
> *One respondent was delighted to see the researcher. He had not been well enough to fill in the diaries himself, but he and his partner were very willing to do this one week retrospectively. Edwin made arrangements for another visit the following week.*
>
> *One respondent had been wondering about the diaries which were delivered through the mail. He could not remember giving his consent. Edwin did one week's diary with him retrospectively. (11 December '92. Overview of 6 days fieldwork Project notes)*

I also took part in the follow-up of service users. I faced the same frustrations as Edwin and I often caught glimpses of a world where discharge planning and our research obviously took a low priority.

Edwin asked me to visit a respondent, a man, who had moved to a new address in a high rise block of flats outside of the city centre. The man had consented to taking part in the study when Edwin met him in hospital, and gave his address for Edwin to go and see him. However, when Edwin turned up at this address, , he was told by a neighbour that the person had moved. The neighbour gave him the new address. Edwin wrote to the man and told him I would be coming to conduct an interview. He thought a visit from a woman rather than a man would be less threatening under the circumstances.

I found the address without difficulty and located the right highrise entrance. However, the door was locked. A woman returning home from the shops told me the block has been equipped with security intercom doorbells to the flats because vandalism had been a problem. She let me in and showed me the lifts. I was reassured by the friendliness and domestic activity which surrounded the woman who let me in. The flat I wanted was on the ninth floor.

As soon as I entered, all signs of routine everyday life evaporated. The entrance hall and lift were empty and the building filled with an eerie silence. Although it was clean, freshly decorated and free of the smell of human waste and Jeys fluid which greets the visitor to many council blocks of flats, this absence of life was threatening and sinister, rather than reassuring. I clutched my alarm canister as I went into the lift which took me to the right floor. The corridor was empty, the only sound was from the wind whistling around the outside corner and through the emergency stair entrance. I located the door and knocked. A dog started barking, there was a sound of a chair scraping and a muffled voice told the dog to be quiet.

I shouted my name and errand through the letter box, but there was no response apart from the sound of the dog moving and the whispering voice urging it to be still. I waited ten minutes or so, then I wrote a message on a piece of paper and shoved it through the letter box. I wrote that I would be

> *returning the next day at a certain time, but when I did, there was*
> *obviously nobody in the flat. (Fieldnotes, February 1993).*

We did not try and make contact again. Had I been to the wrong door? If not, what had happened to this man to make him hide like this? Was our study so imposing that he could not tell us to our face that he had changed his mind about taking part? Or was he on the run from things more dangerous and decided to take no chances? The police? Drug deals gone wrong? Social security frauds? Fear of his disease? I was filled with an urge to see him and to make contact, to submerge this threat or suggestion of fear, secrecy and rejection in the humdrum activity of our research project

However, many people were pleased to see us. One man, an artist who had been working in Amsterdam, particularly appreciated Edwin's company as a reminder of his time in the city. Edwin is Dutch. He helped his partner translate a legal document from Dutch to English after the respondent died during the discharge study. Edwin was invited to the 'wake' which was organised simultaneously in Edinburgh and Amsterdam.

Similarly, I reaped many rewards from the personal contact with service users and acquired both information and insights which would have been lost through a postal survey.

Just before Christmas 1992 I went to see Margaret, who five weeks previously agreed with me to take part in the study, but from whom we had received no diaries. We were particularly keen to get her story. She was discharged while still needing treatment and dressing of an infected wound, but the community liaison nurse had not been told and no home nursing care had been organised for her before she left hospital. The liaison nurse spent a whole morning trying to find out what arrangements had been made, by whom, so that she could

contact Margaret's GP and organise home nursing follow-up. We wanted to find out how this gap in co-ordination was experienced by her.

She let me in when I said who I was and why I had come. She was pleasant and helpful. She told me she had completed her diaries and that her partner had posted them. I apologised for the mix-up and asked if she minded telling me what she could remember about her service use since leaving hospital in case the diaries really were lost. She did not mind at all and I spent a pleasant hour with her discussing her care. Her partner turned up and introduced himself. A girl who was introduced as the girlfriend of Margaret's son, in prison, came by. She told me a community nurse had been to see about her dressing. Her GP knew she was out of hospital and had been to see her. She appreciated the service - she had no complaints. Whatever problems had occurred in the organisation of her care had clearly been contained before the effects reached her.

After the salient facts about her hospital discharge had been established, we talked informally for a while and exchanged stories about ourselves and our families. It turned out that I had met her brother, who was also HIV positive, in the in-patient ward of the City Hospital IDU. I caught a glimpse of the complexity of service provision beneath her prosaic tale of hospital discharge.

Margaret's brother Martin was also HIV positive and was recently admitted to the City Hospital Infectious Diseases Unit. I had met him during his stay there in October 1992. Although he had refused to participate in our study, his girl-friend Debbie had asked for our help to prevent his GP from prescribing him cyclozene, a drug against hay-fever which is popular among some drug users because it is injectable. Martin had injected it in his foot, which was swollen and painful. The drug also had a bad effect on his mood, and he was already showing signs of dementia. It was obvious that his girl-friend was having problems looking after him. She brought him food and juice and tried to make him eat and look after himself. He refused her offerings and her care, and he was abusive and unpleasant to her. She looked tired. I checked about the drug

prescribed by the GP. The senior registrar who looked after Martin in hospital had written to the GP asking him not to prescribe it .

As we thus got to know people better, we became aware of the numerous ties of past history which linked the people we were seeing and recording as individual admissions to and discharges from, the wards of the City Hospital Infectious Diseases Unit.

> *One day I arrived on the ward to see Fiona, who was in hospital for the third time since the discharge study started. I knew she was in the process of splitting up with her boyfriend. She said he was using her as a source of accommodation and money. He did not get on with her son. She wanted him out of the flat by the time she came out of hospital. On the way to Fiona's room, I met two nurses who were discussing her and Debbie, Martin's girlfriend. Martin was in hospital, as well, and Debbie was visiting him. One of the nurses said to the other: "Did you know that Fiona's partner is Debbie's brother? I didn't know, either, until he phoned up and asked for Debbie. Just think! They've both been coming here for all this time, and we never knew!" (Fieldnotes January 1993)*

Accidental discovery of relationships turned out to be a factor in staff's experience and learning of the setting, not only the researchers'.

I also began to understand the nature of some of these links, and how they structured relationships and events:

Naively, as it turned out, I assumed that Debbie would be sympathetic to Fiona's wish to get her brother out of her flat. After all, Debbie was suffering at the hands of her own boyfriend. However, obvious rules about family and conjugal loyalty superseded sisterly solidarity in this case. *"The cow"* Debbie muttered under her breath and went on to say what she felt about Fiona's treatment of her brother. The atmosphere was heavy with accusations and animosity, but no fights or quarrels broke out.

Often, however, fights and intrigues do break out between patients using the City Hospital in-patient or out-patient facilities because they know each other from a variety of contexts outside hospital and bring with them old, unsettled scores - or start new ones- when they are admitted (Brettle 1990).

The networks which linked people using the City Hospital Infectious Diseases Unit were dense and the nature of service users' relationships to each other were clearly a factor of organisation of care on the wards. When I tried to unravel the systems of relationships among service providers I learned how these interacted with the relationships among service users to affect organisation of their overall care. The picture became very complex indeed and we became entangled in these complexities. For a long and frustrating while we were taken further and further away from the principle of discharge.

Service providers

Service providers were easy to contact and, with one notable exception, extremely forthcoming and helpful in the study. However, like the service user study, the study of service providers gave us a sense of lack of control, albeit in different ways.

Our job was to chart and record what had been arranged in terms of follow-up care for each of our study participants who left hospital, and to approach each service provider identified as involved to ask what their role had been. Very soon, however, we realised that unless we happened to be present on the ward when arrangements were made, it seemed impossible to collect this information. The nurses worked in teams on a shift basis, and whoever had been responsible for arrangements for a particular patient would often be off duty when we came on the ward to find out what had happened. In most cases, nobody seemed to know who had been responsible, anyway. The arrangements made were noted down in the patients' record, but these were sent off

immediately after discharge to the secretaries to type a discharge letter to the GP, and the notes could not be located.

Our frustrations were succinctly summed up in this note from Edwin to me:

> *I went to the ward to find out what arrangements had been made for the discharge of NN. I asked a nurse. She did not know what had been done. She went off to try and find out for me. She came back and said that she did not know who had made the arrangements for NN going home. She thought maybe the community nurse had been contacted. In fact, on reflection, she "was almost certain that the community nurse had been contacted".*

> *(Fieldnotes November 1992).*

Deciding whom to involve in the service provider study was difficult moreover because of disagreements about who was or was not involved in a person's care. When they were admitted to hospital, patients would be asked who was their main support, both professional and lay carers, so that these people could be contacted when they went home. However, it was well known that some patients left out names of people who were important in their day-to-day support and included others who were not. Thus, one service user in the longitudinal study gave my name, although my role was in fact negligible in terms of the routine practical support she was receiving. Service providers, as well as researchers, became entangled in uncertainties and disputes over who was, and who was not, part of people's support network:

Peter, a married man with two children had consented to take part in the discharge study. His wife was there when I discussed the study with him and she seemed equally eager to take part. A community psychiatric nurse, Sarah, regarded herself as involved in their support and visited the family regularly. She knew Peter had not asked for her help and thought of her support as forced on him, but she was an important source of help to Peter's wife, particularly regarding the family's housing problems and the wife's efforts to rehouse the

family. When Peter was discharged in December 1992, Sarah was not notified because Peter had not told the ward staff about Sarah's contact with the family. Sarah found out about his return from hospital through another client she met in an Edinburgh shopping centre.

There was sometimes an element of coercion in the way service users became linked into services:

> *I had introduced myself to Paul and was trying to explain to him the discharge study and persuade him to take part. Paul had been admitted to hospital because of a drug overdose after an incident in the out-patient clinic where he fell out with his doctor over the amount of drugs he was being prescribed. He looked at me suspiciously and asked: "Are you the psychiatrist? They say the psychiatrist is coming - I don't want to see her" I assured him I was not the psychiatrist, and he relaxed and invited me to sit down in his room.*

We talked at length, but not about what mattered to me, namely the study.

> *Paul was stoned and very talkative. Among other things, he talked of how his behaviour in out-patient had been put down to mental instability on his part, and how he resented this. He told me 'they' were trying to force psychiatric services on him. He did not want it. Just before I was to leave, one of the ward nurses popped her head around the door and said: "Paul, you can go home this afternoon. This is just to tell you that a community psychiatric nurse is coming around to see you at home on Thursday morning". Paul turned to me and nodded knowingly. (Fieldnotes November 1992).*

Surveillance and complexity

Our search for information about arrangements made for individual service users' discharge was often fruitless, but yielded other, rich material. During this process, we became aware of the close links between service providers in the

setting, and the many formal occasions and informal encounters where they exchanged information about people and events. For example, we attended the psycho-social meetings where co-ordination of support to individual patients was discussed and we acquired information about service providers' involvement in service user respondents' lives. It was obvious that there was a great deal of information being exchanged. Increasing areas of service users' lives were 'appropriated' for professional care and scrutiny and this 'scrutiny' was extended through the many ties which connected service users outside of the hospital setting.

A consultant told me:
Consultant:

> *You know that time Cameron was assaulted? He always said they were drug dealers. But I have heard another story - that it was a vigilante attack. He had been selling to kids in the area and some people decided to do something about it... Who told me? It was NN* (another service user who had participated in our study. He had been passing information on to us about other people participating in our research). *These stories are told to me, and it is impossible to know what is the truth..*
> *(Taped Interview August 1994)*

This high and intense level of information exchange, together with a tendency to draw people into the care and attention of professionals, produced complexities which had repercussions both for service provision and our research. I had at times a hand in the production of this complexity.

After Anne was given the AIDS diagnosis in late 1992 (indicating a transition from latent HIV infection to active and accelerating disease) she had been missing from home a few times when her counsellor and I had been calling. We asked in the out-patient clinic if they had seen her. The nurses told us she has defaulted twice - *"most unusual of her"*. We asked the liaison community nurse if she had seen her. She said she had been to her home a couple of weeks

previously to give her inhaled pentamadine against pneumonia and that she had seemed OK, but that she and her husband *"had been drinking"*. By now, all these stories begged the question: was she in crisis somewhere, unable to cope with her AIDS diagnosis?

I caught up with her a while later. She seemed fine. She said she had been ill with a chest infection and had to call out her GP and that accounted for one of her missed out-patient appointments. The second appointment she was busy with a court case in which her husband was involved to get compensation for injuries caused by a neighbour's reckless driving. I didn't ask her about her drinking. It was coming up for Christmas and we were all drinking anyway.

This evolving complexity required adaptation of the original research strategy. For example, rather than relying on one, 'official' list of people involved in any service user's care, I ended up presenting key services linked in to the City Hospital with lists of all people who had consented to take part in the study and asking them what patients they were involved in helping. This strategy yielded added information about the numerous links between people and the information which was held by various service providers. The form we had devised for service providers seemed hopelessly inadequate to catch the intricacies of information exchange and involvement, and I collected all information by personal interview. An exception was the GPs, whom I could not contact personally because of time constraints. They were sent a postal questionnaire. I also left questionnaires in the notes of 'our' patients who were expected in out-patients and asked the doctor seeing them to fill them in.

The discovery: power and complexity

We were producing rich and interesting information, but we were lost in its detail. The central riddle of discharge remained unsolved. With Edwin out interviewing most of the service user participants, the responsibility for the service provider side of the study fell on me. I seemed to be endlessly and

fruitlessly chasing an order or a principle which was not there. The Project Advisory Group expected us to document and chart the process, in order that gaps could be identified and filled. What process? If there was one, I certainly was not documenting it. I would lie awake at night counting all the people who had 'slipped through the net' and left without my recording who had made what arrangement for their care after hospital. I dreaded the day when we had to present our service provider respondents with our findings and I visualised myself publicly conceding defeat.

Then, half-way through the discharge study I was talking to the community liaison nurse about the service user respondents involved in the study and her involvement in arranging their after-care. She told me of several instances when people who needed nursing care at home had left hospital without her being notified. Unless she happened to be there on the day of their discharge, information often did not reach her. She described how, like us, she had to chase the nurses on the ward to find out what arrangements had been made and who had been contacted, and how this was sometimes impossible due to lack of written documentation available on the ward and the absence of a named person who had made the arrangements. At that point, and with immense relief, I realised that the overarching feature about discharge in the City Hospital Infectious Diseases Unit was disarmingly simple and had been staring me in the face all along. It was precisely this: **nobody knew exactly what was going on**. Once I had established this fact, it was possible to begin to work out the main principles behind the process of discharge which generated this result.

The people who held the power to make decisions about discharge were often those who lacked the information to assess the repercussions of those decisions. Decisions about discharge were made by the consultants, or by patients who decided to discharge themselves. Consultants made decisions within constraints such as shortage of beds, the obligation to preserve order on the wards, patients' wishes, clinical need, etc. The patients often had affairs to sort out at home, or they simply wished to avoid the hospital. Decisions to discharge set in motion a train of events which were unpredictable because the system was so complex.

The effects of the decisions were picked up by workers with less decision-making powers, for example CPNs, nurses or social workers.

One day early on in the study, I met Chris, a community psychiatric nurse, outside the Infectious Diseases building. She was furious. She told me that Pam, a service user respondent in the study, had been discharged that morning. She had been selling alcohol and drugs to the other patients and had been drinking herself. The ward nurses found her increasingly difficult to cope with. The ward had several elderly and frail patients at the time who found Pam's behaviour and its effects on other patients disturbing. The consultant supported the nurses' view that Pam had to leave for the sake of the other patients and the staff. She was taken home by taxi, Chris said. She had to be carried out to the waiting car - she could not walk herself.

Pam had been in hospital several weeks. Medically, she was ready to leave hospital, but she stayed on because she did not want to go home to her ground floor flat where she felt vulnerable and exposed to burglars. She did not want to go to Milestone, either. Her support workers were at a loss finding a solution to her situation. There was no other flat available for her to move.

She lived in a flat provided by SATA, the special accommodation team and received support and regular visits from the team's social workers. She also had a community psychiatric nurse and a social worker who visited her regularly when she was at home. A friend and neighbour called on her regularly, and a voluntary organisation provided her with lifts to her GP and to hospital when she attended the out-patient clinic for regular check-ups.

A case conference between the workers who were to support her when she got out of hospital had been arranged for the afternoon of the day I met Chris. The purpose of the meeting was to organise her care when she got home. And now all the careful planning was undone and her social workers and her community psychiatric nurse had to drop other commitments and arrange visits and support for Pam on only a few hours' notice.

*"I am so **angry**"* Chris said to me. *"**They** (the consultant and ward nurses) **knew** we were having a case conference today. They **could** have waited until we had everything in place!"*. *(Fieldnotes October 1992).*

The consultants' decisions clearly had a part in producing the complexity of service co-ordination which engendered in workers a feeling and worry that there must be gaps and deficiencies in the organisation of care after people's discharge from hospital. Small wonder, then, that workers articulated their experience of the service system in terms of 'stress' and 'hype'.

'Power' was clearly implicated in the production of complexity and with this discovery we had identified a source of power which structured the organisation of the setting and affected the way people working in the setting experienced it. Conceptualising 'power', in this case, in the consultant's actions, was however, not straightforward. He in turn was working to obligations and responsibilities which were contradictory and which also restricted his freedom of action. Thus, he had fulfilled his obligations to support his own nursing staff and the other patients on the ward, and in the process he had made life difficult for the workers who were to look after Pam at home. He might stand accused of not seeing and realising the implications of his decisions, but not of irresponsible misuse of power.

The consultant himself did not feel powerful. For example, in an interview in August 1994 he told me that one of the ward staff had sustained a needlestick injury, and that his whole morning had been taken up with the incident. Needlestick injuries on a ward with AIDS patients have serious implications as a potential source of infection for staff. The consultant said:

Thank God we have had no infection among members of staff. If one of my staff contracts HIV, that's it. I'll pack up then. (Taped interview August 1994)

I will return to these issues in chapter five. At the time, however, we had neither the leisure nor the distance to take these reflections any further. We had to press on with the practical implications of our findings from the discharge study.

Findings: order of a different kind

From a service user perspective, the situation regarding the organisation of hospital discharge seemed less chaotic than might have been expected from the providers' lack of control over what was going on. On the whole, things seemed to work for service users because the service providers went out of their way to make things work. Thus, Margaret in the example above had no idea of the community liaison nurse's difficulties in organising her home care.

The main exception to a general satisfaction with discharge arrangements came from a former nurse who was looking after her dying husband at home on her own. Her case was interesting in that she took on the role of a nurse and thus had nobody to shield her from the inefficiencies of the system. The difficulties she experienced were those of a nurse who negotiated the system. This example suggests the hard work staff, particularly nurses, put into shielding patients from the shortcomings of the system. These are comments from her diaries:

> *Disaster! What happened to our night sitter! I'm exhausted! Our night sitter is the most important help. I will have 4 nights looking after my husband without help now! (Saturday 28th November 1992)*

> *All intravenous antibiotics for home come from City Pharmacy. Unfortunately they never get the right amount and this involves numerous phone calls, a lot of anxiety and a real hassle! (Saturday 5th December 1992)*

> *We received emergency prescription from the City for fluconazole, which my brother-in-law picked up on his way to visit from Perth. Unfortunately, it comes in glass bottles and they supplied no air inlets. Another phone call*

and drive thru' town to pick them up. I wish that something would go as planned!! (Wednesday 9th December 1992)

Something else goes wrong! The TPN was prescribed to run over 12 hours despite the fact that drugs are given at 21 hrs, 23 hrs and again at 8.00. Why do I have to keep sorting things like this out! (10th December)

Another service user had difficulties getting the right fitting for his oxygen bottles when he returned home from Milestone. There was a hold-up of supply while the hospice, the community nurse and the City Hospital Infectious Diseases Unit decided who was responsible for the prescription. The respondent contacted Milestone and the problem was sorted out.

When things did not work out, there were always people who could be contacted. As seen in the example about Pam, service providers made a point of making themselves accessible to patients and colleagues and exhibited a remarkable degree of flexibility in helping them sort things out. Because so many service providers were around, and because they all knew each other, information was passed around and quickly reached the person who could best deal with the problem.

Fiona had left hospital before she, strictly speaking, was well enough and steady enough on her feet to cope on her own at home. However, she persuaded the consultant to let her home. Fiona's community psychiatric nurse was critical of the consultant's decision. This consultant was a colleague of her regular doctor, who was on holiday. He did not want to tell me why Fiona had left, and she herself was dementing badly at the time and was unable to tell me when I caught up with her. However, while still in hospital she had told me that she was worried about her son who was accused of defrauding her social security book. She said she needed to sort things out. I assumed this was her reason for wanting to go home.

A few days after she got home she fell against the gas fire and burned her leg badly. She phoned the community liaison nurse based at the City Hospital and told her. This nurse contacted Fiona's regular community nurse attached to her GP practice. She went around to her house, dressed the wound and provided the necessary follow-up care.

> "*I was very surprised that Fiona phoned me*" the community liaison nurse said. "*She has not been my patient for a year and I have not seen her for a long time. But she must have kept my phone number and for some reason decided to ask me for help*" (Fieldnotes December 1992).

As the example of Debbie and Fiona illustrates, people - both service providers and users - were connected in close knit networks of acquaintance, kinship or friendship. Information travelled fast and reached people in the end, often through circuitous routes. For example, Sarah found out about Peter's discharge through another client.

Similarly, in May 1993, a welfare rights worker told me he was going to see Tom in hospital to sort out funeral grants, a will etc. Tom was very ill and did not expect to get home again. The welfare rights worker had been told about Tom by another client of his. He phoned Tom up in hospital to ask if he could be of help.

The system of co-ordination on discharge was not without flaws, but it worked reasonably well for service users because of the informality and flexibility of the systems of interaction among their service providers, and because of the many channels through which information was transmitted throughout the system. However, the informality of this system was also its weakness, for there was no mechanism whereby the success of communication was fed back to the workers involved.

Implications and recommendations

The material we collected on service organisation on discharge suggested that the activity of communication and liaison revolved around the hospital. Our findings suggested that a hospital-centered system of care can provide good care and follow-up after people leave because hospital-based providers follow people out of hospital, into their home and community settings. The hospital-centered system appeared as an effective provider of care in the community albeit at some cost to service users of privacy and control. In particular, district nursing care, organised from the hospital, worked well. We were able to reassure staff working in or linking into hospital that in spite of feelings of lack of control and a sense that the system of discharge did not work, their dedication and flexibility meant that gaps in co-ordination experienced by them usually did not transmit down to the level of service users.

We proceeded to feed back these main findings to participating service providers over a period of several months. Most of these meetings were held in the City Hospital, in separate meetings for ward nursing staff, psycho-social staff, out-patient staff and in-patient staff, including consultants. Meeting were also held in the Royal Infirmary GUM Department and with the CAST team.

The time and work required to carry out the discharge study made us reject the plans for a second study. Instead, a member of our Project Advisory Group, the community liaison nurse, picked up the discharge organisation and its improvement in her own study of communication between hospital medical staff, general practitioners and community nurses on discharge from the City Hospital of patients with HIV infection. Her study, which had been running parallel to our own, confirmed our findings. Recommendations from the two studies were identical: 1) identifying a named nurse for each patient who would be the key worker with responsibility for co-ordinating all care in hospital and on discharge, 2) a written checklist of tasks to be done on discharge for each patient, 3) a copy of the document containing arrangements made for each discharge to be kept on the ward and 4) no discharges requiring district nursing care to take place without good warning to the liaison district nurse. These

suggestions are also part of the 1996 Discharge Standards for Lothian Hospitals and have now been introduced into routine procedures on the City Hospital Infectious Diseases wards (Lothian health Board/Lothian Council Department of Social Work, 1996).

Hidden dimensions in the 'hospital-community interface': welfare benefits and housing

The most interesting of our findings, however, were of a different order from practical aspects of discharge arrangements. Other gaps in co-ordination opened up, notably one between, on the one hand, services providing material support such as welfare benefits and housing, and, on the other, the medically focused system of care. Along with this discovery a divide emerged between the service users and providers in terms of their perception of major issues in service co-ordination. There was a striking difference between service users and providers in their understanding of and their way of talking about issues and problems of service co-ordination.

Before we started the discharge study, we had talked to over 70 service providers in various agencies and only once, in an interview with a welfare rights officer in a voluntary organisation, had the importance of income and material support been stressed as a vital element of service (Huby, Porter and Bury 1992, Huby, van Teijlingen, Bury and Porter, 1993). We had spent considerable time and effort locating the key services for interview, but nobody had told us that the Council Welfare Rights Advice Shop was a vital contact for many people with HIV.

The moment we started talking to service users, a different picture of problems in service co-ordination emerged from the one we had obtained from talking to service providers. The difference in perspective was dramatic and sudden. Perhaps the contrast was so dramatic because it appeared during my very first interview with a service user. Anne took part in the pilot. I had come to see

Anne in her home a week after she was discharged from hospital. She told me everything was fine. Services worked fine. The GP had been notified. She did not see anybody. I was slightly taken aback and a bit disappointed. There was not enough 'meat' in this situation for us to test our research strategy properly and anyway things were not supposed to be this easy. I asked her if there was really nothing that did not work? Well, there were her benefits, and their lack of phone which made it difficult for her husband to get her to hospital quickly if she took ill in the middle of the night. Her mother-in-law had a heart attack while at their house, and they did not get her to hospital quick enough because Anne's husband had to go out looking for a phone. Eagerly, I asked her to tell me all about it.

> *"Oh"* she said, *"I didn't know you were interested in this sort of thing! I though it was only the GP and nurse and stuff"* (Fieldnotes October 1992)

She told me she had put in for Disability Living Allowance several months ago. This would increase the family's income from £48 per month, to over £100. A council welfare rights worker was helping her. The DSS had lost her papers, and her welfare rights worker put in a new application. He had said he would come down and see Anne and her husband to keep them informed of what was happening, but he had not been.

They needed a phone. She had put in an application to a voluntary agency which provided small grants to help people with HIV. This was several months ago. However, she had not heard. Finally, she and her husband wanted to move flats. They were living on a ground floor flat, and the husband's brothers were forever knocking on their windows late at night on their way home from the pub. They got no peace. Anne had talked to a woman who lived in a flat on the second floor of a block around the corner. She had said she wanted to exchange flats. Anne had put in an application to the housing office for an exchange. However, she had not heard from them.

I obtained her permission to investigate. I went to see the welfare rights worker. He was very apologetic and obviously felt bad about not having been to see his clients. But he had heard nothing from the DSS and had nothing to tell them. I went to the voluntary agency to whom Anne had applied for money to install a phone. They had closed her file because she had failed to confirm her application in writing. They did not know she was still waiting to hear from them. I went to the local housing office. They found her application for an exchange, but the other party had not put their application in, and the case could go no further.

A month later in November 1992, Anne's DLA, with a substantial sum in back payment came through.

In the next chapter I will describe in more detail how for Anne and numerous other service user participants, the main issue in service co-ordination appeared to be one of wrestling a basic or an improved (at times considerably so) living from the social security benefit system. Contacts with this system presented problems of a different order and magnitude from their dealings with the system of medical care in hospital and at home.

The co-ordination of care on discharge from hospital was an issue for service providers and not for the majority of service users. It was not that service users did not experience problems on discharge. Examples above demonstrate that problems did arise, and, although service providers were at hand to help solve them, they clearly represented a disruption and sometimes considerable distress to people's lives. To most service users, however, the issue of co-ordination on discharge was simply of little consequence compared to other problems in their lives.

Thus, Chris' passionate anger about Pam's sudden discharge was totally absent from Pam's account of the circumstances of her return home from hospital. Pam's dementia was progressing and was exacerbated by her drinking and drug use, but she was aware and articulate about things that were important to her.

She remembered nothing about the discharge itself, although she complained constantly and bitterly about lack of routine care and attention from people who were supposed to look after her. In fact, people called on her regularly, but she forgot they had come, she was not in, or she was asleep or too stoned to answer the door or phone when people called. Similarly, for Margaret, not only was the care she had received on returning home of high quality, it was not uppermost in her mind at the time. More important was her dramatic loss of weight and her efforts to obtain a grant to buy new clothes that fitted her. Also, one of her sons had died of a drug overdose and she was trying to get a grant to buy a gravestone.

On closer examination, the inefficiencies in the benefit and housing support system affected the work of service providers also and contributed to the feeling of stress and lack of control which many service providers were experiencing. Workers with no remit of welfare benefits work spent considerable time helping people fill in forms and interpreting rules. Aspects of clinical and psychological management and support were, as it were, suspended in uncertainty while benefit applications were pending, lost giros being chased up or improvements or change in accommodation attempted. Thus, Anne's consultant who was treating her ever more frequently recurring chest infections was unhappy about sending her home to her damp flat which she could not afford to heat adequately. He knew her living conditions exacerbated the chest problems. When Anne's DLA payment came through her welfare rights worker told me to inform Anne's consultant. *"He has been very concerned and been waiting for this a long time"* the welfare rights worker told me. Indeed, when I told him, the consultant was visibly relieved.

However, the importance of welfare benefits and housing assistance remained hidden, unarticulated and submerged in service provider discourse about organisation. It was not that they did not experience and know about the problems. They were a 'non-issue', like home-helps and community nurse was a 'non-issue' for service users.

The failure of the planned quantitative methods for the discharge study now appears a blessing. Had the postal diaries succeeded, we might have picked up people's lack of passion about post-discharge co-ordination as 'satisfaction' with services and failed to register what was really important.

Questions about power

The research, both for the project and the PhD, in important respects fanned out from our experiences of studying discharges. In the first instance, the discharge study led us to look specifically at the City Hospital Infectious Disease Unit and the discharge study produced the beginnings of an ethnography of this unit. Forty three out of 49 service user participants were discharged from this unit and the in-depth follow-up of these discharges produced a wealth of material about this particular setting and the way 'power' structured the local context of service organisation in this unit. 'Power', through the actions and decisions of people with structural power in the hospital settings, namely the consultants, was a central factor in the production of complexity which so threw the service providers and completely unstitched our carefully planned research strategies. With our search for the 'order' of discharge then began my own chase for the conceptually elusive nature of 'power' and its part in structuring the rationale of service organisation and its discourse in a range of settings. The material generated by the study of discharges thus forms the basis for a comparison between the IDU and the Royal Infirmary GUM (chapter six).

During the discharge study I also became aware of the way service users were controlled by the complexity of the system of services upon which they had come to rely. This control was partly instrumental, in the way for example their drug use and use of services was restricted. More importantly however, they were defined psychologically and socially in the interactions between their service providers. Some of the ways in which people responded to this control forms the subject matter of the last two chapters (seven and eight).

The material which we had collected on hospital discharge made us radically revise our assumptions and priorities for the whole project. The concept of the 'hospital-community divide' defined as lack of co-ordination and communication between hospital-based services on the one hand, and primary care, 'community-based' services on the other, was clearly too simplistic. There were divisions and gaps, but of a different kind. The main gap was caused by a lack of integration of services for material and social support in the medically focussed service system.

The gaps we identified were also of a different order from practical aspects of service co-ordination. The questions around hospital/primary care interface were part of an explicitly articulated political contest between hospital specialists and general practitioners. The gap between welfare rights and medical care services was hidden in the discourse of service provision in the medical service settings we were studying. Lukes (1974) suggests that one of the ways in which institutions and individuals maintain positions of power is to keep challenges off the political agenda. In the next two chapters, I seek an answer to the following question: how do welfare benefits and housing issues remain hidden from the medically focussed care system, a system which so effectively exposes other areas of service users lives?

Chapter 4   Power and the Invisible:

Welfare Benefits and Housing

The webs of significance which we spin

Why were welfare benefits and housing needs a 'hidden' dimension of service provision among workers in the medical settings we were studying?

In this chapter I begin to address this question through a detailed description of the system of welfare benefits and housing assistance as it was explained to me by people with HIV who took part in the study and the welfare rights workers and others who helped them negotiate the system. In the next chapter I go on to describe what happened when we tried to make welfare benefits and housing needs visible in the City Hospital IDU. On this occasion, the power dynamics which excluded welfare benefits from the agenda of service provision in medical settings were revealed.

I describe the system of housing and benefits through strategies people in the study employed to obtain assistance. I also describe how these strategies then became the object of very different interpretations from various people who observed and commented on them. These interpretations, in turn, revolved around both a contrast and a contest between definitions of strategies as, on the one hand, 'self reliance' and 'enterprise' and, on the other, manipulation' or 'fraud'. I aim to demonstrate that because of the way the benefit system works, it is in most cases extremely difficult to maintain an absolute and 'objective' distinction between these two definitions of behaviour. Thus, relating different interpretations to an underlying reality of appropriate or fraudulent use of the benefit system is impossible. Neither is this the main task, because the issue here is not the reality or otherwise of welfare benefit fraud, but different interpretations of it. Thus, the same behaviour aquires completely different significance for actors who operate with different sets of interpretive tools: what is 'fraud' to one person is 'enterprise' to another. These disagreements are of

more than semantic interest. I hope to show that different interpretations and the way they are contested have social consequence.

The description of the welfare benefit system expands a theme which had emerged during the discharge study, namely differences in perspective on both process and outcome of service delivery. Thus, in the example of Chris the CPN and Pam her client, what to a consultant was an exercise in controlling chaotic behaviour in a drug user on a hospital ward produced chaos and stress in the people who were to look after the patient after she got home. Similarly, Margaret's case illustrates that what was to staff a chaotic and badly organised discharge was to the patient a satisfactory arrangement which was in any case of little consequence compared to other concerns she had. The present chapter elaborates the description of such discrepancies with reference to theories about semantic networks.

My description borrows from Good's (1994) use of the idea. He uses the term to discuss ways of comparing classification of bodily and mental symptoms of illness in different cultures. The idea of 'semantic networks' means that terms used to describe bodily symptoms aquire their meaning through relationships to other terms in a semiotic field and not by their relationship as signifiers to a physical body as signified. Good compares this perspective with empiricist and naturalist accounts of illness, where symptoms are mapped on to the idea of an acultural and 'natural body'. His use of the term also differs from for example Levi-Strauss' structuralist analyses of accounts in that these networks are more than mere semiotic products of binary oppositions. For Good, semantic networks are rooted in lived practice and bodily experience. Moreover, because they are linked to lived experience, semantic networks are also structurally contingent and acquired and confirmed through social practice inherent in certain structural/social positions. As such, networks are culturally 'deep' in that they operate on the level of basic assumptions and 'taken for granted' knowledge. They are thus not merely explanatory models, but also generative of thought and action.

In this chapter I aim to build up a 'map' of the semantic networks which generated the various definitions of 'fraud' and 'self reliance'. I begin to link different interpretations to different structural positions in that I describe the roles of the doctor and welfare rights workers as vital antagonists in the contest around these different interpretations. In the next chapter I describe in more detail the structural dynamics which fuelled this contest. I suggest the way different interpretations of welfare benefit strategies link into a wider net of assumptions and meanings which condition certain points of view in their occupants. This description and analysis leads to an explanation of why welfare benefits remained hidden in service provider discourse in the IDU.

However, first I want to replace the term 'semantic networks with 'semantic webs'. This has three reasons. First of all 'web' is more expressive than 'network' of the way people in the study became entangled in the complex and finely meshed nets of meanings around 'manipulation' and 'self reliance' in the case of welfare benefits and 'stress,' 'hype', 'control' and 'chaos'in the case of the organisation in the IDU (for an example of a semantic link between 'chaotic drug use' and 'welfare benefit fraud' see Brettle 1995). Secondly, as I will describe in the next chapter, the assumptions upon which the networks rested went deep and were not easily untangled. I myself became caught up in these assumptions when I tried to unravel them in order to explain how they affected people working in the IDU setting and what they might do to ease their working situation. Thirdly, it so neatly suggests Geerz's well known definition of 'culture':

> 'Man is an animal suspended in webs of significance he himself has spun.....These webs constitute culture whose analysis is....not an experimental science in search of law but an interpretive one in search of meaning

> (Geerz 1975 p. 5 quoted in Cohen 1989).

The system of welfare benefits and provision of housing for people with HIV infection

'Needs' or 'rights'

The bureacratic classification of HIV infection (Sontag 1988) means that at some stage in their progression from latent infection to symptomatic disease and terminal illness people are entitled to special sickness and invalidity benefits, whether or not they are in work. Entitlement to improved public housing is also a consequence of increased disability. Most people included in our study were living on state benefits. In the discharge study 40 out of 49 people were living on state benefits. In the follow-up study, 14 out of 17 people were dependent on state support. Poverty and material need were for these people an issue before, and beyond their HIV infection.

Assistance beyond basic income support is allocated according to criteria of medically defined 'need'. For those of our respondents who depended on state support, their HIV infection provided access to not inconsiderable increases in benefits income and made them eligible to improved housing. The use of HIV positive status as a 'ticket' to improved living conditions was a matter for debate and discussion about equity among many service provider participants. People with HIV were already 'overprovided' in terms of services (see chapter 2), whereas others with similar needs, for example old people, lacked support. The same argument went for benefits. Some service providers saw many HIV positive people's dealings with the benefits system as, at worst, overt attempts to 'manipulate' and 'defraud' the system. I was also told by a researcher and trainer who had worked with local DSS office personnel that these workers deeply resented the arrogant and 'pushy' way some used their HIV positive status to demand special and preferential treatment. I will go on to argue that clear lines between 'legitimate' and 'fraudulent' strategies are difficult, if not impossible to draw because of the way the system of benefit and housing allocation functions. It is clear to anybody with any experience with the system that these allocations are not made according to overt rules which bases allocation of resources on 'objective' criteria of 'need' for assistance. Rather,

knowledge of the informal rules by which the system functions and skills in negotiating and 'working' it are required to obtain results.

Finding out about entitlements and applying for support entered many service user study participants in protracted and complicated relationships with the benefits and housing support systems, the working of which was by no means always clear. The system of grants and housing allocation, the criteria of eligibility and the processing of applications were also changing during the study period. The knowledge and skills needed to negotiate the system are outwith the ken of many 'lay' people, and most people in the study at some point enlisted the help of a specialist welfare rights or support worker. There were a small number of local welfare rights workers known to possess special expertise in benefits for people with HIV and used by people in our study for this reason. These were from the local authority Welfare Rights Advice Shop and one particular voluntary organisation (now closed). The social workers based at the City Hospital and linking into the Unit for Infectious Diseases were also a source of help. One of them held a dedicated HIV/AIDS post. In the case of housing, a range of specialist housing workers and workers providing general social/emotional support, for example community psychiatric nurses or social workers, were used for assistance.

Doctors play a vital role in people's strategies to obtain benefits because their testimony to a clinical need for material assistance beyond income support is required to submit a legitimate claim. This link between the welfare benefits system and systems of medical care means that welfare benefits workers joined the contest around defining and prioritising 'needs' in the medical settings I studied, particularly the IDU. In the context discussed here, the contest revolved around the legitimacy of a claim to benefits and the process by which legitimacy was decided. This became an important issue and an area of contest between a range of players: the service user, the doctor, the welfare benefits worker and other workers who took on the role of patient advocate.

Among our respondents, differences in views as to the basis of eligibility to benefits were linked to radically different ways of interpreting behaviour aimed at obtaining them. These interpretations were linked to fundamental views as to the moral status of claims on state support. The contest mirrors in important respects a debate in the literature, particularly in the literature on disability, concerning the moral and political basis for legitimate claims to state support.

Oliver (1996) contrasts the principle of 'citizens' right' with 'individual need' as the moral basis for legitimacy of claims. Since the inception of the welfare state, entitlements based on 'need' have been central to provision and policy of state welfare assistance. 'Need' is however, not a quantifiable and naturally occuring entity, rather, its definition is a political and moral question. Smith (1980) suggests that 'need' is often poorly conceptualised in policy and its definition is left for individual welfare representatives to work out in daily practice. Most research into 'need' confuses 'need' as a topic of enquiry with 'need' as a tool for analysis and therefore remains inconclusive as an aid to clear and efficient policy. He suggests that 'needs' be studied as a socially constructed reality and that definitions of and facts around 'need' be seen as produced by specific professional practices. (Smith 1980).

Doyal and Gough (1991) criticise such relativist approaches to 'need'. They argue that the deconstruction of 'need' as a fact has the political effect of offering an excuse to shirk the responsibility to provide for people who are structurally disadvantaged. They urge 'a coherent, rigorous theory of human need' as the basis for an equitable and just system of distribution of state support. They argue that human need is universal and can be reduced down to two basic needs: physical survival and personal autonomy.

However, writing about welfare for disabled people, Oliver (1996) argues that 'need' cannot be other than a contested entity and outlines the adverse consequence the assumptions of 'need' has had for people forced to argue their entitlement on this basis. The ultimate definition of 'need' lies with social and health care professionals, to whom claimants to support have to present

themselves as 'needy'. The system of welfare based on 'need' functions as an instrument of control which serves to exclude disabled people from society, rather than include them as full citizens. Oliver goes on to argue for the idea of welfare benefits as a citizens' right. This approach avoids some of the issues of interpretation and contest because a 'right' is a legal entity which is enshrined in politically agreed law. Moreover, this approach states disabled people's rights to state support on their own terms. This right goes beyond material support as forms of 'care'. It encompasses legal entitlements to education, employment and independent living. He cites Ignatieff:

> '...As a political question, welfare about rights, not caring, and the history of citizenship has been the ruggle to make freedom real, not to tie us all in the leading strings or therapeutic good intentions'

> (Ignatieff 1989, p 71 in Oliver 1996, p 73)

Broadly speaking, while the welfare rights workers and most service users participating in the study held a view of welfare benefits as a collective 'right', many doctors, who had to testify to the eligibility of claims, operated with the notion of 'individual need' as the basis for claims. In the ethnography which follows I will attempt to demonstrate that rule-breaking as a strategy to obtain benefits becomes 'self reliance' if seen through the lens of a notion of state support as a collective right. The same behaviour becomes 'fraud' and 'manipulation' if interpreted with reference to a notion of 'individual need' as basis for legitimacy of a claim.

Manipulation or self reliance? Two stories about housing

The divergence in interpretation of behaviour as 'manipulation' versus 'self reliance' runs through all my material on study participants' strategies to obtain assistance. This is a description of systems of housing assistance as seen through two persons in the study.

Six out of 16 participants in the longitudinal study had at some point wanted to change their accommodation. Eleven out of 49 participants in the discharge

study were experiencing problems with transfer to suitable accommodation at the time of the study. Some wanted to move to safer, more desirable areas, whereas some wanted accommodation appropriate for their disability and stage of illness. The problems service users experienced with housing were rooted in the shortage of safe and appropriate council accommodation in Lothian. It is part of housing policy in Lothian, indeed in Britain as a whole (Smith 1990) to use allocations of housing as a strategy in promoting health, and procedures are in place to incorporate medical priority into housing allocation. However, because of the shortage of public housing, obtaining public sector housing transfers proved extremely difficult and involved protracted and complicated negotiations with the Housing Department. Housing associations are another source of accommodation, but waiting lists here are also long, and most associations have criteria for entry which exclude some applicants, for example drug users. Finally, Supported Accommodation Team for AIDS, SATA, provides supported accommodation for people with HIV, but has a comparatively small number of tenancies (24 tenancies in 1992). A condition of housing with SATA is that the tenant accepts a SATA support worker whose job it is to make sure that the tenancy is managed responsibly. SATA workers were an important source of support for many who would have faced difficulties in living independently, but according to a worker in the GUM, some people she knew found the idea of a support worker intrusive and had been put off applying to SATA.

The waiting list for a public housing transfer is very long, and an application for a housing transfer requires the proof of medical or social need in order to have a chance of being considered within the foreseeable future. Even then, relying on the standard procedures of applying is unlikely to produce the desired effect, as Liz's story illustrates.

Liz's housing problem

Liz became HIV positive in the late 1980's. When I met her in the summer of 1993 she lived in a block of flats in the area of Edinburgh where she grew up. She is a single parent with one child. She lived with Paul, a boyfriend (not the

father of her child) from 1991 to 1994. She felt that Paul was using her as a source of accommodation and money, and he was sometimes violent towards her. She was worried about the wellbeing and safety of her child while he was living with them. However, she found it difficult to ask him to move out. Her parents used to live near her, and they were an important source of practical help for her. They looked after her child when she was in hospital, and they helped her with transport to hospital and other appointments.

Early 1993 her parents were offered a bungalow in one of Edinburgh's most sought after council house areas. They had been on the housing list for decades, as they were looking to spend their retirement and old age in suitable accommodation. They were unsure whether to accept the offer, because it would mean moving away from Liz and leaving her without immediate support. However, she encouraged them to move and promised she would try and get accommodation near them. She wanted to get out of her flat in any case. It was on the third floor and it would be difficult for her to negotiate the stairs when she became more disabled. She also wanted to get away from Paul.

Priority in allocation of housing is decided on the basis of 'need' which, in turn is measured in '(housing) points'. In order to move up the list, an applicant therefore has to accumulate 'points' by demonstrating social or medical 'need'. Medical 'need' is given priority, and high priority is given to people with 100 points or more.

In order to qualify for a transfer within the foreseeable future, and before she became critically ill, Liz needed to get on the Council's 'priority list'. However, at the time of application, she was not ill enough to qualify for this status. On the suggestion of her mother, she went to her local councillor and asked him to intervene on her behalf. He presented her case to the Housing Committee and managed to get her 'Committee Priority'. This put her next in line to applicants with top medical priority, but not high enough to ensure her a transfer. In the summer of 1994 she received a letter from the Housing Department updating her on her situation as far as prospects of a transfer was concerned. She did not

understand the letter and phoned the Department to find out what it meant. She was told that 1000 people were waiting to be moved before her case could be considered. She rang her Community Psychiatric Nurse to tell her. According to the CPN Liz had shouted down the phone in frustration:

> *"YOU'LL BE LONG DEAD BEFORE YOU GET A HOUSE IN THIS PLACE!!!!"* (Interview August 1994)

Towards the end of 1994 her prospects brightened somewhat through the council's decision to double the 'points' for people on the waiting list who had 60 medical 'points' or more. This brought her up to the 68th. place on the waiting list.

Meanwhile, Paul had moved out of her flat in the summer of 1994, and Liz's brother, who wanted to get out of his parents' home and get a place of his own, had moved in, taking over her child's bedroom. Liz' community psychiatric worker knew enough about the rules of housing allocation to look into the possibility of Liz applying for a transfer on the grounds of overcrowding. She could not share a room with her child when she became seriously ill. The CPN made enquiries on Liz's behalf, and it seemed this was a possibility which would improve Liz' prospects of moving considerably.

The rules concerning overcrowding were, however, interpreted differently according to different interests. Liz's brother wanted her to leave him behind in her present flat, and she wanted to accommodate his wish. Her application would not be considered on these terms. Stuck by a sense of obligation and loyalty to her brother, Liz remained in her old flat.

The system thus presents opportunities for 'working' it to achieve results. Skills, confidence and knowledge in managing the system is needed. Andrew, who arrived in Edinburgh from abroad and managed to settle in good accommodation within a relatively short period, demonstrated all of these qualities. His story illustrates some of the dimensions of 'working the system':

Andrew settles in Edinburgh

Andrew came to Edinburgh in April 1993. He was born in Scotland, but his family had emigrated when he was small. He had quit his job in his new country because of stress and burnout, and he was suffering severe mental problems because of a history of sexual abuse in childhood. He came to Scotland to make a 'fresh start' in a country where he had some family connections and ties. He went to stay with relatives near Glasgow, but they asked him to leave when they learned he was HIV positive. He suddenly found himself homeless and set about finding somewhere to live. He chose to come to Edinburgh because he had heard services for people with HIV were well developed here.

He had heard about the Scottish AIDS Monitor, a voluntary organisation providing support and services for people with HIV, particularly gay men. He contacted the welfare rights officer in the organisation and asked her for advice about accommodation. She recommended he go to a hostel for the homeless, because this would secure him access to the Edinburgh District Council Outreach Team who would have a statutory obligation to help him find somewhere to live. He followed this advice.

I met him in June 1993. He made the contact. He had picked up a leaflet about the study in the Genito-Urinary Medicine Clinic at the Royal Infirmary, where he had gone for medical care. He approached the study as part of his general strategy at the time of meeting as many people as possible in order to find out what was going on and what was available. He became a committed study participant, but he also used the study in order to further his own ends of obtaining permanent accommodation. Before he met me, he had disclosed his seropositive status to the deputy warden in the hostel. He assumed this would bring about a swift referral to the Outreach Team, but this did not happen. On returning from our first interview, he contacted the head warden, who had not been told that Andrew was HIV positive, told him about the study and asked 'if he could mention the hostel and its services'. In Andrew's opinion, this encouraged the warden to contact the Outreach Team and bring Andrew's

appointment with them forward. Soon after his first interview with the Team, he moved into emergency accommodation. Still with the help of the Outreach Team, he started looking for a permanent place to live.

He worked hard to find accommodation. He wrote to all the housing associations in Edinburgh. He referred himself to SATA, but they turned him down (in Andrew's opinion because the referral was not done through a professional support agency). The Outreach Team worked with the Edinburgh District Council Housing Department to find him a flat. The rule is that you can turn down three offers of accommodation before you forfeit your rights. He was offered two flats, both of which he turned down as unsuitable. One was a housing association flat, which he turned down because it was too small. It only had one bedroom, so he would not be able to have guests to stay or friends to move in to help when he became critically ill. The other was a council flat in an extremely poor state of repair and maintenance. There was blood on the walls, and it was very dirty. He knew he took a risk by turning it down, because he would lose his rights to housing if he turned down too many offers of accommodation. However, he explained his reasons for refusing the flat to an official in the District Council, and they were understanding and agreed not to regard this as an offer. He was then offered a third council flat in one of the most sought-after areas of Edinburgh (the area, incidentally, where Liz' parents lived and where she hoped to move). He accepted the flat and moved in November 1993.

Compared to Liz, Andrew's efforts to find somewhere to live bore fruit very quickly. This was partly because he was homeless and his rehousing carried higher priority than hers. However, in Andrew's opinion, he got his flat because of who he was and how he behaved.

Andrew compared himself to Lee, a friend of his, who was also homeless. His marriage had broken down and he had to move out of the family's flat. Andrew had advised him to enter the system via the hostel for homeless, like himself, and had helped him negotiate the various hurdles on the road to rehousing.

Lee's 'needs' for good accommodation in a safe area was greater than Andrew's, because his children were staying with him in periods. However, Lee ended up in a block which was often vandalised and where several flats were boarded up. Crime was common in the area.

Andrew said:

> *The system is discriminatory. It depends on who you are. If they like your face, they'll give you a nice place. But my friend Lee. They gave him a flat in Niddrie, because he's got a lot of earrings and looks a world apart from me. But they like my face and gave me this flat. (Interview November 1993)*

There were several dimensions to Andrew's success in 'working the system'. Social class played a part. He had worked as a social worker and he knew the language with which to negotiate about the rules. For example, he was able to persuade the Housing Department to bend the rule considering the number of offers he could turn down before losing his right to council accommodation. He had the confidence to find out about ways in which the systems functioned and how he could make them work to his advantage. He picked the rules which suited his purpose and tried them out. If they did not get him what he wanted he chose another set of rules. His application for long-term disability benefits was turned down because his physical health was too good. He reapplied on the grounds of psychiatric illness, a reason which was justified in his case. (His application was however, not accepted). Finally, he occasionally 'used' people to get what he wanted. Thus, he 'used' the project to get a quick referral to the Outreach Team.

However, although he might negotiate when rules were applicable, Andrew always played by them. Nevertheless, his achievements in obtaining housing and material support were variously interpreted. His consultant said about him:

> *Yes, he is very enterprising. But also very ......manipulative. (Interview November 1993)*

But is this not one and the same thing?

The system of housing allocation is slow. Simply following the official procedures is unlikely to produce results. It is necessary to 'work' the system in order to get anywhere, and the help and advice of professionals is often needed. These aspects of the system of housing allocation appear in magnified form to many people who rely on the system of welfare benefits for regular income or assistance with extra expenditure because of illness or disability. More so than the system of housing, the obvious absence of clear and consistent criteria for allocation of benefits lays users open to allegation of 'misuse' and 'fraud.' The following description of welfare benefit grants and the system of their allocation expands the discussion about 'self reliance' and 'enterprise' versus 'fraud' and 'manipulation'.

Welfare benefits grants

There are a number of grants for people who are unemployed or cannot work because of illness or disability. The system is constantly changing and the following description is out of date. However, at the time of my study the most relevant and important grants to the study participants were:

Basic income support. This is the basic form of support for people not working or on low pay. In 1994/95 the basic income for a single person aged between 18-24 was £ 36.80, for people aged between 24 - 30 it was £44.10. Couples received £73 per week. People with dependent children could claim between £15.95 and £36.80 per week per child, depending on their ages. Income support can be paid to top up other income, for example Unemployment Benefit or earnings from part time work (under 16 hours per week). People on income support are exempt from NHS prescription charges. Income support is paid weekly. Claimants must show that they are available for work and 'taking reasonable

steps' to find work. Claimants must therefore 'sign on' as unemployed in the local job centre once a week.

People with special needs, for example families, people with an illness or disability can claim premiums on top of the basic income support personal allowance. Disability premiums cover e.g. extra laundry expenses, heating costs and the cost of a healthy and balanced diet.

Benefits to cover short-term periods of illness. (Sickness Benefits).

Benefits to cover people with long-term or permanent disability or illness, for example Invalidity Benefit or Severe Disablement Allowance. The most important of these was Disability Living Allowance (DLA), intended to help people meet extra expenses incurred by reduced mobility or need for extra care. DLA was the most important source of permanent increased income for service user study participants, and it was also the processing of this benefit which caused most administrative difficulties.

Social Fund, Community Care and various charity grants to cover one-off expenses such as installation of a telephone, purchase of household equipment or clothing.

I now go on to describe in more detail the main welfare benefits grants available to people with HIV in the study period. I want to build up a picture of ways in which various aspects of the system interacted to create an experience of inaccessibility and chaos for many claimants. I also want to demonstrate that the way the system 'works' makes the question of legitimacy of strategies used to obtain benefits difficult to determine.

The question of eligibility
Statutory Sick Pay and Sickness Benefits:

There are benefits available to cover people during periods of temporary illness. Statutory Sick Pay is paid by employers to employees who are unable to work because of illness. Sickness benefits are paid to people who are unable to work and who are unemployed, non-employed or self-employed. Both benefits are paid up to 28 weeks. Sickness benefits are higher than income support, and are paid two weekly, by post. There is no need to 'sign on' as unemployed to obtain the payments.

A period of 28 weeks on sickness benefits entitled the claimant to apply for long-term disability or sickness benefits, for example DLA, Invalidity Benefit or Severe Disablement Allowance. There is thus a progression through the system of benefits where stages have to be negotiated according to fixed time scales. People's particular circumstances do not always fit neatly around these bureaucratic rules, the ignorance of which may cause complications:

Tom.

When I met Tom in September 1993, he was asymptomatic from his HIV infection, but had recovered from a period of depression caused by financial difficulties. He had lost his job some months previously, and, thinking he would obtain another job soon, lived off his savings rather than signing on as unemployed. However, he did not find another job and he accumulated debts. When he finally signed on as unemployed and obtained sickness benefits, he was told he should have signed on as soon as he lost his job because he would have to wait 6 months to apply for long-term invalidity or disablement benefits. By this time, his debts had grown and he saw no way out of his financial difficulties.

Tom obtained the help of a welfare rights worker and gradually sorted out his finances.

Tom's case also points to the intricacies of the question of eligibility to benefits: was he entitled to apply for permanent disability benefits? He was not symptomatic, and physically he was able to work. If he was unemployed because there was a shortage of work, he was not entitled to sickness benefits. However, his HIV infection affected his chances of finding another job, and his financial circumstances clearly affected his ability to cope with his illness.

What, then, is the relationship between 'clinical need' and 'rights' to benefit? This moral/political question was answered in different ways depending on people's knowledge of the rules and the structural and social position from which they evaluated the issues.

Doctors played an important role in people's benefit strategies, because their signature was needed to testify to 'clinical need'and thus make a claim legitimate. Important differences in perspective emerged between claimant, welfare rights worker or patient 'advocate' on the one hand, and, on the other, clinical staff, particularly doctors. Finding a doctor who was sympathetic to your case was an important part of the strategy of obtaining benefits.

Alan

When I met Alan, in the spring of 1993 he was HIV positive but asymptomatic. He suffered few effects from his HIV infection, but he drank heavily in periods and was unwilling and perhaps unable to hold down a permanent job. He had worked as a cleaner in pubs and cafes - in periods he has had two jobs. However, when I met him he was living off basic income support - £44 per week. He found it hard to manage. He tried to eat a balanced diet and look after himself, in spite of, or rather, outside of, his drinking bouts. He would apply for one-off payments from the Social Fund and charity funds to cover clothes and furniture and was sometimes, but not always, successful.

His GP of several years refused to give him a 'sick line'. In his view, Alan was not symptomatic, and therefore not entitled to sickness benefits. Alan knew that quite a few doctors in the practice he attended signed HIV positive people

off work and onto sickness benefits. People without HIV were signed off, as well. According to Alan, his GP had said to him:

> *"the gravy train has to stop somewhere!" "Ha!"* Alan said to me, *"It never bloody started in this case!"* (Fieldnotes November 1993)

Alan's view was, that he had paid his taxes and contributions while he was working, and he was entitled to support now he needed it. Although he was well at the time, his infection would progress and he would deteriorate physically. If he were given an income which helped him lead a healthier lifestyle at an early stage in his disease, he would remain independent of services and welfare for longer and thus save taxpayers' money in the long run.

A while after I met him, Alan moved and got another GP. He also went into Milestone for respite care and got help from a social worker there. His new GP gave him a 'sick line' and the hospital consultants renewed the sick line every three months after that. Alan got sickness benefits. These benefits increased his income by £ 18 per week and also meant that he could apply for DLA after 28 weeks on sickness benefits. The Milestone social worker helped him fill in the forms.

The question of entitlement to benefits is thus by no means easy to determine, and there are several views concerning the rights and wrongs of each case.

How the welfare benefit system works: Disability Living Allowance and Mobility Allowance

I now go on to describe ways in which the difference in interpretations about 'eligibility' were played out in specific cases of welfare benefits applications. I use the 'Disability Living Allowance' and 'Mobility Allowance' as examples, because these were the most important sources of extra income for the service users in the study. I also want to illustrate the vital position of doctors in determining eligibility to benefits and the random and unpredictable ways in

which doctors' views were elicited by the DSS in order to support a claim. If the 'wrong' doctor was approached, judgements of eligibility were often made on the basis of poor knowledge of both patients and the welfare benefits system and applications which might have been deemed 'just' were not considered. Thus, doctors' role in the system of processing applications had consequences.

Benefits for permanent illness or disability:

There are several forms of support for people who are unable to work after 28 weeks on sickness benefits. Invalidity Benefit and Severe Disablement Allowance are payable to people unable to work after 28 weeks on Statutory Sick Pay or Sickness Benefit. Invalidity benefit is drawn from National Insurance contributions, while Severe Disablement Allowance is paid to people who have not paid sufficient contributions.

The most important benefit for the majority of service users in the study was a benefit paid to people with an illness or disability which puts them in need of assistance with mobility or with personal care. Until April 1992 this was called Attendance Allowance and Mobility Allowance. It was then changed to Disability Living Allowance (DLA).

Disability Living Allowance (DLA):

The DLA was introduced in April 1992 and replaced the former Attendance Allowance and Mobility Allowance for people under 65 years. People in work whose job performance is affected by their illness or disability may claim Disability Working Allowance, but the uptake of this benefit nationally has been low (House of Commons Social Security Committe 1993) and none of our study participants drew this benefit.

Disability Living Allowance consists of two components: Care component (to cover extra costs for personal care) and Mobility component (to cover extra costs for help with mobility, e.g. taxis). There are three rates of the Care Component and two rates for the Mobility Component, depending on level of disability. An

application for DLA thus has twelve possible outcomes, ranging from refusal, to a possible award of £76.30 per week (Director of Social Work 1993/94) This sum comes on top of other benefits such as income support and thus means a considerable increase in income for people on basic benefits. As will be described below, the processing of claims could take months, sometimes more than a year, and if granted, benefits would be back-dated to the date of first application. These back-dated payments could amount to several thousand pounds.

New procedures and systems of applying for and processing claims were introduced with the new allowances. Before April 1992 the application form consisted of two pages which were relatively easy to fill in. Once a claim was lodged, the DSS arranged for one of their medical officers to see the claimant and assess the level of disability and the legitimacy of the claim. This system was replaced by a lengthy 'self assessment form' where the claimant him or her self provided the information of daily functioning and ability and obtained the signature of a medical doctor to testify that this information was correct. There was no need for a medical examination, except in very few cases. The medical examination to which claimants had to be subjected under the old system was described to me by study participants who had been through it as a humiliating and traumatic experience. Its elimination was welcomed nationwide during the consultation period for the new benefit (House of Commons Social Security Committee1993) and was no doubt an improvement in terms of the material and personal cost of processing claims, both to the benefit agency and the claimants. However, the new self-assessment form for DLA was detailed, complicated and 40 pages long. In theory, claimants were expected to fill in this form themselves, but in reality most people needed help to do so. The completion of forms needed experience in formulating answers to the best effect, and an experienced member of staff needed on average one to one and a half hours to help a claimant fill in a form properly (House of Commons Social Security Committee, 1993).

For a claim to be effective, claimants were required to describe themselves as unable to function. This often affected their self-perception and esteem and had emotional repercussions which required extra input from support workers.

Applications made under the old system were transferred to the new system after April 1992, and the new system took some time to be established. The changes resulted in a backlog of applications waiting to be processed. In the reorganisation, many applications were lost or mislaid, as happened to Pat in the previous chapter. This was a common problem to all applicants, not only applicants with HIV infection. The Director of Social Work Report (1993) and the House of Commons Social Security Select Committee' report concerning the Delivery of Disability Living Allowance and the Disability Working Allowance contains examples which echo the experience of many participants in our study. The report concluded;

> 'We are left with the clear impression that the delivery of Disability Living allowance has for many people been a nightmare'.
>
> (House of Commons Social Security Committee 1993 p v)

Who is cheating whom? the tribunal

In these circumstances, it is impossible to link the interpretations of benefit seeking strategies as 'fraud' or 'self reliance' to any consistent and 'fair' operation of rules. This is a story about a service user study participant Rhona's and her welfare benefit worker Peter's long struggle to obtain Mobility Allowance for her. The story was told to me by Peter in October 1993:

The tribunal

Rhona applied for Attendance Allowance and Mobility Allowance in September 1990. She was turned down for Attendance Allowance, and a DSS Benefit Agency officer wrote to her consultant, telling him that Rhona was refused Attendance Allowance and asked him to provide medical evidence to support her claim for Mobility Allowance. The consultant wrote back saying Rhona had

not been in the clinic and he did not have any recent evidence about her health status. He suggested they contact her GP at the time. The GP wrote back saying she was <u>not</u> ill. Her claim for Mobility was, not suprisingly, turned down.

Peter helped Rhona to reapply. A junior doctor in the hospital out-patient clinic, who saw Rhona more often than the consultant, and the doctor in the hospice, who had also seen her recently, provided the medical evidence she needed for her claim. There was a review of her case in October 1991, when the Attendance Allowance Board awarded her the Attendance component of the claim. The Mobility component, however, had to go to a tribunal in September 1992, with a medical officer and Benefit Agency officers in attendance. Rhona was accompanied by to the tribunal by Peter and one of his colleagues, Karen.

Rhona was an outspoken and forceful character to most of the people she knew. On this occasion, however, she changed her person. She swallowed a load of pills and smoked a lot beforehand, so that she would appear breathless and ill at the tribunal. Karen and Peter took her in Karen's car. Karen was worried that if they were stopped she would be charged with posession of illegal drugs! Peter described her act during the tribunal:

> *Rhona played the lost wee soul. She had them 'eating out of her hand'.*
> *(Interview February 1993)*

She raised her large blue eyes to the judge, she was polite, helpless and innocent. She appealed to their compassion and mercy. She had to show them how disabled she was, how badly she could walk. This 'test' of reduced mobility was the most difficult to 'pass' and the most degrading part of the process of applying for mobility allowance. Rhona passed it with flying colours. The medical officer and another tribunal member rushed up to hold her arm as she took a few gingerly steps, then helped her back to her seat. She was awarded her Mobility Allowance.

Peter and Rhona took a taxi back to her house. They were shouting and slapping each other on the back in celebration of their 'victory'. Rhona spotted one of the tribunal members on his bicycle and slipped back into the role of the 'lost wee soul' while he was within sight, then resumed her celebrations. (Interview November 1993)

Rhona was presenting herself as more ill than she really was. For example, she was quite capable of walking further than she did at the tribunal. On the other hand, she was symptomatic of AIDS related illness at the time. She was beginning to have recurring chest infections. Nevertheless, in one sense her behaviour amounted to manipulation of the system at best, fraud at worst.

However, the determining factor in her approach to the tribunal was the comparative ease with which her HIV positive partner, Scott, successfully negotiated his way through the maze of benefits, although he was not as ill as her. At the time of the tribunal, he had no symptoms from his HIV infection, whereas she was becoming ill and would clearly benefit from increased income within the near future. The exchange of stories about applications for benefits and their results was a common feature of interaction between people with HIV, and the networks through which this information travelled were extensive and close-knit. It was obvious that luck or circumstances around the application, rather than stage of the disease or degree of disability was the main criteria for a successful claim. Rhona's argument was, that if somebody less ill than herself was granted benefits, while her own applications on the grounds of advanced disease and disability was turned down, why should she 'play fair' in her dealings with the system? Who is 'cheating' whom?

Rhona's argument is supported by examples of inefficiencies in the system of processing and allocation of benefits other than DLA and Mobility Allowance

More on the complexity of the system of welfare benefits
Changes in benefits and the knock-on effect of delays in the processing of benefit applications.

Several benefits are only available to people who already receive special support for disability or sickness. Delays in the processing of one benefit may thus delay the application for others. In addition, the benefit system is constantly changing, with some benefits disappearing. At worst, people lose out on benefits alltogether because one benefit is stopped before their application for other benefits is processed.

Independent Living Fund
This was a benefit payable to disabled people with Disability Living Allowance to help them pay for extra help in the home and thus avoid institutional care. It was initially paid out of national funds. However, in November 1992 the Fund closed to new applications because the money (significantly cut) and responsibility for its administration were transferred to local authorities. People who had applied for DLA before November 1992, but whose papers were lost or applications were not processed, lost out on this benefit. Demands were made that the government pay compensation to people who had lost out on benefits because of the delays in administration of the DLA. In Lothian, Councillor Brian Cavanagh, chair of the Social Work Comittee, supported this claim. (Herald and Post, 1993)

The system of DLA and Mobility Allowance allocation was not working smoothly during the time of our study and this had repercussions for other benefits. Moreover, the complexity of bureaucratic procedures working under strain combined with the random and unpredictable inclusion of doctor's opinions in the processing of applications to produce adverse results for many claimants. Claims made under 'special rules' illustrate this particularly well.

The doctor's role as adjudicator of 'just' or 'unjust' applications:

'Special rules' in Disability Living Allowance (DLA) and Mobility Allowance

Normally, a person is eligible for DLA only after a six months period of receiving 'sick' certificates from a medical practitioner. However, some people with a rapidly progressing terminal illness might need benefit support before the six months period is over, and for this reason the 'special rules' for terminally ill people were introduced. These claims require the submission of form DS1500, signed by a medical practitioner testifying to the possibility that the claimant may die within six months. The 'special rules' arrangements were introduced in order to speed up processing of claims for people who needed benefits quickly. However, this was not achieved, and many claimants died before the claims were processed. One reason might have been the inefficiency of the new system. People applied inappropriately under 'special rules' in order to have their claims processed more quickly, and the job of sorting the appropriate applications from the inappropriate ones slowed down the process for all claimants (House of Commons Social Security Committee, 1993).

For the people in our study, the inclusion of a separate form DS1500 signed by a medical practitioner was an additional source of administrative delays and confusion. This is another story told to me by Peter about his own and Rhona's experience of dealings with the Benefit Agency. In February 1992 Rhona's consultant said she had only about 6 months left to live 'unless she changed her lifestyle' (meaning unless she cut down on her drugs and cigarettes).

By 1993, Rhona was receiving DLA Mobility and Attendance grants. In August 1993 she satisfied the criteria for the highest award for the care component. This would increase her income by £ 14.90 per week. An application was submitted the first week of August. It was sent to the Disability Benefit Centre for Scotland, Argyle House, for them to forward it to the National Benefit Agency offices in Blackpool. Rhona's consultant had completed and signed the DS1500, but he sent it direct to Argyle House, rather than to me. I would have sent all the papers off at once.'

Argyle House claimed to have lost the DS1500. However, they had sent the consultant a receipt for the form, so we were able to disprove this claim. Argyle House then asked for a photocopy of the receipt, together with a completed questionnaire about the benefit claim (this is sent to all claimants as a matter of routine). I sent them all they asked for. They then phoned back and asked for Rhona's signature to the papers. I told them I would go back to Rhona and get this. However, (before I went to see her) they phoned me and told me not to worry - they had found the original DS1500 and my papers and forwarded it all to the Benefit Agency in Blackpool for processing.

I phoned the Benefit Agency in Blackpool (to make sure the papers had arrived and the claim was being processed). However, Blackpool denied knowledge of the claim. I phoned Argyle House, who told me not to worry - post sent by internal mail can take 14 days to arrive. They gave me a phone and extension number to ring.

One morning a few weeks later I tried to ring Blackpool to find out what was happening to the claim. I was going to see Rhona and wanted to bring her up to date on her case. I was told I could not get through to the department I wanted on the extension number Argyle House has given me, and I was given another extension. I tried this. I was told I could not get through on this extension and that I had to try the first extension. I phoned Argyle House and told them I could not get through to Blackpool. They told me they would try. A short while later Argyle House phoned me and said they had got through no bother, but they had not asked for the information I wanted. I gave up and went to see Rhona without the information.'

The trouble is, that this claim might take a year to be decided. Meanwhile, Rhona is getting iller and iller. (Interview October 1993)

It is very difficult for even an expert medical practitioner to decide whether a patient is likely to 'die within the next six months'. The clause leaves room for considerable variance in personal judgement and interpretation. The procedures whereby medical practitioners were selected to give judgement on the topic were unpredictable and random and did not ensure that the doctor who knew the patient best or was favourably disposed towards them was approached for an opinion. This is another story told to me by Peter in October 1993. It concerns another of his clients, Jenny.

Jenny was a single parent with a child aged 7. She was symptomatic when she applied for DLA in spring 1992. The mobility component was awarded, but the attendance component was turned down. It was not accepted that she was ill and needed care. A second claim under special rules was put in July 1992 and sent to Argyle House. Peter asked for the application to be held there until the DS1500 was completed and forwarded by a junior doctor who was seeing Jenny in out-patient's. However, Argyle House contacted Jenny's GP who said that in her opinion, Jenny was 'not terminally ill'. The claim was sent to the Benefit Agency in Blackpool with the GP's statement, and it was rejected.

In January 1993, Peter wrote a letter to the Benefit Agency asking for the case to be reconsidered. Jenny's out-patient doctor signed a DS1500, which was submitted with a new claim. The claim went to a tribunal in October 1993. The Care allowance was awarded, with a substantial sum in back-dated payments because of the delay in processing the application.

Peter later told me that this case was resolved too late for Jenny to benefit. She died in December 1993. She deposited the money in her child's bank account to help in his upbringing.

Jenny's GP did not know her very well and did not see her very often. As I will go on to discuss in the next chapter, the marginality of doctors as far as the welfare benefits system is concerned shields them from knowledge about the effects of the complexity of the system on patients' lives.

The role of the welfare rights worker

Colluding in fraud?

The complexity of the welfare benefit system can also be made to work to users' advantage. Because the system is anonymous and individuals easily get 'lost' misuse of the system is possible. Some of the study participants were deliberately and knowingly breaking the rules, for example over housing benefits. One person was claiming housing benefit although he was staying in the house of a family member and not paying rent. A married couple was passing the husband off as a tenant and he was claiming housing benefit. I was slightly concerned that these respondents would be found out and discussed this with a welfare rights worker. I asked if this was not a bit risky? The worker said:

> Sometimes it works to your benefit that the DSS is so disorganised - that one department does not know what the other is doing. (Interview October 1993)

The welfare rights workers described were not shocked that people were claiming benefits which were, technically, not their due. In fact they were often condoning it, as Peter in the case of Rhona's tribunal. It is thus possible to interpret their behaviour as collusion in fraud. According to the welfare rights workers I spoke to, this is indeed an interpretation often made by DSS officials. In their own view, however, it was impossible to help clients obtain their legal entitlements unless they occasionally bent rules when the system did not work. Moreover, the rules and regulations concerning benefit allocations were often unclear and internally contradictory. Part of their job was to 'test' the system in order to establish clearer interpretations of the rules. The following examples of benefit law provide examples of this aspect of welfare rights workers' jobs.

Disability premium and severe disability premium.

These are benefits designed to cover extra expenses incurred because of severe illness or disability, for example, improved diet, heating, and extra laundry expenses (due to incontinence, night sweats, etc). People eligible are already on DLA (see below) or have been signed off 'sick' for six months or more.

Welfare rights officers were able to establish precedence and argue a case for some claimants that if the DSS adjudication officers on first claim ignored evidence of illness or disability, people could get Disability Premiums back-dated to the date of a first claim. The complexity of Rhona's dealings with the DSS and Benefit Agency continues. Peter told me:

Rhona and her partner Scott put in a claim for back-dated Severe Disability
Premium at the same time in 1988. Scott was awarded his without
problems. However, the DSS claimed to have lost Rhona's papers. In
1989, an Act of Parliament closed this 'loophole'. Scott was OK- his back-
dated Premium was awarded before this happended. But the DSS argue
that because Rhona's papers are lost, she is not entitled. I try to follow this
up in a low-key way and at the same time I try not to raise her expectations.
The funny thing is, that Scott's claims are going through no bother,
although she is a lot more ill than he is. (Interview October 1993)

An important aspect of the welfare rights worker's job was to make the system
of rules clearer and more consistent.The examples cited above indicate that
benefit applications submitted on a local level may affect the national criteria of
eligibility by establishing judicial precendence for adjudicating claims. Peter
once told me:

A lot of welfare rights law makes room for individual interpretations. These
laws are for poor people and have no higher court ties. This low level
legislation is loose, you can bend it. For example, mobility allowance can
be argued for people who can walk quite far. (Interview March 1993)

Welfare rights officers see some claims as strategic in establishing precedence
and clarifying national guidance and rules. This is important, as the national
guidance is constantly changing in ways which may appear inconsistent and
unclear.

The Social Fund

The Social Fund was introduced in 1979 to help people improve living
conditions at an early stage of illness or disability and thus avoid institutional
care. In 1994, the national guidance for adjudicating officers considering claims
was changed. The new guidance made it more difficult to obtain a grant, but

more importantly, inconsistencies seemed to exclude eligible people from having their claims considered altogether.

'New types' of expenses should be given priority over items needing replacement because of wear and tear. There was room for various interpretations of 'new types of expenses'. Thus, a Social Fund Officer put the argument to a welfare rights officer that 'clothes could not be awarded as high priority anymore. People have always needed clothes so they could not be a new need'. (Lothian Regional Council Advice Shop, 1994). More importantly, this part of the guidance effectively worked against the aim of helping people under threat of imminent care. Repeated applications to the Social Fund because of deteriorating circumstances would reduce the chances of a grant as this was taken to indicate 'recurring need, whereas somebody who claimed first time because physical deterioration was not at an advanced stage would be considered.

The new guidance also established that grants should only be awarded to people who were proved ill or disabled, i.e. people already in receipt of DLA or Severe Disability Premiums. However, the award of these benefits was also suggested as a reason for rejecting the claim to Social Fund grants, because unexpected or expected major expenses should be covered by budgeting the income from extra benefit.

From a potential claimant or a welfare rights worker's point of view, rules and regulations like these are difficult to understand or interpret, and practice is developed through the day-to-day process of submitting and evaluating claims. Thus, local welfare rights officers responded to the Social Fund guidance by putting in several claims for extra diet cost under Social Fund. 'Diet' is not a 'new' expense, but it can persuasively be argued that improved diet is important to prevent somebody severely ill or disabled from 'entering care'. These claims were submitted in order to test the system, establish precedence and develop strategies of applying which were then shared with colleagues nationally and locally.

One of these applications was successful, and the local welfare rights agency was advised that 'it is likely that the Directions will be altered to prevent future awards'.

In some cases, then, successful outcomes of claims establishing precedence are seen and detected as unintended 'loopholes' on a national level and legislation is introduced to close them. The work of a welfare rights officer is in some respects one of remaining 'one step ahead' of changes within the system, and anticipating the opening and closures of avenues for succesful claims.

The marginality of welfare benefits: do people know we exist?
Welfare rights workers often complained to me that they felt marginal to the service system as a whole, and that their experience and expertise went unrecognised. Peter, Rhona's welfare rights worker, once discussed with me the role of welfare rights workers in the overall system of services:

> *We have a unique position as welfare rights workers. Many people (whom we are helping) have been living on the margins of society. Welfare rights is seen as delivering a service which makes a difference.*
>
> *Our job as welfare rights workers is to make sure people's income is maximal. Some people say that people we are helping (e.g. drug users) should not be given this money, that they cannot handle it responsibly. We get this a lot from social workers. For example, in the case of back-dated payments, they ask 'what will they do with the money?' You control people by controlling their income, you know. But in our experience, people use the money responsibly. On holidays, or on improvements to the house. In any case, we do not make judgements about misuse of money or fraud. We simply put people's case forward. (Interview March 1993)*

He summed up his own and his welfare rights colleagues' position in the system of care as follows:

> *The service delivery is all hit and miss. There is no co-ordination. We are working in isolation. If people were referred to us as part of the service, if doctors knew what paperwork to send with the patients, to whom, things would proceed so much quicker. (Interview March 1993)*

On a later occasion he complained again about the lack of a formal structure integrating welfare rights work with medical care and he asked me:

> *Do other agencies know about us - do they know what we are doing?*

This question was echoed by one of his colleagues who cried out in exasperation:

> *"DO PEOPLE KNOW WE EXIST????!!!"(Fieldnotes August 1993)*

I was able to assure them that they are well known to other service providers, and that the value of their work is recognised.After I realised the importance of welfare benefits and housing issues, I went back to the service providers who had been silent on the issue in my first report (Huby, van Teijlingen, Porter and Bury 1993). Although the questions through which I had elicited material for these reports were open, I had not thought of asking them about the provision for material need because nobody had told me it was important. I went back and asked workers in medical settings, in social work agencies and in voluntary organisations what they knew of welfare benefits and how clients' efforts to obtain material assistance affected their own work in providing emotional, medical or practical help. It appeared that welfare benefits work occupied a large amount of people's time. Helping people obtain information about benefits and entitlement to benefits, helping them understand and complete forms, referring them on to welfare rights workers and helping them find out what was happening to their applications was an important part of the work of counsellors, community psychiatric nurses, psychologists, social workers, nurses. The uncertainty of outcomes of pending benefits and housing transfer

applications affected people psychologically. Attending medical appointments took second priority to sorting out benefit and housing matters. Peter and his colleagues were often mentioned to me as an invaluable source of help in benefit matters, both to clients and workers.

The complexity of the systems of material assistance thus created and magnified complexity in other areas of provision. People's dependency on services increased, as did the number of workers involved in providing services to one person. This complicated the task of co-ordination and liaison. Moreover, clinical management and emotional support were suspended, as it were, while people were chasing lost applications or giros and waiting for decisions about applications to be made. Finally, workers in medical, social work and voluntary settings had to deal with the emotional and practical consequences of failed or delayed applications.

Questions about the invisible

Why, then, did the welfare rights workers labour under the impression that they were not known and valued by other service providers? Why had our many advisors to the project not told us how important welfare benefits were to people with HIV? Why did service providers in the medical settings we were studying not articulate their knowledge of how the systems of material support impinged on and complicated their day-to day work? **And why did nobody try to improve the situation** by, for example, strengthening liaison and communication between welfare rights and other forms of support?

Surely, I thought at the end of the discharge study, it must be because workers in medical settings do not fully realise and understand the way systems of welfare benefits and housing assistance work, and how the relationships between this system and systems of medical/emotional support function. Providing this knowledge and this overview was an obvious task for the project, which was at this stage explicitly beginning to address the complexity of the

system. Our attempts in this respect, together with the reactions it elicited, are the subject for the next chapter.

Chapter 5: Rationality as Argument ?

The power dynamics of the IDU revealed

An attempt to make the invisible visible

This chapter describes our attempt to make the invisible visible by encouraging medical service providers in the City Hospital IDU to think about how the systems of allocating housing and welfare benefits might affect their own work and consider ways in which the links between welfare rights services and their own services may be made to work better. We approached this in a way which - we thought - would make our audience see the advantage to them of giving welfare benefits more explicit recognition. We were less than successful in our attempts. Our eminently 'rational' arguments were caught up in the power dynamics of the unit and we became discredited as 'gullible' in the process. An analysis of these dynamics and the way our arguments became a part of these leads to a critique of Habermas' theories about 'rationality as argument'.

In our search for the discharge process in the City Hospital Infectious Diseases Unit we had collected a considerable amount of material about the way people experienced the system in which they were working. In particular, we had collected material on the stress service providers seemed to experience from their work. Indeed, in our desperate search for the process of discharge, we had ourselves experienced this stress. This was not the distress and accumulated grief which came from working with young people who were ill and dying, although this affected us all to different degrees at different times. The main source of stress was caused by not knowing what was happening, where the right information was and an anxiety that we never would find out. For us, this did not have consequences beyond a poor research report. For service providers, their ignorance might mean that people's lives and health was at risk.

It seemed to us that the feeling of stress and lack of control was linked to the complexity of the system of co-ordination and communication at the City Hospital Infectious Diseases Unit, and I wrote a discussion paper about the system of liaison in the Unit. I suggested ways in which the system worked to produce stress and what might be done to alleviate it. Here, I will focus on the following two points raised:

1) The large number of people involved in providing services to a few patients, together with the high level of communication between them, produced considerable amounts of divergent and contradictory information about each patient. This surveillance of patients in turn created an experience of 'chaotic' patients which translated into 'stress' of caring for them. The 'stress' experienced was partly produced by the system, and could thus be addressed by simplifying the systems of communication.

2) Welfare benefits were a hidden dimension of co-ordination which affected all other work with an exponential knock-on-effect on other areas of service provision. I suggested that if this aspect were simplified, and welfare rights services better integrated into services, co-ordination work would be easier and some of the stress alleviated. I thought service providers in the City Hospital setting would welcome the explanation of inefficiencies of the DSS as an external source of their difficulties.

We presented the paper to all service providers in the City Hospital Infectious Diseases Unit as a confidential internal discussion paper and called a meeting of all interested staff in February 1994. The paper aroused considerable interest and the meeting was well attended. Twenty-two service providers from the City Hospital setting turned up. We had shown the paper to three people beforehand to get a sense of the likely reaction: the head of the Regional HIV Psychology Team, one research nurse and one junior out-patient doctor. They found the paper both interesting and illuminating. The psychologist and the research nurse had even taken the time to write detailed notes in response. None of them thought it contained anything which would be too controversial.

This positive feed-back was not repeated during the meeting. For one thing, it happened to fall on a bad day. Unbeknown to us, a patient had drawn a knife in the out-patient clinic the previous day and staff had been threatened. The difficult, often dangerous conditions under which people in this Unit work was uppermost in people's minds. The consultant with a main role in HIV management took the lead in the discussion and united service providers against 'us' - the researchers. According to the consultant, we did not understand the work of service provision in this environment. He (justifiably) argued that my analysis lacked historical depth. I had not sufficiently appreciated the constraints under which people worked in the Unit, and my account did not bring across why it was that organisation of the Unit worked to produce complexity and stress.

Patients in this Unit were being overtly manipulated, scrutinised and controlled because staff had to make sure that the system of prescribing drugs of abuse was not misused. Staff, in turn, were being scrutinised and controlled by the Home Office and the service could be closed down if the system of substitute prescribing was not seen to be tightly policed. Staff also had to be protected from the infection which patients carried around and the violence which often erupted around them. This also required scrutiny and control of patients.

The meeting brought out a collective resistance to systemic change which was generally absent when we met with providers, including the consultant, individually. This resistance was articulated through a discussion around power and control. Importantly, the dynamics of the discussion which took place in the meeting reflected the dynamics of interaction in the Unit as I had observed in multidisciplinary meetings. I will try to show that lack of willingness in members of IDU staff (with decisionmaking power) to integrate welfare rights in the work of the Unit was a logical outcome of these dynamics. Changing perceptions of welfare rights work among staff in the IDU would thus require more than imparting information and knowledge. It requires restructuring of the local systems of practice through which local knowledge and perceptions of

welfare benefits are produced. This will involve changing relationships both among staff within the Unit and also relationships between the system of allocation of housing and welfare benefits and the system of medical services.

On stress, power, pleading and relative truths

The meeting

Generally, the discussion during the meeting supported our suggestion that much of the stress is caused by the many conflicting versions of who one particular patient 'was' and what (s)he 'needed'. However, I had clearly underestimated the sociological insight, sophistication and reflection of my audience. The paper suggested that it was the lack of certainty about what version to believe which caused stress and uncertainty. However, everybody who spoke at the meeting acknowledged that there are many 'truths' about one patient or one situation. Given this basic premise, a discussion ensued concerning the negotiation about whose 'truth' was to be acted upon, as the main source of stress.

The medical staff, particularly the consultants, were seen to have most decisionmaking power because they carried the responsibility for decisions made. Their 'version' of the patient or a situation thus carried most weight. Other staff 'pleaded' their version of the patient to the consultants. Our paper and the arguments it put forward were caught up in these dynamics of contest about 'the truth'. The consultant's main criticism against the paper was that I had presented my understanding, which he saw as based on service users' version of what was happening as 'the truth'. He challenged my arguments on the grounds that I had been taken in, or 'manipulated' by the patients to whom I had been speaking.

What I've picked up meaning, was in one sense the assumption you make is that what you were told was in some way 'the truth'. There is a solid truth being told to you by a patient. In that certain case. Now I would say that it is a multifaceted thing. I don't know with many of my patients what is the truth of their circumstances.....

His own version of 'the truth' was not challenged. Rather, the whole meeting united in public behind the consultant. The above and the following extracts are from transcribed tape recording of the meeting.

Pleading

The pleading a worker does is in inverse proportion to the structural power (s)he has of making decisions. On the subject of 'pleading' a patient's case to the consultants, two community psychiatric nurses suggested this was a source both of stress and job satisfaction. (This is summarised from both people's comments):

Community psychiatric nurse (CPN) 1:

One of the things in this team I'm in, is that there is a great deal of status, people don't move on, people don't leave. Many of the staff have stayed for many, many years, and I say, whilst we are all very stressed, why are we all staying?......

Community psychiatric nurse 2

> *I think, you know, the system is big and a bit cumbersome, but it's...*
> *proved itself to be quite flexible. A lot of the stress in my job as a CPN is,*
> *there are so many different opinions of the client. Everybody you come into*
> *contact with..sort of gives you...what they think their experience has been*
> *and often our job is to sort of do a bit of pleading for the client and say*
> *"please just give them one more chance'....A lot of the statutory and non-*
> *statutory agencies that are put in touch with the negativity of the*
> *client...and some of our job is to say "please try one more time". And I*
> *think that people do respond to that, actually, that's what I've heard...the*
> *positive attainment that you can actually see where it's heading, You know*
> *what I mean. You can see the result.*

I asked if anybody pleaded to the CPNs on behalf of clients, and one of the
CPNs said that no, he did all the pleading. There was laughter and suggestions
that this proved he was more gullible than other service providers. But this
perception of 'gullibility' in the nurse can be seen as a result, rather than a cause
of, his position in the system of 'pleading'. Community psychiatric nurses have
very little structural power and influence. The only way they can make things
happen for their clients is to 'plead' with people with more structural power.

The psychologist, manager of the team of CPNs and higher than the CPN in the
hierarchy of authority and influence interjected:
Psychologist:

> *(Pleading) I dislike it intensely......we feel like a bunch of bleeding*
> *hearts!...But I think that it's central to some of the stress that everybody in*
> *the system who knows the patient believes that they know the patient best.*
> *And I think we just have to accept that. I don't think that -there's nothing*
> *wrong in that, there's no one person who is probably right. They're all just*
> *looking at the same person from different angles.*

She also pointed out that along with the power of the medical staff went responsibility:

Psychologist:

> *It's very stressful when it fails* (asking consultants to make arrangements). *I think it fails very rarely because of the nature of our medical staff. But at the end of the day, they are the ones who 99 times out of a 100 have the power to make decisions about many things. And we're talking on behalf of patients, and it's stressful, or at least it's annoying, if the doctors don't listen to what you're saying. (There is laughter). And I'm sure that has something to do with the stress. And I think it's really important that we respect the fact that the doctors are carrying the can, you know, and they have the right to their opinions as well even if we may sometimes differ. But don't get worked up about it.*

The psychologist and the consultant elaborated on the topic of 'carrying the can':

Consultant:

> *There is the worry that...whoever it is that if you say, give the person a last chance or another 20 mls of methadone, and then a month later it's obviously a disaster doing that, I mean that (has something to do with) the stress....Particularly, it's the pattern that you're putting yourself ...*

Psychologist:

> *..on the line*

Consultant:

> *...on the line...You're saying that it's your credibility that's up there, the client lets you down, your credibility takes a dive.*

Psychologist:

> *But it's also difficult to be played_with. You know I'm putting pressure on you to do something that puts you in a difficult situation, so the whole thing is not easy in either way.*

It was in this context that welfare benefits and housing was discussed:

Psychologist:

> You see, I think one of the other stressful things is the fact that almost all of us most of the time are offering a service that they're not asking for. They are asking for things that either we can't deliver, or don't deliver or don't particularly want to deliver - I mean they want welfare rights, they want housing - they don't particularly want to sit and talk about how they feel about the virus. They want us to go to the shops for them or do something else practical.

Involvement in welfare benefit claims meant, for the consultant, involvement in fraud:

Consultant:

> Welfare rights is an extremely important area and I suspect that one of the reasons why, which you haven't touched on is, the other problem with stress is fraud. I mean, we're asked to collude in fraud - frank fraud, on occasions. ...This is that again it depends on where you're coming from. If you're coming from the client's point of view, an extra £20 per week to buy food is extremely important and that seems perfectly reasonable. But it may be that you are going to write something or say something that is absolutely....."Will you write me a letter", you know. If I say this person has got AIDS, he will get more money than if I say he has not got AIDS. And on numerous occasions we are asked to commit fraud..."I want a clothing allowance - you've got to write, please write me a letter saying I've lost weight". "But you haven't lost weight - in the case notes there is no mention of weight loss ever." "But I need to buy some carpets". "Why do you need to buy some carpets?" Well, I spent the clothing grant on something else so I want you to get me another clothing grant." (Taped meeting February 1994)

The question of 'fraud' and the relationship between welfare rights workers and doctors

In the previous chapter I described how the inconsistencies and inefficiencies of the welfare benefits systems makes it all but impossible to obtain benefits by adhering to overt rules. The system itself thus conditions a certain kind of rule breaking behaviour which then becomes the subject of interpretations and contest. I also described the doctors and the welfare rights workers as important protagonists in this contest.

Where welfare rights workers saw 'self reliance' many doctors, including the consultant who took the lead in our meeting, saw 'fraud'. I will go on to discuss this contest in more detail and outline its practical consequence both for service users and for other service providers involved in their care. The consultant's link between his experience of stress and the invitation to collude in 'fraud' allows us to see this contest in the context of the structurally contingent constraints upon his actions and ways in which these influenced his relationship to the welfare rights workers.

The difference in the doctors' and welfare rights workers' interpretations were linked to fundamental differences in views as to the moral status of claims on state support, and also to the experiential knowledge they had of the system. To welfare rights workers and many applicants, the principle of equity and allocation of benefits according to 'need' simply is not working. With this knowledge, rule-breaking becomes 'self reliance' and 'enterprise'. This view is also linked to a notion of state support as a collective right. Many doctors operate with a notion of 'individual need' as basis for legitimacy of a claim and have little or no experiential knowledge that in practice, objective criteria of 'need' often seem irrelevant. Doctors do not hold the detailed knowledge and experience of the welfare benefit system which allows a different interpretation. First of all, it is unlikely that a medical doctor has any personal experience of real, long-term dependence on the welfare benefit system. Secondly, in daily

professional practice the details of the system is not something which a doctor is required to consider or to manage.

Not only did the doctor interpret service users' behaviour differently from the welfare rights worker. They also had a different view about their relationship. This is important, because this relationship is instrumental in obtaining benefits in that a doctor's certificate of eligibility is needed to submit an application. While the relationships between consultants and staff in the IDU was based on staff pleading a patient's case to the consultant, the welfare rights worker's approach was a direct challenge to the consultant's authority because he did not plead. The consultant said during the meeting:

Consultant:

> *'The experience that I've had of some welfare rights agencies is that*
> *they dictate. They dictate what they want you to put down. It's not*
> *a question of asking for your opinion. It's "You will write down" and "You*
> *will say this person has night sweats and has to get up at four in the*
> *morning". (Taped meeting February 1994 My emphasis).*

Peter, Rhona's welfare rights worker, had in November 1992 and March 1993 commented to me on the role of medical doctors in judging entitlement to claims:

> *Other workers lack training in welfare benefits. Doctors, for example, who*
> *make the decisions about benefits entitlements - about who should, and who*
> *should not, have benefits. **The doctor's role should be provision of***
> ***information, not judgement.** (Interview March 1993 My emphasis)*

He saw the doctors' role in testifying to the legitimacy of a claim as a matter of control, and he linked this to the particular structural position of the doctor:

> *The closer to the centre you get, the more judgemental they get, the more*
> *it's a matter of control. Junior (hospital)doctors, e.g. (naming examples)*
> *are easier to work with than consultants.*

He also said (slightly contradicting himself):

> *GPs are more judgemental, hospital doctors not so much . (Interview*
> *March 1993)*

Thus, along with the difference in interpretation of rule breaking behaviour and the moral basis for a claim to state support went different interpretations of the purpose of a doctors' certificate.

The relationship between the welfare benefits system and the system of medical care in the City Hospital IDU thus revolved around a contest between professionals with very different views about the ways in which the system works and their respective roles. This difference in perspective was inevitable given the different experience they had of the welfare benefit system and the way it 'worked'.

At the point when the doctor was asked to sign a certificate of eligibility to benefits the two different opinions became the object of contest in the specific power dynamics in the IDU. In the medical system, the consultant's and senior doctors' view of a patient or situation carried weight because doctors take the responsibility for decisions made. One generative rule of interaction in this setting is that **senior doctors are not manipulated_** because they carry responsibility. The welfare rights worker's request that they simply 'provide information ' then becomes profoundly challenging because, as the consultant demonstrated in the meeting, he is well aware that there is no such thing as 'neutral information'. Medical doctors are asked to pass opinions on eligibility of claims based on criteria of medical 'need'. Seen from their perspective, some applications for benefit can quite reasonably be deemed 'fraud' and 'manipulation' because they break overt rules The doctors' professional standing and credibility is under threat if (s)he signs a 'fraudulent' application. Ceding to the welfare rights worker's request that he simply 'provide information' would thus mean that the consultant willingly lays himself open to 'manipulation.'

The power to make decisions and judgements about people's 'rights' to assistance lies with the doctor, and his view of the situation prevails. At the stroke of a pen, the experience and knowledge held by welfare rights workers and service users may be brushed aside as 'fraud' and irrelevant to service provision.

I am not shirking the issue or ideal of a fair and equitable welfare benefit system, and I am not denying that many people with HIV (and many people not infected) may be obtaining benefits which are not their moral or political 'right'. I am merely pointing out that the system as it exists at the moment prevents equity and the application of any openly and politically agreed principles in allocation of grants.

Neither am I suggesting that either party had a 'right' or 'true' perspective on welfare benefits and the system of their allocation. Both perspectives are perfectly 'rational' within the contexts in which doctors and welfare rights workers operate and their perspectives were rooted in their different everyday working experience. This experience, in turn, was underpinned by certain structural arrangements. The doctors' decisions regarding their stance to welfare rights services were made with reference to a complex set of obligations and responsibilities which went beyond their personal situation and interest. The generative rule of interaction in the setting, namely that consultants are not 'manipulated' was structurally contingent. The danger to doctors of professional discreditation and punishment from being seen to collude in 'fraud' or from careless prescribing of substitute drugs is real and concerns not only the doctors, but also other workers and users of the service. If doctors are seen to operate a lax system of substitute prescribing or granting of welfare benefits certificates, there is a possibility that the service may be shut down. In the past, doctors in Lothian, both GPs and hospital doctors, have been reprimanded by the Home Office for being too liberal (i.e. letting themselves be 'manipulated' by patients) over substitute drug prescription.

The point I wish to emphasise is that the contest between different views had effects. The doctors' position of structural power means that their opinions have social consequence. A careless comment on a DS1500 form or a refusal to sign it may set in motion a series of events which affect the clients' lives and also complicate the work of the welfare rights workers who have to resubmit applications, chase up lost forms and apply for tribunals. Similarly affected are also nurses, counsellors, community psychiatric nurses and others who help people with their applications and deal with clients' emotional 'fall-out' from their protracted negotiations with the DSS. As is often the case, the person with power to make judgements of, for example, eligibility often knows little about the context in which their judgements have an effect, and current practice does not encourage the doctors to develop this knowledge.

Our suggestions that welfare rights services be given higher priority thus met with a resistance which was anchored not only in the attitudes and opinions of individuals such as the consultant, but in the social dynamics of the environment in which these individuals operated. The following continues the discussion at the meeting and discusses the effect the project had on welfare rights services.

Resistance to change: the limits of research rationality.

During the meeting, improved communication between the medical staff and welfare rights workers suggested itself as a measure that might increase the understanding and co-operation between these two categories of professionals and thus make their work easier. One of the project grantholders, a former general practitioner asked whether a welfare rights officer working within the hospital setting had ever been considered. This might help patients, but would be even more important as a source of advice and information and support to staff who are trying to help patients with their claims. She sympathised with the consultant's feeling of being 'dictated to' and said:

The reason I ask is because when I was a GP, that's how it felt to start with. But we made a conscious effort to improve our relationship with welfare rights people and get to know them. The balance of power changed - we didn't get told. We actually had dialogue. And it was really constructive. I just wondered whether there had been any attempt to do that? (Taped meeting February 1994)

A discussion ensued about the difficulty of basing a welfare rights worker in the hospital setting: how to find space? Where would the money come from? How would you find an agency that could spare the staff? The grantholder persisted:

Grantholder:

I still haven't really understood this. If there were no problem with money and no problem with staff, and no problem with space now_would it be OK, could you imagine that it might be fruitful?

A chorus of voices:

Yes!

Grantholder:

that's what I am asking

Consultant;

Sure, absolutely.

Grantholder:

Could it improve communication?

Consultant:

Absolutely. You could also say, be tempted to say, "go down the hall to number 8 - that's the guy you want to talk to. That testimony I can't deliver, just go and see so-and-so. So, absolutely, I would be.....

A research nurse:

An immediate weight off your shoulders! (Taped meeting February 1994)

There seemed in the end to be a positive response to our suggestions that closer links between workers in the Unit and welfare rights officers might prove constructive and beneficial, but we had to dig hard to find it. More importantly, this understanding, if understanding it was, did not translate into change in practice, as I describe below..

The study had some effects in strengthening welfare rights provision. As a result of this study, a social work post at the City Hospital, which was left unfilled when the incumbent left in April 1993 was 'unfrozen' in 1994. Welfare benefits advice and assistance formed an important part of this worker's responsibilities. A part time specialist welfare rights post for HIV in the Council Advice Centre was funded from social work funds in 1994, again on the strength of findings from the study. However, welfare rights remains marginal and tangential to the system of medical services. In the round of 1996/7 spending cuts the Health Board, on the advice of among others, the consultant and psychologist present in the meeting described above, decided to withdraw funding to continue welfare rights assistance provided through a voluntary organisation which had closed down. This has had detrimental effects for other welfare rights workers who have taken over the extra workload without added funding. Instead, the health board made the decision to fund continued provision of a buddy service for gay men because infection rates are increasing among this group. At the time of writing, I and the other two grantholders are challenging the decision, with some effect. The Health Board is negotiating with the Social Work Department about joint arrangements for funding a strengthening of welfare rights assistance.

This report from our meeting with City Hospital IDU staff and the current cuts in welfare rights provision for people with HIV in Lothian suggest the limits of a research project in facilitating change. Imparting knowledge and insight is not enough. Our efforts to change the views on welfare benefits by 'rational' argument alone of course had limited effect. Our eminently 'rational' suggestions fell on deaf ears because relationships between the medical service

settings and the welfare rights settings were not arranged to carry a discourse where our reasoned arguments found resonance. Our suggestions and the information with which we backed them up were not translated into 'facts' about welfare benefits which were seen to have relevance for action. The staff in the IDU might have reluctantly accepted our arguments on an intellectual level, but this acceptance was shallow and soon lost.

Through the ethnography presented so far I have attempted to build up a picture and an understanding of ways in which people acting in the system of services - whether as providers or as users - interpreted the system very differently because they saw and experienced it from different positions. The 'rationality' of these interpretations cannot be judged according to absolute and objective criteria. Rather, each perspective and interpretation made perfect sense in the contexts in which they were constructed. For example, the contest between the consultant and the welfare rights workers over the definition of 'fraud' in welfare benefits was carried out from their respective positions which made them interpret the same information differently. The meeting and its outcome illustrate how these different interpretations are more than a matter of semantics. They are structurally contingent and they go deep. This has implications for strategies of social and individual change. The structural underpinnings of relationships in the setting concerned needed to change in order to improve communication between welfare rights and medical services. As a research project, we did not have the power to effect these changes. Information alone does not necessarily change the way people think because knowledge is experiential. Information becomes 'fact' only in the context of everyday experience and 'facts' are constructed through contest and argument over the interpretation of behaviour, events and other information.

This raises a number of questions. For example, is communication then possible, and if so, how? Can workers in the medical settings we studied learn other knowledge and construct different 'facts' about e.g. welfare rights than that which is produced in the relationships which structure their everyday work? In the following, these questions are considered in the light of theories on

'rationality' as a product of communicative action. This discussion revolves around a critique of Habermas because he has made the link between rationality and communication a cornerstone of his theory.

Rationality as argument - a critique of Habermas

In the introduction, I made reference to Habermas's project of modernity and his efforts to salvage the benefits of modernity from deconstruction by postmodern theory and re-establish 'reason' as a force which can reverse the disastrous effects of technological advances. He rejects narrow definitions of rationality as strategic means-end calculations and evaluations of the 'rationality' of systems of knowledge and action with reference to an external immutable reality. 'Reality' itself is socially constructed and for Habermas, 'rationality' is a product of politically agreed criteria of 'equilibrium' between instrumental and symbolic/value oriented action. He shifts the focus of 'rationality' from 'consciousness' (of knowledge) to 'language' and communication. The criteria for 'rationality' is for him a communal product, decided through communication. He develops the notion of 'argument' as a basis for integrating reason with dialogue.

Critics of Habermas point out, however, that his ideas about 'argument' are politically naive in that he defines 'argument' according to linguistic criteria and therefore misses out crucial political aspects of speech acts. Paradoxically, according to Steven Connor, Habermas' theory converges with the postmodernist Lyotard, with whom he disagrees fundamentally, in that:

> ...Lyotard and Habermas have in common a conviction of the centrality of discursive ethics to moral and political reasoning in general, and share a remarkable tendency to translate political into linguistic questions'
>
> (Connor, 1992, cited in Myerson 1994, p. 17)

For Lyotard, dialogue and argument proves and demonstrates the impossibility of communication because

'there are as many universes as there are phrases. And as many situations of instances as there are universes'

(Lyotard 1988, quoted in Myerson 1994 p. 17).

Disagreements or 'differends' are born from, rather than resolved through, dialogue and argument. Because human beings are born to social contact, the situation of fundamental discongruity is inevitable. We are destined to talk past each other, shared communication and a shared reality only an appearance.

A consideration of Habermas thus addresses the theoretical issues set out in the introduction to this thesis: writing an ethnography about contested realities is a balancing act between, on the one hand, deconstructing these realities altogether, and, on the other, progressing an argument rooted in a lived experience. Habermas is thus vital to the argument about rationality constructed from the ethnography. His theories are, however, complex and his productivity vast. What I present here is a critique of some of his theory which I have sometimes derived from others and which I see as particularly relevant to issues arising out of my own material. Should I misjudge him I hope he would have detected his own criteria of rationality in the spirit with which I conduct my argument with him.

The meeting and its outcome is a basis from which to evaluate ideas of rationality as argument. It illustrates how it is not the content of knowledge systems and their internal logical validity which are at issue, but the structural dynamics whereby different 'rationalities' are constructed and contested. This process has social consequences which are often unintended and even invisible to many. Locating the structural points from which these consequences stem is, however, difficult. It was the dynamics of relationships within the setting which mediated the consultant's perspective from a personal opinion to a structural fact. These dynamics interacted with constraints built into the culture and structure of the British welfare system.

This does not absolve for example doctors as people in positions of structural power from the responsibility of evaluating the consequences of their actions. It does, however, raise a crucial question concerning knowledge: how do we learn other perspectives and other knowledge than that which we acquire through everyday experience? This requires the action of stepping out of everyday roles in order to assume others which make us see the world in a different way. I note that some positions are easier to step out of and reflect upon than others and not all rules are rigid. Thus, the consultant who attended the meeting was quite capable of 'bending' the rules in cases where he was in control of the bending. He did this creatively and in a way which resolved conflict and provided a way out of difficult situations. For example, when Mary, a drug user, was demanding more pain-killing drugs than had strictly speaking been prescribed for her and had the nurses on the ward up in arms and very angry, the consultant intervened:

> *Mary and the nurses were locked in argument over whether or not she needed extra pain relief. I came along and I said: "Look, this is a special case - Mary is dying, this is palliative care and outside the remit of ward policy". When the situation is locked like that I see my role as coming in and sidestepping the argument by finding another way of defining the situation. But it is not easy - it is a mine field. (Taped interview August 1994).*

Another example is given in chapter 7.

This poses questions of cause and effect which is at the heart of the debate concerning rationality as argument. Choosing to change roles means that knowledge has already changed, and the more important the role, the more difficult it is to change. What then comes first: the knowledge or the action? Subsumed in this question is: how much choice do we have in determining the course and outcome of argument?

To address these questions I will present a brief outline of Habermas' theory on rationality' and then proceed with a critique based on Myerson's Rhetoric,

Reason and Society (1994) and Gough and Doyle's A Theory of Human Need (1991).

An outline of Habermas' theory on communicative action

An outline of Habermas' theories is found in his Theory of Communicative Action'(1984 and 1987). He places his theories in the context of 'grand theorising' around the development of modern society as following an inevitable expansion of scientific knowledge. He broadens an understanding of 'rationality' from mere means-end calculations in a critique of e.g. Weber and also discusses Marx and others whose theories link 'rationality' to the logic and contents of systems of thought and knowledge. Habermas then substitutes his own theory about rationality as communication.

Habermas on Weber:

Like other 'grand thinkers' Weber theorised the transition from 'primitive' 'traditional' and small scale to 'modern' complex society. Underway, he diagnosed the ills of progress and modernity and their causes. However, unlike others, for example Marx, he did not offer a way of repairing the damage.

Weber's theories of modernity rest on his distinction between types of action. Value-rational action is based on moral and political values. Rational-instrumental action is based on purposive means-end calculations. Economic and administrative rational action systems differentiate and diversify to increase man's instrumental mastery of the world. Several such local instrumental-rational action systems combine to develop 'Occidental rationalism' on a societal level.

Rational/instrumental and value/rational action contexts have, for Weber, their separate logics of development and he sees systems of instrumental-rational action as cut off from moral-political foundations. He sees the evolution of history and modern Western society in terms of encroachment of purposive-

rational action contexts upon value-rational contexts. He also sees in the expansion of rational action systems an erosion of meaning. Rationalisation makes the world orderly, reliable and mastered, but it cannot be made meaningful. He has an ambiguous stand on modernity and expresses its, for him, insoluble paradoxes: For example, he sees bureaucracy as a foundation of democracy, and yet sees in totalitarian systems the logical conclusion of a development towards bureaucratisation cut off from the action- spheres of morals and values.. For Weber, then, the inextricable development towards increased rationalisation was undermining the very values on which this development was founded. He offered little in the way of resolution.

Habermas criticises Weber on two main accounts:

1. His typology of actions is too crude. He analyses rationalisation of action systems only in terms of cognitive-instrumental action. In reality, action is more complex and can be aesthetic-expressive, moral-practical, cognitive instrumental all at once.

2. He equated Western capitalist patterns of rationalisation with societal rationalisation generally. This generalisation precludes a more detailed analysis of 'rationalisation' in various contexts.

Habermas on Marx:

Marx' approach was altogether more optimistic, and based on the subtlety of his analyses of experience and knowledge as acquired through positioned action. For him, the relationships of production determine the development of empirical knowledge. Scientific knowledge will become 'rational' and a truly liberating force for human ingenuity and mastery when released from unequal and unjust relationships of production. Habermas also discusses Adorno and Marcuse. These thinkers had seen the promise of revolution denied and were more pessimistic than Marx in their views of the liberating role of rational/scientific knowledge. They saw scientific knowledge as harnessed by forces of oppression.

According to Habermas, all these thinkers have a notion of an encompassing societal rationality, linked to an expansion of instrumental and strategic rationality-of-action contexts. The logic of this history is conceptualised differently, but the process is inherently inevitable. He suggests (1987b) that the development of theories needs to be based in detailed analyses of specific institutional and organisational settings so that social theory does not foreclose direction of development. According to Myerson (1994) he then proceeds to build a theoretical edifice which is based on an ideal appreciation of language and so internally consistent that it precisely excludes consideration of context.

Habermas:

Whereas Weber differentiated between types of action between which modernity posited ever-widening distance, Habermas differentiates between two levels or aspects of society and theorises the relationships between them. He terms these two aspects 'systems' and the 'life world', where 'systems' refer to the systems of material reproduction of the 'lifeworld' which is the communicative infrastructure of everyday life,

> where actions are co-ordinated through harmonizing action orientation.

> (Habermas 1984 pxxviii)

The distinction between these two aspects is twofold. It is, on the one hand, a distinction between two fundamentally different ways of approaching the study of society. Studies of 'systems' are approached 'from the outside-in' as descriptions and analyses of material reproduction. Studies of the 'lifeworld' aim for knowledge about the everyday 'taken-for-granted- world which maintain cultural resources through communication and must be 'emic', 'from inside-out'.

On the other hand, the distinction also refers to different functions of social action: 'systems' are constituted through instrumental action, whereas 'lifeworld' is constituted through symbolic action.

Habermas theorises the articulation of the relationships between these two aspects of society. In theory, this can take any form, in reality, with the development towards modernity, functions of material reproduction have increasingly shifted to mechanisms that are differentiated from the lifeworld. Rational-instrumental systems of action are 'decoupled' from the lifeworld and function by means of non-linguistic media of co-ordination of action, for example money and power. However, 'systems' remain firmly anchored in the lifeworld because this is the field of social integration. He re-interprets Weber's diagnosis of modernity: Institutionalisation of purposive-rational, economic-administrative action happens as the anchoring of money and power in the lifeworld.

In so doing, he diagnoses the ills of modernity in a way which suggests their remedy. According to Habermas, the principles of systems spill over into the lifeworld and affect modes of communication here. The development of 'expert cultures' cut off from the communicative infrastructure of everyday life means that processes of mutual understanding are cut off from important cultural resources. Altering communication and the organisation of communication is thus a way to secure an equilibrium between, on the one hand, the lifeworld as social integrative field and, on the other, the increasingly differentiated systems of economic and political action-fields as the means of its material reproduction.

> This concept of **communicative rationality** carries with it connotations based ultimately on the central experience of the unconstrained, unifying, consensus-bringing force of argumentative speech, in which different participants overcome their merely subjective views and, owing to the mutuality of rationally motivated conviction, assure themselves of both the unity of the objective world and the intersubjectivity of their lifeworld

(Habermas 1984 p. 10)

Concerning argument itself, Habermas says:

> We use the term argumentation for that type of speech in which participants thematize contested validity claims and attempt to vindicate or criticize them through arguments

(Habermas, 1984, p. 18)

This vision of communication structures which produce rational argumentation and politically agreed criteria of action seems hopelessly idealistic in that it totally ignores the play of power and the way some groups are barred from political processes (Gough and Doyle 1991) . Habermas claims in response that his vision is an ideal which in any case is implicit in any communicative action, for according to him, the faculty which allows us to choose 'argumentation' as a form of communication is in our possession as a biological 'given' developed through evolution of language (Myerson 1994). Habermas' theory of language includes the possibility of complete understanding and congruity of meaning between persons occupying different positions and operating in different social contexts. Language itself originates in exchanges of signals which lead to harmonization and co-ordination of action. The task is to re-establish the original act of communication whereby truly argumentative speech is possible.

His theory depends on our ability not only to conduct a rational argument, but also to agree what 'rational' argument' is.

'Rational' vs 'Irrational' argument

'Rationality as argument' transgresses, for Habermas, boundaries between value-rational and purposive rational action. A rational argument has the same form whether it concerns morals, aesthetics, scientific findings regarding cause-effect relationships or economic calculations. His theories about 'rationality as argument' includes an assessment of the right and rational way of arguing and also an evaluation of people as rational or 'irrational'. The theory of rational communication thus includes as a premiss a moral obligation to argue 'properly' (Myerson 1994). 'Rational' people expose themselves to critique and show a willingness to re-evaluate their views and opinions in the light of arguments. They accept the rules of a rational argument (as outlined by Habermas) and show willing to argue properly when challenged. A refusal to participate in

arguments on these terms is 'irrational', including refusals to enter an argument because power differentials works in the person's disfavour.

The ideal end to this process of argumentation is what Habermas calls 'universal validity claims':

> Only the truth of propositions and the rightness of moral norms and the comprehensibility of and well-formedness of symbolic expression are, by their very meaning, universal validity claims that can be tested in discourse

> (Habermas 1984 p. 42)

A 'rational' dialogue occurs only if statements are understood (this ability to agree on the exact meaning of symbols used is, for Habermas, part of our linguistic heritage) and the only possible rational response to a statement is a 'yes' (I agree) , a 'no' (I do not agree) or a temporary 'yes' or 'no' (I will consider the statement):

> Whether the speaker raises a validity claim implicitly or explicitly, the hearer has only the choice of accepting or rejecting the validity claim or leaving it undecided for the time being. The permissible reactions are taking a 'yes' or 'no' position or abstaining'

> (Habermas 1984 p. 38)

This stance has been the target of critique. For example and as I pointed out in the introduction, according to Myerson (1990) 'argument' has a several shades of meaning: it can be both 'reasoned argument' and 'disruptive struggle', or a ritual exchange of views where no positions change. How far can rationality be defined in advance of argument? According to Putnam (1981 in Myerson 1994) the rules of the argument are part of what is being negotiated. Because Habermas fails to explore fully the ambiguity of 'argument' he does not adequately deal with the issues raised. Argument and communication are for Habermas 'rational' if it leads to agreement, but this view precludes from 'reason' a history of arguments and conflict which has created new ideas or perspectives and moved the debates on, without necessarily 'harmonizing action orientation'.

Habermas and Putnam in argument

Myerson imagines an argument between Habermas and the mathematician Hilary Putnam. Like Habermas, Putnam views 'argument' as central to 'rationality', but he counts as 'rational' also those arguments which do not lead to agreement and co-ordination of action. For Putnam, language and human communication cannot function outside a historic and social context, and symbols and concepts therefore do not mean the same to participants in an argument. A 'fact' is not a natural entity, but a product of a social context and will be interpreted differently by people inhabiting different contexts. For Putnam, then, argument rarely leads to full agreement because speech cannot be completely co-ordinated. However, argument changes the way issues and problems are conceptualised. A series of arguments lead to refinement in and reconsideration of the validity claims put forward. This is not a process of deconstructing reality however. In the process of rationally evaluating claims and counter claims 'facts' appear as important because they are needed to present and critique claims. Argumentation thus leads to **respect** for facts and **arguments** about facts although not necessarily to agreement about their interpretation.

For Putnam, then, all arguments are not rational and an acceptable argument does not necessarily lead to agreement. There are nevertheless criteria which can be agreed universally for validity claims with 'truth' value (see introduction, chapter 1). These are:

> 1) the desire that one's basic assumptions, at least should have **wide appeal**; 2) the desire that one's system should be able to withstand rational criticism; 3) the desire that the morality recommended should be **livable**

> (Putnam 1981, quoted in Myerson 1994 p. 51).

According to Myerson, these criteria root Putnam's theory of rationality in a social and historical context because what has 'wide appeal' and is 'livable' changes over time. Basic notions of 'rationality' are thus a matter of argument itself. Furthermore, debates concerning what is 'rational' interacts with human

experience: assessing a morality as 'livable' calls on faculties other than purely intellectual.

According to Myerson,

> these concepts make 'rational' procedure experimental, provisional, almost tentative, thereby avoiding the tensions in Habermas' system, since Putnam's founding model of rationality is attuned to indeterminacy in experience'

(Myerson 1994 p51)

The tensions in Habermas' system derive from his lack of theorising the relationships between argument as a speech act and the experience from which validity claims derive and are critiqued. He considers experience as a factor in rational argument insofar as it supports an ideal of 'unconstrained, unifying, consensus-bringing force of argumentative speech' and the 'unity of the objective world and the intersubjectivity of th(eir) lifeworld' (see above). He discounts as 'irrational' that part of experience which concerns conflict, dissonance, emotional reactions and incomprehension. In this respect, he overlooks the role power plays in evolving notions of 'rationality'.

In defining as 'rational' only those acts of argument where people agree to expose their views to critique and evaluation, Habermas excludes situations where power differentials precludes and prevents a free and equal exchange of ideas. He thus recognises the corrupting effect of power on speech. His theories do not, however, allow a consideration of how power is productive in creating knowledge.

Rationality and power

Habermas sees 'rational argument' as operating on a conceptual level:

> I shall speak of 'discourse' only when the meaning of the problematic validity claim conceptually forces participants to suppose that a rationally motivated agreement could in principle be achieved

(Habermas 1984 p. 42)

Fundamentally, according to Doyle and Gough (1991): Habermas' view of 'harmonizing action orientation' as a result of 'participants conceptually forced' to accept that agreement could be reached' begs further questions about how knowledge is produced. If, as Habermas seems to do, we take seriously Marx's theories about knowledge as a product of situated practice, then the institutional arrangements of relationships of production and communication will determine what people 'know' and put forward as 'validity claims' in an argument. Myerson (p. 47) points out a tension in the idea of 'conceptually forced to suppose': *are these free agents or not?*

As participants in a Habermasian argument perceive the meaning of a statement they realise that they must choose between acceptance and rejection. At this point they realise their freedom to choose, and they also experience their opponent's freedom and dilemma of choice. In 'real life' however, this ideal situation is tainted with the accidental and the circumstantial. For example, the discussion during our meeting was influenced by the fact that knives had been drawn in out-patient the previous day. Would it have been more constructive and fruitful had this not happened? Had positions taken been less passionately defended and more easily abandoned in subsequent debates? Similarly, the discussion in a public meeting was different from that which took place in one-to-one conversation between researchers and participants. In these situations, the dynamics were very different and arguments more constructive perhaps because the public positions of authority did not have to be defended to the same extent. How much freedom do we have, then, in choosing our response to argument?

On a more fundamental level, how can we choose arguments? The more fundamental the ideas and assumptions at stake, the less freedom we have to evaluate them dispassionately and freely.

Through the ethnography presented so far I have endeavoured to convey an understanding of the 'semantic webs' in which experience of work and relationships in the IDU are enmeshed. I have tried to show that various forms of a notion of 'control' are central, to which terms such as 'manipulation' 'fraud', 'gullibility' are juxtaposed as opposites. These dichotomies are profoundly ambiguous and contested, for what is 'fraud' to one person is to another 'self reliance', one person's 'control' is subjecting another to 'manipulation' and what is 'gullibility' to one person is 'perceptiveness' to another. Following Good (1994) I see these semantic webs not as reflecting an underlying reality, but as constituting and mediating it. They are culturally 'deep' in that they are lodged in and shape assumptions and 'taken for granted' knowledge, and they are generative of thought, speech and action. They are not merely a semiotic system of symbols which function according to internal linguistic rules. They are structurally contingent. This anchors the semantic webs in tangible political constraints and consequences. The ethnography thus refutes an idealistic stance on rationality as adopted by Habermas. It also abandons as politically irresponsible a postmodern stance as exemplified by Lyotard because the 'differends' have real and tangible consequences. Reality may be interpreted differently, but the fact that it is contested means that it is shared.

Rationality is malleable - a product of power and language rooted in situated practice. Myerson suggests that because arguments about 'reason' are structurally contingent 'reason' itself is also changeable, mobile and ambiguous. 'Reasoned arguments' can lead to unexpected results. For example, according to Lloyd (1984, in Myerson 1994) Descartes' project was intended as a method of reason universally acceptable and granting access to all regardless of social status, gender or age. It nevertheless became the foundation for discourses which excluded women from rationality and assigned them a status in the irrational and natural which man through reason had to overcome. Arguments about 'rationality' have unintended consequences, which are social and political. In the process 'reason' itself, and criteria for 'reasoned' argument evolve. 'Reason' is, however, not an epiphenomenon of arbitrary dialogues and arguments, but rooted in structural dynamics and modulated by 'power'.

Power is however not only a restrictive force in argument. It produces arguments and their rules and stakes. After our meeting with City Hospital staff, we had started to engage with complex dynamics carrying a discourse which 'produced' certain 'truths' and 'hid' others. In the next chapter I proceed to examine in more detail the process whereby this discourse was being produced and sustained in the dynamics of interaction in the settings I studied. In true anthropological fashion, I approach the task by comparison. I contrast the 'truths' being produced in the City Hospital IDU with the 'truths' produced in the Royal Infirmary GUM. I base my comparison on Foucault's work 'Birth of the Clinic' and use his idea or imagery of the 'medical gaze' as the instrument of power which gives certain features reality and name by bringing them to light, while others are left in the dark, unnamed and unrecognised.

Chapter 6: Studying service provision in the Genito-Urinary Medicine Department

Power and the invisible: GUM and the IDU compared

So far, description has concentrated on the City Hospital IDU because this service is used by the majority of people in Lothian with HIV and because of the number of services provided by this unit, notably its in-patient facilities. The Department of Genito-Urinary Medicine hardly featured in the discharge study because very few people with HIV were admitted to hospital from this department. When the study of discharges was finished I set about trying to redress the imbalance. This was partly because we needed to collect material on the GUM for research purposes. It was also a political move. As I pointed out in chapter two, the high profile of the City Hospital IDU in HIV management and research is a sore point with the GUM and we wanted to show that we regarded the GUM services as important and valuable.

In the spring and summer of 1993 I started the longitudinal, prospective and in-depth study of 16 people with HIV and their service providers. I made an effort to recruit patients in different service settings. I was particularly interested in people who were not high users of hospital services and I contacted voluntary organisations, the CAST team of community psychiatric nurses, SATA, the Supported Accommodation Team AIDS, general practitioners and welfare rights workers in order to contact this group of people. For reasons of confidentiality I had to rely on service providers to approach clients on my behalf and give them information about the study. I wanted people to be able to decide for themselves whether or not to take part before I knew their names and identities. There was no doubt, however, that the service providers who helped me recruit approached only those clients and patients whom they thought were suitable and willing. There was obviously a 'pool' of people who were considered suitable for purposes of this kind, and these people were in contact with a number of services. Thus, some of the people who joined the study were

suggested to me by several service providers. Moreover, the people who were suggested to me by non-hospital services were, with one exception, all regular users of the City Hospital IDU. The study was thus obviously caught up in the very dynamics that made the GUM less visible than the City IDU. The information I collected from the GUM came from patients I recruited directly from this department.

I started the longitudinal study by 'hanging out' in the GUM clinics. I recruited three patients from this department whom I followed for periods between one and three and a half years. I also spoke to a number of patients on a one-off basis. During the recruitment period and in following up the three study participants I spent time in the GUM clinic and got to know the staff. I acquired an insight into the way they perceived their work and the patients for whom they were providing care. This chapter introduces the GUM Department and compares it to the City Hospital IDU as the latter has been described so far.

I discuss perceived differences in the task of service provision in the two departments. I then go on to link these perceptions to corresponding perceptions of differences between their main clienteles: the 'drug users' who form the majority of City IDU HIV patients, and the 'gay men' who are in the majority among GUM patients with HIV. There is a theory among service providers about the different types of people using HIV services in Lothian, and about how services have evolved the way they have because of the behaviour of the people for whom they cater. The argument revolves around the difference in behaviour, character and lifestyles between, on the one hand, 'drug users' and, on the other, 'gay men'. The implication is that drug users are different from, and use services differently from, gay men, That is why the City Hospital IDU (where the majority of patients with HIV are drug users) and the GUM (where the majority of patients with HIV are gay men) function differently.

Roger Jeffery in a study of casualty departments in a town in England describes how staff classify patients into 'good patients' and 'rubbish' based on their ideas of 'real' medical work and 'real illness' versus 'trivia' and 'deviance' (Jeffery

1979). In this chapter I want to question the assumed causal relationships in the theory about 'drug users' and 'gay men' and the nature of work in the IDU and GUM respectively and ask how it can also be said that a service setting construct 'the client' in specific ways. My description of the GUM Department develops the argument that the way the power of senior medical staff structures communication and interaction in this department is different from that in the City Hospital IDU. The process whereby certain client characteristics or behaviours are brought to light while others go unnoticed is thus different in the two settings. The ethnography draws on the work of Foucault and his project of power and discourse. I discuss Foucault's perspectives of power in a summary of the ethnography presented so far and set up the problematic of agency and resistance to power where Foucault's writings are inconclusive. This problematic is the focus for the two subsequent chapters.

The stereotypes: 'the gay man' and 'the drug user'

For the purpose of the discharge study, we decided, in discussion in our Project Advisory Group, to override the common classification of people with HIV into 'drug users' and 'gay men' and we did not attempt to explain features of service provision in terms of these (chapter 3). It is interesting then, that the complexity we uncovered during the study was to a large extent explained by service provider study participants as a result of the nature and behaviour of 'the chaotic drug user'.

For example, in the meeting we held with City Hospital IDU staff we were told that drug users abuse the system of substitute prescribing in trying to obtain more drugs than the doctors prescribe. They also misuse services generally by trying to tap into several services at once. This is why systems have had to be set up in the City Hospital IDU to scrutinise, control and manipulate service users. Drug users are 'chaotic', demanding, manipulative and need to be controlled. *"These people are so chaotic, they make us chaotic, too"* the psychiatrist based at the City Hospital IDU said.

There is a perception among both providers and users in the GUM department that in contrast, the clientele here is easy to deal with. They are articulate, organised and use services appropriately. A clinic nurse in the GUM said:

> *"Our lot don't see many services. They are not like the City lot - who are*
> *used to getting what they can out of the system. Our lot are grateful."*
> *(Fieldnotes October 1993)*

Once I started to spend time in the GUM Department, however, I came to realise that these perceptions had their roots in the different ways the two units were organised. Thus the explanation for this difference in experience of service provision was to be found in the different structural dynamics of the two units rather than in individual characteristics and lifestyles of the people using them. In the following, I describe some of these differences and the way I experienced this difference during fieldwork.

Organisation and practice: the GUM and the City Hospital IDU compared

The GUM department and the care it provides for people with HIV is organised differently from the City Hospital IDU. First of all, the GUM department is smaller both in terms of number of staff and patients and also in terms of physical space of premises. During the fieldwork period the number of GUM full time staff equivalents involved in HIV care was 7.3 compared to 70.3 in the IDU. This excludes staff not employed in the IDU such as the community liaison nurses (Lothian Health and Centre for HIV/AIDS and Drug Studies 1994). By June 1995, the number of people with HIV who had used the GUM department was 321. By the same date, 760 people with HIV had used the City Hospital IDU (counted by the number of people who had tested seropositive (Huby, Porter and Bury 1995). Care for patients in the GUM is concentrated in one location, namely the out-patient clinic. The GUM does not have an in-patient ward, but uses a general medical ward for those of their patients who need an admission.

The policy of the department is to admit only on strict medical grounds, whereas the City IDU will admit people on other grounds, for example drug use or emotional problems. The number of patients admitted to hospital in the GUM is therefore very low compared to the City Hospital IDU, which means that there is less need to find out about patients' home circumstances in order to make arrangements for discharge. It also means that staff activity is concentrated in one area and communication is relatively easy. In the IDU patient care takes place in three in-patient wards and one out-patient clinic. IDU staff acquire sometimes detailed knowledge about patients' home circumstances in order to arrange discharges. This knowledge expands as people go in and out of hospital several times. IDU staff are also spread over several wards covering a larger area, and this makes communication more difficult.

The use of staff resources in HIV work is also different in the two units. Whereas the City Hospital IDU has responded by expanding and drawing in a number of community-based and hospital-based specialist HIV services, GUM has maintained its organisation and developed expertise in its existing staff, rather than creating new posts. GUM medical staff and nurses have developed expertise on HIV management in addition to general STD (sexually transmitted diseases) management. An exception is the new HIV dedicated post in psychology. Two psychologists who are part of the Regional HIV psychology team share a job in the Department. However, they see both people with HIV and others. GUM health advisors have acquired knowledge of welfare benefits and housing and services which help people with HIV get access to material support. A health advisor is a nurse with health visitor training who provides advice and health education to patients in Genito-Urinary Medicine departments. In the case of the Royal Infirmary GUM Department the health advisors also provide pre- and post-HIV test counselling. They also provide some follow-up for people who test positive, but they do not see patients in their homes like the IDU counsellors do.

As I will go on to describe, communication was organised differently in the two departments during the study period. In the IDU, there was an emphasis on formal meetings to exchange information about patients and co-ordinate different service providers' input in one person's care. In the GUM, by contrast, there was no such meeting when I began the study, although several attempts had been made to instigate one and yet another attempt was being made during my study. Communication in the GUM was informal and ad-hoc, something which was made possible by the concentration of staff activity in one location and the smaller number of staff.

GUM staff have access to specialist HIV community workers, for example CAST and the community liaison nurse. However, these workers do not visit the department routinely like they do the City Hospital Infectious Diseases Unit. They do not participate in formal liaison meetings, when or if these take place. Communication, if it happens at all, tends to be formal and more restricted. At the time of the study, a social worker who had built up expertise in HIV work operated in the Haematology Unit and was available to GUM staff and patients for advice on benefits. Department staff also made extensive use of the welfare rights service of the Scottish AIDS Monitor, the first voluntary organisation in Lothian set up to help people with HIV, and also the Council Welfare Rights Advice Shop.

Thus, in the IDU a large number of staff are employed specifically to work with people with AIDS, whereas in the GUM the number is small and AIDS management is only a part of most staff's workload. Moreover, IDU staff have access to and exchange detailed information about their patients, whereas in the GUM there is less communication of such knowledge. Finally, GUM staff do not communicate regularly with 'community-based' organisations such as CAST, SATA and community liaison nurses.

I spent a lot of time in the GUM out-patient clinic during the period of recruitment, which lasted around four months. I got to know the staff and acquired insight into the running of the clinic. It was an enjoyable experience after my time at the City because I felt in some degree of control. From my chair in the record room behind the reception desk I picked up gossip and information about what was going on without even having to get up. People I might want to see were likely to pass at some point during my visit and I did not have to chase them up. It was a welcome change from the feeling I harboured in the City of chasing information which was not there.

The atmosphere in the GUM was relaxed. There was an air of friendly co-operation which was, at worst, jarred by teasing and jokes about disagreements which arose. The intensity of feeling which surrounded disagreements among staff working in the City IDU seemed absent. I once overheard a conversation between two GUM clinic nurses where one complained about a consultant's unreasonable demands and expectations about the arrangements she would make for one of the patients in the clinic that day. However, once this patient went home, the nurse would have no involvement with him. The incident did not linger the way for example a consultant's early discharge of one of Chris' clients affected her own and three other people's workload over several weeks (chapter three).

GUM staff, some of whom had spent time at the City IDU in exchange programmes, compared their working relationships with those in the IDU and decided that GUM was free of tension in comparison. Incidentally, City staff, on their part, saw the GUM as in the word of the psychologist *so laid back, it simply isn't true*. My own experience thus matched the story that work in the GUM is less stressful than in the City Hospital IDU. I wondered if this might not be because the GUM staff in a sense, had less to be tense about. They were less involved than City IDU staff in their patients' lives both in and outside of hospital and were less affected by the complexity.

The City patients are under close scrutiny. Information about their life both in and outside of hospital is exchanged in numerous formal and informal occasions and much of this information is made the subject of formal evaluation and interpretation among staff. 'Need' is clearly visible and the object of professional contest. Not so in the GUM. As I will go to describe, the stereotype of 'organised gay man' using the GUM hid a number of service users who did not conform but whose lifestyles were as ill matched to the appropriate use of the service system as many of the City patients. However, their 'chaos' and much of their 'need' was not visible to GUM staff. This was clearly an important reason why GUM patients were seen as easier to deal with than the City patients.

However, this discovery contains paradoxes and raises further questions. The GUM Department has a small number of staff, who interact in a limited number of locations. In this type of social system it is usually difficult to keep behaviour and character 'hidden' because so much information is exchanged and evaluated in public arenas. In contrast, the scale of the organisation and the large number of fora of information exchange in the City IDU might lead one to expect that some information will be kept private and protected from public display. How, then, was the chaos and complexity of service provision visible in the City setting, and hidden in the GUM? As I will go on to describe, it was not simply that the complexity in the GUM was hidden, out of sight. It was there, but it was not identified, named and given social existence. Moreover, like the City IDU, the style and behaviour of the people with most structural power, namely the consultants, influenced and structured communication and the way certain things were emphasised and given the status of a 'fact' which was to be acted upon. To illustrate this, I go on to present some of the material I collected from the GUM. I begin with a description of Alan, the man who first made me aware of how the complexity of patients' lives are often hidden from the GUM staff.

I recruited Alan in the GUM, but I also knew of him as a potential study participant through his CPN, David. He was a well known character in the department. He was pleasant and easy-going when sober, but demanding and difficult during his periods of heavy drinking. Everybody in the department had

stories to tell about Alan, and yet, I was struck by how little they knew about his life outside of the clinic. This was brought home to me when I came to his flat one day in February 1993 and found him in deep crisis because he was about to become homeless.

A crisis hidden?

Alan becomes homeless

When I went to see Alan one afternoon in January1994 there was no reply when I rang his doorbell. This was despite the fact that I had made detailed arrangements to meet him, and he had chosen the day and time for me to come. This was the second time that afternoon that I had waited in vain for somebody to answer the door even though I had turned up at the agreed time. I was annoyed, frustrated and worried about bothering people who obviously did not want to see me. It was raining and very cold. I did some shopping and returned half an hour later to try again. This time Alan did reply. Relieved, I entered. Quarter of an hour later I wished I had left when my first attempt to get in had failed.

Alan had been asleep, he said. He led me through the elegant hallway of the flat he shared with four other men. There was a big 'no smoking' sign on the wall. His room was very untidy. It smelt of old drink and tobacco and several bottles of pills were lying around. He had obviously been drinking, he was very depressed and had no doubt been taking some of the tablets. I tried to sneak a look at the labels on the medicine bottles, but the names did not mean much to me.

He was homeless and did not know where to go. In ten days he would have to leave his room. He said he had to leave because the landlord was giving up the flat due to disputes over maintenance fees, and that they all had to move out.

But then he did not really believe this. The others just wanted to get rid of him. He did not fit in.

> *"I don't know why,' he said. 'I've been drinking a bit and had too many lovers, that's all I've done". (Fieldnotes January 1994)*

Also, the cheques from the DSS for his rent rebate had not been arriving regularly and he had probably not been pulling his weight as far as the financial upkeep of the flat was concerned. The rent was quite high, but he had been granted this rebate after prolongued negotiations with the DSS.

When I first met him (June 1993) in the out-patient clinic of the GUM, he was in the process of moving to this central Edinburgh flat from council accommodation in one of Edinburgh's housing estates. He told me he had been trying for a long time to get out of the estate, where he was very unhappy because he was being harassed by neighbours trying to get his medication off him. He had been broken into several times. He had signed up for an Open University course in computing and had been given a computer on loan. The computer was obviously not safe in his council flat.

He had found this new flat through an ad in a gay bookshop. He had negotiated with the DSS over the rent rebate, with the help of his Community Psychiatric Nurse, David. He moved in August 1993. He organised the move himself, both the paperwork and the practical arrangements of moving. Moving from the housing estate to central Edinburgh had been a good experience. Transport was no longer a problem as he could walk everywhere and no longer needed to worry about bus fares. He felt different living in a 'good area'.

> *"Even the girl behind the counter in the benefit office is all smiles"*
> (because of my new address) *(Fieldnotes September 1993)*

But now he had to get out. He did not have many options as far as a new flat was concerned. He was not eligible for a council house because he had

accumulated rent arrears from the council tenancy. He did not know his financial responsibility for the tenancy ended only once he handed his keys in and signed papers formally ending his obligations as a tenant. He did this a few months after he moved out, and in the meanwhile he had accumulated arrears of a few hundred pounds. He did not have the means with which to pay this back, and until he did he could not ask for another council tenancy.

"This is it" Alan said to me. He said his whole world had collapsed. He could not possible pick himself up after this. The world had forgotten him and nobody cared. I put away my notebook and panicked. How should I handle this? How depressed was he? Was he suicidal? Or was he trying to control me by putting on this act of helplessness? Should I call somebody? What could I do and say to make him feel better. (And, the researcher in me asked: what data could I get out of this?)

I thought I should find out who knew of his situation and whether anybody was trying to help him.

Alan's service providers
The GUM health advisors

Alan is friendly with the health advisors (nurses who provide pre-and post-test counselling and also do health education and prevention work for sexually transmitted diseases) in the GUM Department. He always goes to see them to get a form so that he can claim back his bus fares incurred by the hospital visit. They always give him one, even when he comes in 'on spec' and they're only supposed to refund visits to appointments. One of them seems particularly close to him. She told me she talked with him at length about his accommodation problems when he lived in the council flat and discussed with him his options of moving. She also encouraged him to sign up for the Open University Course. She discusses his options of welfare benefits with him. She gives him advice, rather than intervening on his behalf. She thinks he is very knowledgeable

about money, how to get it and make it last. She said this about him shortly before I found Alan in crisis:

> *He is very much on the ball. There is nothing Alan doesn't know about or can't get. He's had that sorted out for a long time. He knows all the offices like - I remember we talked, when he lived in (the housing estate), when he'd been broken into lots of times and things like that, he was talking about getting moved and I said: "Did you go and see about such-and-such?" "Oh, I've been there. I've had this money from them on more than one occasion and I cannot go back and ask for more at this stage." He had everything well taped. He is not backwards at coming forwards, which is good. (Interview January 1994).*

(I did note, however, that Alan did not know that he was accumulating rent arrears, and the health advisor did not know, either).

I asked him if he had told the health advisor of his problems. He said he had not. He did not want 'them' to know

> *"I could not face them."*

The consultant, Dr Campbell

I considered Alan's consultant as a source of help, but rejected the idea. Alan's consultant thinks of his responsibility as a doctor in terms of the clinical management of patients' HIV infection. He will write housing letters and sign forms testifying to patients' eligibility to disability benefits, but his social obligations end there. Alan has turned up at the Accident and Emergency Department when he is drunk and feels unable to cope on his own. The A&E has contacted the GUM and asked if he should be admitted. However, such admissions are always denied, partly because the GUM Department does not have beds of their own, partly because the policy of the Department is to admit strictly on medical grounds.

The consultant explained to me once:

> *We know Alan is well looked after by his GP at home, and he never gets an admission, which is what he wants.*

The consultant also has a view of Alan and his destiny:

> *Alan - he will not die of HIV infection, but of a knife in the back, or of alcoholism. (Interview September 1993).*

David, the CPN

Alan has been seeing his CPN, David, since September 1992. His former GP referred him. Since then, David has seen Alan more or less regularly and supported him in a number of ways. For example, David helped him organise the move to the new flat, he has talked to him about his options as to welfare benefits, and he has also discussed his drinking with him. Alan stresses the practical assistance. He once said:

> *"We mostly talk about benefits and stuff. HIV never comes up."*

Alan told me David knew he had to leave his room, and that David was due to see him at home in two days.

Nicole, the social worker

Since the autumn of 1993, Alan has also been seeing a social worker from the hospice, Nicole. Nicole's main input has been helping Alan to obtain welfare benefits. He was on ordinary income support and found it hard to manage. His old GP refused to sign him off as sick as he thought Alan was not physically ill with his HIV infection. (See chapter 4). Nicole has helped him obtain a 'sick line' from the GUM Department, which increased his income by £ 18 per week and got him out of the two-weekly visits to the DSS office to sign on.

There was a great deal of contact between Nicole and David over Alan. Once, Nicole phoned David to tell him Alan had been to the hospice, that he was drunk, and that she was worried about him. According to David, she had even phoned the GUM Department. David went to check on Alan and see that he was all right.

Nicole also knew about Alan's housing crisis. He was due to see her in the hospice to discuss accommodation options a few days before, but she had to cancel the appointment as her child was ill.

Different images of Alan competed as I sat in his room that afternoon and tried to decide what to do. Alan the drunk who will die with a knife in his back? Alan the street-wise who knows to get what he wants? To which Alan should I respond? In the end, having somewhat satisfied myself that Alan would be visited by David in two days and that a capable social worker also knew of his situation, I decided that he was unlikely to do anything to harm himself in the meanwhile. I set about trying to console him and cheer him up.

I tried my usual approach of emphasising people's strength rather than dwelling on their problems. I assured him the world had not forgotten him, that a lot of people valued him for his resourcefulness and initiative. This was not what he wanted to hear. His resourcefulness was precisely the problem. It was just an image, and he was not like that. He was tired of fighting all the time. He wanted somebody to do the fighting for him.

He talked a lot of control, how he controlled people. He controlled his lovers. He could make people do what he wanted. He was not proud of this, but it was a fact of which he was aware. For some reason, this talk of control made me profoundly uneasy. Maybe it was because he associated it with his sexual behaviour and I was alone with him in this little room as he, drunk and drugged, clutched my hand and cried on my shoulder. I tried to assert myself. I asked why he talked of control - was he trying to control me, and if so, to what end? No, he said he was not trying to control me and did not think he could.

Then he went on trying his hardest to do just that. He said that nobody who did not have the virus could understand what it is like to live with it. But he had never talked to me about his HIV infection, and he said he avoided the topic with David, as well. I decided he was putting on an act and said I did not think this was about his HIV infection. It was his housing that was the problem. He had to deal with that, and there were people around who were ready to help him. Yes, he said, but I knew I had not responded the way he wanted. After two hours I left, or, rather, fled, worried about Alan's safety and with an uneasy feeling I had handled the situation badly.

I went straight to the hospital out-patient clinic where I had another errand. I asked casually if anybody had seen Alan or knew how he was. Nobody knew of his problems or his distress at that point. One of the out-patient nurses said:

> *"Alan? - oh he is opportunistic. He turns up when he wants to. He will turn up when he is in trouble". (Fieldnotes January 1994)*

The health advisor thought he was perhaps busy with his Open University Course and had not had the time to come for his regular check-ups.

The next day I checked with David that he really was going to see Alan. He confirmed this. A few days later he told me that he had been, but that Alan had been too drunk and depressed to talk sensibly. David asked him to come into the office in a sober state so that they could have a proper discussion. He stuck a notice reminding Alan about the appointment, on the wardrobe. Alan did turn up, sober. They discussed his options. They arranged a meeting between Nicole and the two of them the same week. Alan did not turn up.

Alan vanishes

He then 'vanished' for a few months. Neither David nor Nicole knew where he lived, nor how to get hold of him. According to Nicole, however, she and David did know what was happening to him, because they heard through other

agencies he had contacted and to whom he had given their names as his main support workers. In an interview I taped with Nicole a few weeks after Alan disappeared (February 1994), she told me

Nicole:

> *We were just discussing how we need to be careful not to duplicate*
> *anything in Alan's case, as he seems to have gone to two different social*
> *work departments to get money.... I'm not quite sure who he's talked to.*
> *We know what's going on. It's very interesting. At the moment he's*
> *giving us messages, but not actually turning up.' ...Somehow we know*
> *where he is and what's happening to him - but we can't get hold of him.*
> *(Taped interview February 1994)*

So there we were, the researcher, the CPN and the social worker, all with an interest in Alan's wellbeing, facing a void of silence out of which came occasional messages. I had several questions I was burning to ask: Where was he, how did he manage, whom did he see, and why? How did he feel? Why did he disappear? If he wanted other people to do the fighting for him, why did he not contact David and Nicole, who were in the best position to help him? I found out later that he had gone to Fife to stay with a friend for a while. After he left his friend he had been sleeping rough when he could not find a bed in hostels for homeless.

In the interview, Nicole stressed the importance of service user control in their dealings with services, but she also expressed the distress and worry service providers may experience when their assistance is not being sought:

Nicole:

*You just say to yourself - you have to work out the level of responsibility
that a person can - say they have a certain amount of responsibility - so I'm
not going to panic myself. Except that I do know he has stood on the top of
Greenside Car Park and contemplated jumping off the side. No, no, no!
This man, if he is desperate, he knows where to come. We're not going to
see him. I had just this discussion last Friday: "well, are we going to go
chasing down, or are we not?" And we decided "no" - we would not.
(Taped interview February 1994)*

However, she had decided to leave Alan to get in touch with her. David agreed
with this view. Alan had vanished before, but had made contact with him again.
All he could do was wait until Alan himself chose to turn up and get in touch.
Meanwhile, he was investigating with Nicole how Alan could be housed in
suitable accommodation.

Communication about Alan

Neither the GUM health advisor nor the doctors or nurses who see Alan about
his medical condition knew about Alan's crisis around the time he became
homeless. Neither did they know about David's and Nicole's involvement. The
health advisor knows about Alan's contact with the hospice, but has no contact
with Nicole. David has never been contacted about Alan by the GUM. Alan was
once admitted to the City Hospital Infectious Diseases Unit via the Royal
Infirmary Accident and Emergency Department. David has good contacts here,
and the staff immediately contacted David who went to see Alan. Why does
David have no contact with the GUM department?
David:

I've not contacted Alan's hospital department. I'm not sure if Alan informs them that he sees me. But, you know, Alan is usually quite good about feeding back to me what is happening to him medically, and I've never felt, I mean, I've been in touch with his GP in the past, but I've never felt a great need to contact the hospital. (Taped interview February 1994).

Of all Alan's service providers, only David and Nicole liaised and communicate on a regular basis.

Nicole said about her co-operation with David:

We keep in informal contact and then from time to time three of us try to meet together to make sure things are going in tandem. We've worked out roughly which bits we are dealing with. The community support in going out to see Alan is David, and he does the psychological support bit. I mean. obviously I've got a role there, but the formal psychological support, and the monitoring of his drink problem and his mental health state, that's David. The formal role that I have is around the practical elements, housing, benefits and so on. On the other hand it does not quite work out like that because there are times when Alan may see me a lot more than he does David. A lot depends for Alan on what he is going to get out of it. So if the major issue of the day is housing, he's quite happy to come and see me on a weekly basis. If he is being quite elusive with David, which he frequently is, I would report back to David, and we just keep a weekly tab. So there's a lot of telephoning I suppose, and just (she breaks off) - there's a hot confidentiality issue here....(thinks aloud): Except there's not, because for Alan, he's aware that the two of us, the three of us, we are working together with him. (Taped interview, February 1994).

Whatever control over information Alan has lost in this intense communication between David and Nicole, they support him effectively. Alan turned up in spring 1994, and he is now rehoused. David and Nicole helped him get a SATA

flat. A SATA tenancy comes with a support worker, and Nicole withdrew when a SATA social worker began to see Alan. I went to see him in the autumn of 1994. He told me he was well supported and satisfied with his flat.

Alan came back to the hospital out-patient clinic and told them about his move. The health advisor has a chat to Alan every time he is in, but she has limited information about his life outside of hospital. When I spoke to her a few months after Alan had moved into his new flat, she did not know he is in a SATA flat and she still did not know about David.

There was, however, a lot she did 'know' about Alan and his situation. A while after he disappeared and before he turned up again, it was apparent that information about him had reached the GUM staff. During a brief visit to the Department in March 1994 I asked if Alan had been in. One of the clinic nurses said:

> *"Alan has not been in for ages. This is unusual. Rumours are that he has been kicked out of his flat and might be living rough? Not impossible in Alan's case." (Fieldnotes March 1994)*

The health visitor also knew about his difficulties by then. She also understood why he had not told her of them:

> *"Trouble is, he does not want people to know that he is in difficulties - is falling apart. Keeps up a front. He has been drinking heavily, apparently. What about his computer? Has he given it back to the Open University?" (Fieldnotes March 1994)*

Staff in the GUM are excluded from a lot of communication which goes on about Alan and his situation and are also shielded from many of the complexities of service provision for him. Unlike many patients using the City Hospital, Alan has some control over what the hospital department knows about him because his support workers outside the department do not communicate with

department staff. He is able to maintain a certain image, not the least because the health advisor lets him. The only information she acknowledges with Alan is what he chooses to tell her himself. However, it was thus not simply that the complexity was hidden and that GUM staff did not know about it. The complexity was there, for all to see, but it was rumoured rather than named and did not transform from 'gossip' to 'fact'.

This is also a feature of the way the management of drug users in the department is organised.

Visible but unnamed: The 'chaos' of drug users in GUM

I was often told by GUM staff, in particular by the two consultants, that the service users whom I was following were not representative of the group of patients seen in the GUM Department as a whole, and that I should make efforts to recruit different types of patients. At the time of the study there were 78 drug users with HIV being cared for in the GUM out of a total of 321 patients with HIV (Huby, Porter and Bury 1995). I was told that most of these were either no longer taking drugs, or their drug use was stabilised. However, for some (I was unable to establish the exact number), their drug use is seen to be a major issue as far as clinical management and general support is concerned. It was not a big number, perhaps between 10 and 20, but even this might be big enough to cause disruption in a comparatively small department which operated in one location. Dr McLeod, who sees most of the drug users cared for by the GUM Department, invited me to recruit some of 'his' patients. I tried to recruit some of them through Dr McLeod. I failed. I had to content myself with finding out about them through Dr McLeod. In this extract from an interview in June 1994 Dr McLeod talks about his tendency to protect others from the behaviour and aggression of some of the patients he is seeing. I realised then that I had failed to recruit any of them for the same reason that their behaviour did not impinge on service provision generally in the department. Dr McLeod was keeping these patients to himself and prevented other service providers from

formally discussing or challenging his management of them. We were discussing my difficulties in recruiting some of these patients to the study when he said: (The following are extracts from a taped interview with him in June 1994.)

Dr McLeod:(laughs)

> *Well - the drug users that come here are a pretty difficult bunch, as well (as the City IDU's patients). A lot of ex-users, and they tend to be pretty hot on the confidentiality side. .....let me see. Cameron is a good example, but he is now in Milestone, quite frail (although he's actually quite indestructible, and I will not rule him coming out again). I can think of one guy, who's just a psychopath, you don't want to know - not to come within a million miles of...there's another guy whose problems are just so - he's got a divorce case pending in the next month and is just far too worried about that to think about anything else, so he will be...There's actually one guy I saw today, who's notoriously unreliable, but he might be quite a good case, but he's paranoid about confidentiality. But certainly, I will see him in about a month, and I could ask him. I've got, I can think of a couple of ex drug users who are very paranoid about confidentiality - but certainly I'll have a think about it.*

He went on to tell me about some episodes of violence and to explain why he tends to end up as the main or only service contact for some of his patients. He was talking about one patient who has threatened GUM and other staff:

Dr McLeod:

> *Yes, he's pretty hard going, but he's not a psychopath....at least he's not been psychopathic towards me! But he was up when I was on holiday, and basically threatened people right, left and centre and he took - well, he is supposed to have taken people hostage with a knife....No, not here - in a shopping centre.*

Guro Huby:

What happened then?

Dr McLeod:

> *Well, he - well, I only ever get bits of the story. I never ever ask **them.** I get to hear because these people (other service providers) tell me: "and by the way - did you know that he was holding people hostage with a knife." I don't know what happened. I think he managed to get away.*

This is how Dr McLeod dealt with him:

Dr McLeod:

> *I ask him: "what do you want?" And he goes: "I want this" and I say: "There you go!" and all he usually wants is his valium. And he does not want any questions asked. The trouble is, if I'm not here, and somebody else sees him, they want to ask him a couple of questions, like: "what dose do you take?" (He answers:) "The case notes - can't you read the case notes, what chance have I got of getting good treatment from you!" I mean - that is the way he is. Which makes it all but impossible for anybody else to deal with him. The trouble is, I can't ease him off to anybody else, because he just bites their heads off. So he's very difficult. He has basically threatened, abused, just about everybody he has ever been in contact with - with the exception of me, and he's quite a highly strung character. A doctor who was here on exchange from the City said:" by City standards - he's worse than anything he's ever come across at the City". (Taped interview June 1994)*

According to Dr McLeod, attempts by him to involve other agencies in the care of 'his' patients are met with resistance or seen as inappropriate. I observed the following episode during one of my visits to the GUM out-patient clinics:

I was waiting in the GUM outpatient clinic to see if one of Dr McLeod's patients, a drug user, was willing to see me about the study. After a while Dr McLeod came out, but said that the patient was in crisis and it was not appropriate to ask him to speak to me. He turned to the psychologist, who was sitting in the clinic backroom with some nurses and myself, and asked her for advice. The patient was very depressed because of domestic problems - what was Dr McLeod to do? How did he get hold of the psychiatrist? After a brief discussion, Dr McLeod phoned the psychiatrist to make an appointment. No immediate appointment could be given. Dr McLeod looked worried as he went back to see the patient. (Fieldnotes, May 1994).

A few weeks later, during my interview with him, I asked Dr McLeod about this incident and what happened. Did he manage to link the patient up with the psychiatrist?

Dr McLeod:

Well, he went for a couple of appointments, and then failed to keep three, so the psychiatrist refused to have any more to do with him. Ah - he's just a really, really stressed guy - as I said - he's got this benefit tribunal coming up, and until he gets it out of the way and whatever the outcome is, nothing can be done with him. He just comes in and twitches and panics and agitates about the circumstances.

GH:

Right, but is there no other support where you can refer him on?

Dr McLeod:

He won't acknowledge that he is HIV positive, so it is practically impossible - it is impossible - to offer him any HIV linked support.

GH:

And is that the only support available?

Dr McLeod:

Well, clinical psychology and psychiatry would be my - I mean, he saw the clinical psychologist. Said he couldn't get on with her. And he saw the psychiatrist. But - I mean, he wants people to sort out his problems. He's got huge problems, and he comes along and says: "here is my problem - you solve it for me!" That's his attitude to support, you know - it's hopeless - I mean, I can't go into the tribunal and stand in the dock (for him), which is really what he wants us to do! He wants somebody to go along, put his side of the story, and he'll sort of watch from the sidelines. Then he'll either get a 'yes' or a 'no' and sentence will be passed or not passed - but he actually does not want to have anything to do with it. So he's a very difficult guy to do anything for, because he has completely unrealistic expectations of what can be achieved.

GH:

So you are landed with all this, then?

Dr McLeod:

Yes, he comes to see me every couple of weeks, and spends around 45 minutes going: "I don't know what to do - I don't know what to do!"

GH:

Does he have a GP?

Dr McLeod:

Yes, unfortunately, he's just moved, and his new GP sort of dipped his toes in the water and thought: "God - I don't know what the hell is going on here! "And basically, you know, doesn't have a clue!

Another problem is, he (the patient) is very selective about what he tells you. There is a lot more to the story. I mean, he comes along as Mr. Innocent: "I don't know what I've done - I don't understand how this has happened. I've always been a good person, you know"... and so on and so on. It is blindly obvious that there is more to it than that.

*But his fundamental problem is that he has this benefit tribunal that he wishes to get out of, (he has given inaccurate information about his circumstances). He totally flipped a couple of months ago, and I wrote that he was not fit to attend.. He wants me to do it again. I said to him: "look - there is never going to be a good time. This is just hanging over you. You can't move, because you don't know what is going to happen. And sure, you can postpone it for two months, but in two months you will be in the same boat, you'll be going: "Oh my god, I don't know what is going to happen." And you just can't go like that - you've got to move on. And from what you tell me - which is a selected part of the story - things are not as bad as you say. With a bit of luck you'll get off, and then you can get on with life, but until you know what is going to come out of this one you'll have no chance." So I think he's one of these guys who is in crisis at the moment, but if you can get him through this court case then there's a chance to say: "Now that's out of the way, let's plan for the future".
(Taped interview, June 1994).*

Although Dr McLeod sees the drug user patients himself, his relationship with some of his patients is known and there is a 'view' about these relationships. I observed the following incident in the GUM staff canteen:

One of Dr McLeod's patients, a drug user who is prescribed methadone (by the CDPS), had been admitted by him to hospital a few days after he got home from the hospice. The patient had diarrhoea. A junior doctor was going to clerk him in, and she had an informal discussion with a senior colleague in the canteen before she went over to the ward to see the patient. Dr McLeod was not present. The two doctors went through the case notes and looked at the patient's history. Other people joined in, both nurses and junior doctors. They all knew the patient. After some discussion they laughingly decided that the patient had managed to get an extra prescription for methadone from the hospice, in addition to the one given him by his GP when he got out. He had been taking more methadone than prescribed when he got home from the hospice and was now withdrawing because he was back on his 'normal' dose. They made a few jokes about the patient and Dr McLeod's lack of awareness of the way he was being manipulated. (Fieldnotes, September 1993).

The information which did circulate about for example Dr McLeod's management of his patients was not often formally discussed or made relevant to patient care. There was a tacit acknowledgement that he did not want it discussed and it was somehow not done to challenge him (he was a consultant).

I was discussing communication about patients in the department with Alan's health advisor. She said it did not really happen. Even with a new meeting to discuss patients with HIV being set up at the time, there was resistance. She was 'not going to name names', but some doctors just did not want others to know about their management of their patients. She did not know why. She put it down to lack of confidence or a wish or a need to protect status.

At the time, I assumed she was referring to Dr McLeod. Later, I realised that she might equally well have been referring to Dr Campbell, the other consultant in

charge of most of the HIV work in the Department. He was the senior of the two consultants.

Role of the Consultants

Mike and his consultant

Two people, one of my co-grantholders and the psychologist based at the City IDU, presented me with a theory about the different styles of communication and management between the GUM and the City IDU. This theory concerned the personalities of the two consultants who had taken a lead role in developing the departments' HIV work. They suggested that because of the central role of these two doctors in establishing patterns of interaction and practice, their personalities have an effect on the organisation of the departments overall.

I described in chapter two how the system of services which emerged around the City Hospital IDU was influenced by the style and personality of the consultant who had taken the lead in developing the Unit's AIDS services. This consultant is outgoing and exhibits his concern for his patients by becoming intensely involved. By contrast, the GUM consultant is more restrained. He keeps his distance and acts according to rules of procedure, for example in the way he operates the criteria for admission to in-patient wards. He is concerned with protecting patients' confidentiality and privacy. However, his behaviour can be misinterpreted as lack of interest, as the following examples illustrate:

The examples concern Mike, a long standing service user with the GUM who had become infected with HIV. A close friend of Mike, also HIV positive, had taken suddenly ill with a brain tumour and was deteriorating rapidly. Mike helped look after him and care for him, first in his home, then in Milestone, where he stayed until his death. Mike and I discussed the care the friend was getting. Mike asked:

What is the relationship between Milestone and Dr Campbell (the GUM consultant)? Do they communicate? Because Dr Campbell has not been to see my friend in Milestone. Do they know in the GUM that he (the friend) has gone in, and do they know how ill he is?

My friend is quite upset. That is why he went to the GUM, because Dr Campbell was a friend. Now, if it was me, and I knew one of my patients was dying, I would go and see him. (Interview September 1994)

Dr Campbell was, however, accommodating when nobody else was around to help. Mike's friend had told me on a previous occasion that he had once rung Dr Campbell late at night at his home when a friend of his who was visiting had taken suddenly ill. Dr Campbell had come out and seen to him. Mike's friend was appreciative of Dr Campbell's willingness to help.

Years later, Mike was himself very ill. He had been admitted to the City IDU because there was no bed for him in the Royal Infirmary. I found out about Mike's illness and hospital admission from Dr Campbell. I asked if I could go and see Mike. Dr Campbell advised against it:

> *"No, that would not be appropriate. He is really very ill isn't he?"*
> *(Turned to junior doctor standing behind him). "We do not really expect*
> *him to get out this time, do we?" (Fieldnotes May 1996).*

I made contact with Mike through a nurse I knew at the City IDU. She asked Mike if he wanted me to come. I went to see him. He was a lot better, he said, and he was expecting to get home in a week. He asked if I had seen Dr Campbell. He also asked me to tell the staff in the GUM that he would appreciate a visit, or, if they were too busy, a note or a greeting as a sign that they knew he was in hospital and kept informed of his progress.

The patterns of interaction which prevented information from being publicly acknowledged and owned was thus rooted in the behaviour and style of the

members of staff with most power, the two consultants. Other staff in the department found this problematic, and attempts were made to change the situation by instigating a meeting to broaden the discussion of management of patients with HIV to include more staff.

Challenging the power of the consultants? The GUM meeting

The model for such a meeting was provided by the City IDU, where some GUM staff had worked. A senior registrar took the initiative to start such a meeting. In a taped interview in Spring 1994 she told me why:

Senior registrar:

> *The way the clinic works, there are obviously two consultants who see HIV patients and they see HIV patients in a different way.........- so it often meant, that because I never do a clinic - John (Dr McLeod) - I didn't really know what was going on with his patients and he does tend to see all of them himself. But also as far as Stuart (Dr Campbell) he tends, maybe one or two doctors try and see each patient rather than be seen by general crowd. Obviously it varies quite a lot but particularly when people are less well they do tend to see one person most of the time. And we felt that it was important from the point of view of people being away or on holiday or whatever, that we all had a general overview of patients, particularly if they are becoming unwell and might need to go into hospital, it was important that we all knew what it was about....... And then while (I was) at the City it became apparent that they were doing that on a regular basis and it was very useful indeed -*

I think we felt that perhaps that......there should have been more of us who knew the out-patients. It can become incredibly stressful (when patients are) deteriorating rapidly, getting more and more anxious about their health.........some patients, if they could, I think would spend their life up here. Very stressful (for the doctor who sees them). It would help if you can get someone else to see your patient. From the patient's point of view as well, it's quite good to have somebody else just to tell them what has been happening.

We found also between consultants to discuss management, how we would, you know - a lot of out-patients have become HIV attitude positive....HIV attitude positive - it means that the virus is replicating more actively and that perhaps you should be thinking about if they're on AZT already, introducing another agent such as DDRs to try and prevent the virus from replicating so rapidly because some of these patients will get symptoms just from that fact alone - they can get diarrhoea and night sweats... It's a good forum in which to say, "Look this is what's happening and this hasn't happened before, should we have a policy decision about this, should we be saying to all of these patients, this is the situation, these are the options...." So it's been good from that point of view to have the kind of group discussion whereas before it might have been casual discussion in a meeting about something else that that would be brought up. (Taped interview April 1994)

It was perhaps not without significance that the initiative for the meeting came from a senior registrar. Junior staff were excluded from patient care by the consultants, who 'kept patients to themselves'. The senior registrar was young, bright and ambitious. She clearly saw scope for change and improvement in the way communication was organised. As next-in-line to the consultants, she was also making a role for herself in the department.

The inclusion of staff other than doctors in the discussions was, however, another matter of contest. I asked the senior registrar how much was discussed in these meetings about psycho-social support?

Senior registrar:

> *Well, I'd like to say 50/50 but it's not quite as much as that. The majority of the time we talk about clinical problems, but certainly it's felt important that psychologists and the nursing staff are also there because a lot of patients will talk to them on the emotional personal point of view and a lot of that information is, in fact, very useful if you're seeing a patient every three weeks always coming up with different problems doesn't quite fit together and then find out that in fact he's got a big problem with his relationship. It's very useful that you have all the information together and certain patients you realise there is more going on than you suspected from the clinical point of view. (Taped interview April 1994)*

When I discussed the meeting with Alan's health advisor, however, she did not share the senior registrar's view about the inclusion of information and issues other than clinical management. She felt she was not really wanted in the meeting. She would be given very short notice to attend. The message she got was 'you can come if you like, but we don't really need you'.

Some things are 'seen' and given name and reality while some things remain in shadow and invisible, although there right in front of us. What was made visible in the settings I studied determined both practice and perspectives in service provision. The mechanisms by which certain features of behaviour and character were made to stand out and others recede were clearly rooted in the way interaction and communication among service providers and between service providers and users had evolved in the GUM and the City IDU, and the behaviour of the most powerful people, namely the consultants, structured this communication differently in the two settings.

Themes of shifting patterns of visibility and light, silence and darkness in changing institutional contexts are central in Foucault's work on power and discourse in clinical settings. From the start, my material has suggested his masterly analysis of the power of the medical 'gaze' in Birth of the Clinic (Foucault 1972) and the ethnography has been informed by this work. Reading Birth of the Clinic and considering Foucault's theory however raises a number of issues around the individual's response to and role in the production of discourse which then defines what she 'knows' of self and others. What follows is a brief outline of Birth of the Clinic and others' critique of Foucault which raise a problematic of agency and resistance. This problematic is then addressed in the last section.

The workings of power - a short discussion of Foucault

Particularly since Foucault (1982) 'power' is no longer seen as invested in institutions superimposed on social relationships, but part of the social nexus and inherent as **a potential** in all relationships. The dynamics of 'power' is what transforms unstructured language into socially effective discourse of discipline and control (Turner 1994). Discourse constitutes the world and its 'truths'. It creates objects, identities and events and also the significance and sentiments which attach to these (Foucault 1981).

In Birth of the Clinic Foucault takes us back to 18th century France and analyses the 'mutation of medical discourse' which took place during that period as the result of a restructuring of medical institutions. This restructuring happened on several levels. There were political changes: the need for state control over increasing populations, and, as an instrument of such control, the medical profession had to be controlled and incorporated through training, accreditation, and employment. There was increased use by local and national government of doctors as officers of public health. There were also moves towards state ownership of hospitals. These political/organisational changes produced the 'Clinic' as a special unit attached to hospitals where selected 'cases' were made

the object of teaching and observation. These changes coincided with changes in the language and theory of philosophy and science. However, the real point of mutation is found beyond the 'thematic content' and 'the logic modalities' of the changes. In Foucault's inimitable style we have to:

> Place ourselves....at the level of the fundamental spatialisation and verbalisation of the pathological, where the loquacious gaze with which the doctor observes the poisonous heart of things is born and communes with itself'

> (1972 Preface p. xi and xii)

The way language organises experience was changed, because the space where 'things' become 'words' was 'carved up' and named in new ways.

The restructuring was accomplished by eye as the privileged sensory instrument
What is said is what is seen.

The 'new' medicine came to rest on the notion of **the case** and later, **on the individual.** Disease was a unique constellation of symptoms and variables **in an individual.** The doctor's task was to train the eye to isolate and name these variables, to estimate their probable interaction and hence the likely course of the disease. Because the doctor was looking at an individual as a unique case, the doctor-patient relationship became central and the doctor's 'gaze' made the person stand out as unique. The patient became the 'object' of the doctor's gaze, and at the same time became 'subject' of his own knowledge. With the birth of the 'Clinic' was born the 'Individual':

> That opening up of the concrete individual, for the first time in Western history, to the language of rationality, that major event in the relationship of man to himself and of language to things....

> (1972 preface, p xiv).

'The individual' - subject or object?
The 'old' (pre-18th century) mode of medical knowledge was a 'closed' system where 'truth' was an absolute given for man to discover. With the Birth of the

Clinic, man's quest for knowledge of himself tore loose from absolutes, be they God's, nature's or man's. It became open-ended and endless, for in nature the possible constellations of factors and variables that shape 'man' as being are infinite. The vista which opened up to 'the gaze' was endless.

Foucault's project concerned the 'archaeology' of discourses which reveals the dynamics by which they unfold. These dynamics are rooted in history, not in static natural 'givens' such as man's biology or innate characteristics of language. They are, furthermore, modulated by 'power' as a productive force of discourse. At the heart of this 'archaeology' is the way discourse produces 'man' as both object and as subject of his own knowledge (Foucault 1982). The term 'subject' of his own knowledge is, however, ambiguous. 'Subjectivity' implies both submission to history and individuals' critical awareness of its course. While the tension in this ambiguity might have potential for understanding how we as individuals relate to structural contingencies of our own self-awareness, Foucault's critics are not satisfied that he takes this ambiguity anywhere other than a mystification of his own position.

According to Best and Kellner (1991), Foucault's position on 'the subject's' status as a reflective agent of her own history changed throughout the history of his intellectual production. Fardon (1985b) suggests that in his early work, notably The Order of Things (Foucault 1973) he concentrated on theories of the archaeology of knowledge and analysed the dominant epistemes which developed at various stages of European history. In this work he convincingly analyses the Birth of Man as a knowing and knowable being, only to proclaim his Death and dethronement, his subjectivity deconstructed into nothing but a product of language, desire and the unconscious - 'an epiphenomenon of prepersonal forces' (Best and Kellner 1991, p. 42). In his later works, he was more interested in the language of conflict and power and in the micropolitics of control as this was articulated in specific institutions (Fardon 1985b). Birth of the Clinic is one example. In these later works he collapsed 'power' and 'knowledge' and, according to Fardon, the discontinuities of epistemes and discourses were replaced by the continuities of power as a mystical force that

makes knowledge effective as truth. 'A regime of truth' emerges, wherein the agent is dissolved because the truth is out there, to be adopted wholesale by the subject. Foucault's later work on 'the self' can be read as an attempt to resurrect the individual as agent with the power to define his own identity within structural and discursive constraints (Best and Kellner 1991). However, according to Turner (1994), the emphasis in this work was on structural and discursive constraints, with individuals' reactions to these little more than mechanic reactions.

Foucault's refusal to come down on either side of the 'subject/object' divide has thus provoked his critics (e.g. Fardon 1985b, Turner 1985 and Turner 1994) but also inspired his supporters (e.g. Rabinow and Dreyfuss 1982). Dreyfuss and Rabinow claim that he offers ways out of theoretical impasses which evolve out of a Kantian 'subject/object dichotomy, for example the imponderables of relationships between individual/society, structure/agency, structure/meaning. They suggest that Foucault takes us beyond these dichotomies by showing us **why and how** they have become so important to the way we think about ourselves:

> Our culture attempts to normalize individuals through increasingly rationalized means, by turning them into meaningful subjects and docile objects.
>
> (Rabinow and Dreyfus, introduction, p. xxiii)

The problem lies for many of his critics in Foucault's failure to reveal his own subjectivity. According to Fardon (1985b): For Foucault

> Power relations are thus both anonymous and intentional, non-subjective and strategic. The 'gaze' which makes these dynamics visible is that of the analyst, whose agency is not questioned, whose dissolution is not contemplated.
>
> (Fardon 1985b p. 145).

and above all, whose 'gaze' is itself not scrutinised. Best and Kellner (1991) argue that because Foucault fails to proclaim his own agency, he does not adequately theorise the relationship between the structural and the personal in individuals' definitions of themselves and their identity.

The question of subjectivity is also one of authorship of history. If 'what is seen is what is said', who 'sees' and who speaks/writes? - to whom does the 'gaze' and the pen belong, and through what history is his/her subjectivity constructed?

Whose 'gaze'?

Foucault writes in, Birth of the Clinic, that we can only develop our understanding of ourselves through language and discourse developed historically. We are thus dependent on the intellectual work of our predecessors and the transformations they have effected in the cultural tools at our disposal for understanding and perceiving ourselves. If discourse is driven by dynamics of power, then is the analyst him/herself not caught in these dynamics? And how does this condition the eyes which see and that which is seen?

Turner (1994) presents a polemic against what he claims as Foucault's construction of the a-political and critically unaware subject, reacting to power by mechanical and individual acts of deviance rather than through creative acts of collective and political resistance. He places Foucault's work among the French thinkers claiming a 'poststructuralist' perspective. He suggests that their work must be read in the context of French intellectuals' and academics' frustration with their lack of influence in France's political arena and particularly their position after 1968. 'Structuralism' took firm hold of French academic imagination from the 1960's, as it provided a politically safe and uncontested alternative to Marxist structuralism and Sartre's individualism - both having failed to provide theoretical answers and political tools in the political reality of post 2nd World War France. 1968 came as a shock to French intellectual leaders, e.g. Levi-Strauss and Foucault, whose theories did not provide explanations as to how an uprising of such a social scale could happen at all, and who personally failed to fully grasp that the uprising was in large measure directed against them and their entrenched privileged position in the French intellectual and academic

bureaucratic hierarchy. The uprising was also against theories which operate on the apolitical and hence safe terrain of the Saussurian *langue* and fail to legitimise alternative expression and activity on the level of *parole*. Hence 'Prenez la parole!' as a slogan scribbled over Quartier Latin walls during the protests. The failure of the uprising to produce political/structural changes in the French political establishment only served to confirm structuralism as the only viable paradigm for an intellectual elite with no political influence and

> Reinforce the dismal calculus of political futility which had provided the main condition for the rise of structuralism in the first place.

> (Turner 1994 p. 34).

It was thus clear, Turner says, that after 1968 the theorist would come up trumps who could incorporate the activist, intensely personal, affective and eroticised expression on the level of 'parole' of the *soixant-huitards* into the safe, apolitical framework of linguistic structures (la langue).

> To continue to be structuralist at the level of general assumption, while appearing to be anti-structuralist on specific points. This comes to more or less the same thing as integrating matter with anti-matter; but, as events were to prove, what is impossible in physics may be achieved in the hyper-reality of French Social Philosophy.

> (Turner 1994 p 35).

According to Turner, to accomplish this feat, Foucault constructed 'power' as an abstract, mystical force, *mana* which permeates and constitutes social relationships. This abstraction of 'power' makes Foucault's work impossible to critique. Attempts to make him come down on a more specific definition and use have failed, e.g. his article *On Power and the Subject* in Dreyfus and Rabinow (1982). Here, Foucault writes that throughout his work he has been interested in how 'the subject' is constituted by the various discourses which have developed historically through changes in European institutions of control. He claims to be only indirectly interested in power, but in this article he tries to be explicit about his use of the term. Power is not inherent in institutions superimposed on social relationships; it is rooted in the social nexus. Situations where power comes into being are, in this article, situations of conflict.

> At the heart of power relations and as a permanent condition of their existence there is an insubordination and a certain essential obstinacy on the part of the principles of freedom. There is no relationship of power without the means of escape or possible flight.
>
> (Foucault 1992, p225).

However, this brings us closer to neither 'power' nor 'the subject' as it is not the 'subject' as reflective agent which escapes or reacts to 'power', but 'the principles of freedom'. Turner calls Foucault's use of the term 'power' a 'rhetorical trope' which allows him to brush off critiques of his work as 'the self-deluded operation of power in discourse', whereas he, Foucault, provides the only analysis not so deluded.

As I discussed in the introduction, 'power' can be seen and analysed as a 'different thing' to different people. Unless part of the language and perceptions of people studied, power cannot therefore be used to explain their actions. Foucault's critics have pointed out that although his studies of institutional arrangements whereby discourse is constructed are detailed, and therefore convincing, his analyses draw on historical texts, not on contemporary ethnographies of how people in daily interaction contend with discourse and its effects. Turner (1985) goes so far as to say that his analyses are methodologically flawed, because he does not use data on non-discursive practices, but uses literature, and uses it selectively to choose texts which support his theories. Turner (1994) suggests that because Foucault fails to root his use of key terms such as 'power' and 'discourse' in specific social/political contexts, he fails to give his subjects of research life, critical awareness, the possibility of self-authorship and agency of change.

This critique of Foucault has implications for ethnographic writing and raises issues around the way 'objects' of research are represented as 'subjects' of their own histories. On this note, I return to my ethnography. The next chapter presents two service users, one drug user and the other a gay man, caught up in the dynamics of the City Hospital IDU and GUM respectively. I describe ways in which they deal with the very different roles set up for them as service users and

try to address the question: Are they masters or victims of their own histories? Or, to add to Dreyfus and Rabinow (1982, introduction p xxiii) are they 'docile objects and meaningful subjects'- or reflective agents?

SECTION 3

AGENCY AND RESISTANCE

Chapter 7: About control, manipulation and marginality:

two stories about resistance to power and the GPs role in HIV management

The margins as a structural and analytical position

In this chapter I move the discussion of 'power' on to a consideration of 'agency' and 'resistance'. I continue the comparison between the City Hospital IDU and the Royal Infirmary GUM. I present stories I collected about two different service users with apparently contrasting lifestyles and circumstances. They were involved in the very different forms of organisation of services in the City IDU and the Royal Infirmary GUM respectively. I contrast and compare the way in which their public characters were defined by the systems of relationships in which they operated, how they reacted to these definitions and defined themselves within the settings concerned. I also discuss the ways in which they presented themselves to me.

The two persons concerned conformed more than anybody among my service user participants to the stereotypes of 'chaotic drug user' and 'articulate and organised gay man'. They were also the service users who came to be most special to me and my relationship to them has been the object of much reflection and thought on my part. In conclusion, I address the question of an ethnographer's authority to make statements about ways in which subjects of research 'really' perceive themselves.

Because they were so different and because they conformed so closely to the stereotypes of a 'gay man' and 'drug user' they are useful analytically. They are good to think with. My description and comparison of them is based on a case study approach, described by Mitchell (1983) as comparison between one or more cases or events for the purpose of theoretical, rather than statistical

generalisation. As Mitchell also points out, this approach is a basis for ethnographic research, and all monographs are in an important sense, case studies. The strength of the approach is the analytical and theoretical potential of in-depth knowledge of a small number of cases. Because I knew the two individuals for such long periods (approximately three years) and knew them in a variety of situations, my description is akin to an 'extended case study' which Gluckman writes:

> ...deals with a sequence of events sometimes over quite a long period, where the same actors are involved in a series of situations where their structural positions must continually be re-specified and the flow of actors through different social positions be specified.

> <div align="right">(Gluckman 1961, quoted in Mitchell 1983, p 194)</div>

I concluded the previous chapter by suggesting that Foucault is problematic when considering agency and resistance to power, and the difficulty lies in the lack of clarity in the distinction between 'object' and 'subjects' of discourse. Agency involves reflection and comment on own subjectivity (Fardon 1985b). Because Foucault does not adequately account for his own lived subjectivity, his analysis of resistance excludes agency and limits itself to automatic reactions to power as domination. In this chapter I attempt to address this problematic.

Following Tsing (1994) I choose 'the margins' as a site from where to do so. In her definition 'margins' are

> An analytical placement that makes evident both the constraining, oppressive quality of cultural exclusion, and the creative potential of rearticulating, enlivening, and rearranging the very social categories that peripheralise a group's existence.

> <div align="right">(Tsing 1994 p279)</div>

Margins are a site from where the 'instability of social categories' such as 'manipulative drug user' and 'gay men in control' becomes visible. However, for Tsing, this analytical placement refers to academic, as well as 'native' discourse. She imagines a conversation between Foucault and Gramsci. Gramsci 'assumes too much' about individuals' awareness of political interest and the potential of

this awareness for social transformation through resistance. Foucault, on the other hand,

> In showing the convention-laden assumptions behind resistance obscures the suspense that infects the possibility of change.

<div align="right">(Tsing 1994 p279)</div>

I try and grasp this suspense by focusing on the way a theoretical distinction between the 'subject' and 'object' of power and discourse translates in the analysis of detailed ethnographic data. I see this focus as a key to understanding and writing about objects of research as agents of their own history.

In so doing, I also discuss the two service user study participants' relationships to their general practitioners. This is appropriate to the analytical and theoretical concerns of the chapter, for as I will go on to describe, the GPs were in both cases marginal to the main activity of service provision and its co-ordination. This gives me the opportunity to compare the marginality of the GP to that of the ethnographer and to comment on the task of description and analysis compared to action. Discussing the role of the GPs also allows me to address the main initial topic of our project, namely the role of the GP in HIV care, with the benefit of the analytical and theoretical work which I have undertaken since the project's inception. The assumptions around the GPs role with which we set out, together with their sources, have been described (chapter two). I will briefly recap our initial position and outline some of the process through which we came to change and deepen our understanding of the GPs role.

GPs and HIV

The apparent lack of general practitioner involvement in care for people with HIV in Lothian was a major focus of interest for the study from the beginning. The perception of lack of involvement derived from the literature on GPs and was found also among various Lothian care professionals involved in HIV care (Huby, van Teijlingen, Porter and Bury 1993). With the discharge study the role of the GP became a topic of fascination and mystery. Figures from the discharge

study suggested that the GP was an important service provider: the GP was the service contacted by the largest number of people after they left hospital-probably because of their involvement in prescribing substitute drugs to drug users. The findings also suggested that the GP had very little contact with other service providers. GPs appeared to see people, but in isolation (Huby, van Teijlingen, Porter and Bury 1994). The material collected during the longitudinal study confirmed the finding from the discharge study that care is hospital centered. Most of the communication about the people with HIV whom I met happened in hospital-centered networks of care workers. GPs in particular were peripheral to most of what was going on. I described in the previous chapter how my attempts to recruit people who did not use hospital services failed. Try as I might to locate my research activity 'in the community', I was pulled back as by force of gravity to the hospital-centered network of care workers, particularly to the City Hospital IDU.

Although GPs were not actively involved in the organisation of care for people with HIV whom we were studying, they clearly were involved in their care. However, the nature of their contribution only became clearer some way into the longitudinal follow-up. The strength of the ethnographic method is the attention to detail and context in a study of interactions among and between service users, GPs and other service providers, together with discussions with people as to how they perceive these relationships and the outcome of specific interactions. This method gives insight into the nature of GPs' contribution to HIV care in ways which the more traditional survey methods discussed in chapter two cannot do.

A theme which recurred during our study was some people's appreciation of their GP, and the GPs' perception that they 'did nothing for' their patients with HIV. On closer examination, it seemed that the GPs' exclusion from the constant exchange of information was of value in that (s)he was experienced as less controlling. Also, GPs were not the arbiters of life and death that the consultants were. Diagnosis of AIDS and other information about disease progression is given by the consultant, and consultants, not GPs, are the potential source of a

cure. People's relationship to their GPs were less tense than their relationship to the consultant in particular. Issues of control such as control of the disease or control of patient behaviour were less important.

My discovery of the potential value in GPs' exclusion from hospital-centered networks of care was accidental. In conversations with doctors (consultants and GPs) I would, where this seemed justified, throw in a comment that 'NN seems very happy with your treatment of him/her'. I intended this as nothing more than an ice breaker, to show that I was genuinely concerned with valuing good service provision rather than out to finding faults. I was, however, struck by the difference in response between a consultant and two GPs. In the consultant this comment triggered off an outburst of frustration about how difficult a particular patient was - how he misused the consultant's time and resources, but how the doctor nevertheless tried to accommodate the patient, who was dying. Two service user participants were the patients of the GPs, and they also presented complex issues of management. Both service users had expressed heartfelt appreciation of their GPs, and one of them also expressed real affection. In these GPs, however, my comment elicited a shrug of the shoulders:

> I don't know why - I don't do much for her or Yes, I know, but I can't think
> why. Apart from writing prescriptions and giving the usual platitudes I
> don't do much. (Interviews March and October 1994)

My subsequent data collection and analysis provided the opportunity to look more closely at the relationships service user participants had to their GPs. This material suggests arrangements which are outside the range of common discourse around the role of GPs in HIV care because they are not 'seen' in the same way that the complexity of their patients' lives remained a blind spot to the GUM staff. In the description of episodes from two people's history of service use I will suggest that it is precisely in the GPs' marginal position in the hospital-centred system of services that the potential value of his/her contribution lies because this can allow individuals space away from the controls and complexities of hospital-centered provision. In this respect, the GPs' role is

similar to that of the ethnographer, although the implications of the role are different for the two because the GP is concerned with practice and action, the ethnographer with reflection and analysis.

The description to follow continues and expands the dichotomy of 'manipulation' versus 'control' and 'self reliance' from which much experience and interpretation of events and characters in the service settings studied revolves and in terms of which the two individuals to be described here were defined and predicted. I will argue that for both, the creation of social spaces where those dichotomies lost their grip and rigidity was an essential part of the way they managed their identities. Both the GP and the ethnographer, by virtue of their marginality, helped create such a space.

Control or manipulation? Rhona's and Mike's stories

One of the two service users is Rhona, a drug user and unemployed. She died in spring 1995. She was a strong character and 'larger than life' in the way she lived out the stereotypical behaviour of a 'drug user'. This included traits such as a tendency to violence for which Scott, her partner, was often the target. Most of all, however, she was described by others and often described herself, as being 'manipulative' particularly in the way she tried to obtain more drugs than prescribed. She has appeared in chapter 4 where the question was raised concerning the difference between on the one hand, 'self reliance' and, on the other, 'manipulation' of the welfare benefit system. This description attempts a closer examination of her 'self reliance' and 'manipulative' behaviour and its context in the set up of services she had organised for herself around the City Hospital IDU.

The other is Mike, a gay man, who is a barrister, not on substitute drugs. He is seen by all, including myself, as remarkably in control and self reliant. He gets what he wants without manipulating services. I try and describe how he

achieves this control within the set up of support he has established and which includes the GUM Department.

Rhona

There are many stories in circulation about Rhona. This story tells of the time in late 1993 when she went into hospital to reduce her methadone intake from 150 to 110 mls per day, although she really wanted her prescription for methadone increased.

Rhona had organised a complex system of support for herself. She sporadically saw a consultant, Dr Don Green, either in out-patient clinics or when she was admitted to hospital, something which was happening every two or three months at the time of the incident described here. She also saw a CAST worker, Paul. At the heart of this story about Rhona is some unclarity as to who at the time decided on the amount of drugs to substitute heroin she was to be prescribed. Initially, her consultant used to decide on her methadone and benzodiazepine prescriptions, but early in 1992 she went to the Community Drug Problem Service (CDPS) in order to have her drug prescriptions stabilised here. She saw a CDPS counsellor, Kate. The CDPS took over the responsibility of deciding her regular dose of substitute drugs and informing her GP, Dr Peters, who provided her with regular, routine prescriptions for her substitute drugs. He also treated her minor and non-HIV related complaints. Before I tell the story of the drug reduction, I give a brief description of Rhona's service providers.

Rhona's service providers
The consultant, Dr Green
Rhona had a complex relationship to Dr Green, her consultant. In Rhona's description, the relationship was profoundly influenced by an incident which took place early 1992. Rhona was in hospital with a chest infection and,

according to her, Dr Green had told her 'she had six months left to live unless she changed her lifestyle'. Around this time, Scott, Rhona's partner, was also in hospital, in a coma after he was assaulted by two men who came to the house one night and attacked him with knives and broken bottles. Their child, who had been in the house when Scott was assaulted, was taken into care. Scott was not expected to recover. Under the circumstances, Rhona saw herself forced to give her sister custody rights over the child.

Both she and Scott subsequently recovered and regretted Rhona's decision. This was a continuous point of tension and conflict between them. Scott accused Rhona of being a poor mother for giving away the child to 'her cow of a sister'. They also found themselves involved in protracted dealings with the Social Work Department over care orders for and their access to their child. This involved accusations against them of neglect in the period before Rhona's episode of illness and the assault on Scott. She thought herself the victim of an authority (The Social Work Department) with whom she had no opportunity to argue or reason. She felt she was doing her best, and succeeding, in being a responsible parent while their access was being negotiated. In her view, however, the social workers were 'two faced'. They would say how well she was doing to her face only to go on and write damning reports about her continued lack of abilities as a mother. In her view, this judgement of her was based on inaccurate information. (She let me read the reports and I was able to verify their lack of accuracy of details. I was not present when she spoke to the social workers and was unable to verify her view that they were 'two faced'). The child custody case had repercussions for her and her partner for two years. With the help of Paul, her CAST worker, and Kate, her CDPS worker, their access to their child was largely resolved.

Rhona often associated her difficulties over the social work department's care order on her child with Dr Green's inaccurate assessment of her chances of survival. She also resented his authority and what she saw as his arrogance and found him intolerable when 'he got on his high horse'. She enjoyed telling me about the times she brought him down. Once, according to her, she threw an

ashtray at him in front of a group of medical students during a wardround. She was smoking (according to a negotiated settlement between her and the ward staff) when he entered with the students and said to them:

> "Here we are - we spend thousands of pounds treating these people, and what are they doing? They go on smoking."

According to her, the exchange continued as follows:

> *Rhona: "Excuse me, Dr Green, you have told me to smoke one cigarette every two hours. It is down in my notes."*

> *Dr Green : "I have told you no such thing. There is no point treating you if you keep on smoking."*

> *Rhona: "Excuse me, Dr Green, I will not stop smoking. I enjoy it - and what do you enjoy, Dr Green? Flying off to America to find out if the virus was brought by a green monkey? It wasn't brought by no fucking green monkey - you know that! It was probably two homosexuals or perhaps a prostitute being gangbanged and everybody spreading it around from that."*
> *(Interview October 1993)*

Dr Green denies that Rhona has ever been violent or abusive to him, and I have been unable to verify this story. Regardless of whether she articulated herself to him in this way, however, she had clearly reflected on the economic cost and social value of their respective behaviours.

Dr Green was, nevertheless, clearly special to her. In October 1993 she had visited the out-patient department. She had asked for an appointment with a clinical assistant, rather than with Dr Green because

He chooses the moment I am at my weakest to pick on me. (Interview October 1993)

According to Rhona, this had started with the incident with the ashtray. The reception staff had laughed - they knew the situation. She told of how she was sitting there expecting to see a clinical assistant when Dr Green walked in, and everybody asks: 'Who is Dr Green seeing? (Many patients want to see him, because he is an authority on HIV management, but he is increasingly busy and has to delegate clinical management to other staff). 'I don't know' Rhona had replied. He wanted to see her. She was clearly honoured.

Dr Green talked to me about his relationship with Rhona:
Dr Green:

> *I have known Rhona for a very long time, although my perception is that latterly I have less to do with her. My perception is that is her choice. And I don't know whether that is because she's more worried about what I'm going to tell her in terms of her medical condition or whether most of the distancing that occurred was because I was better at fixing her drug habit - that is controlling what was going on with her drugs than other people - and she therefore decided to take herself off to see other people, for example CDPS. Because I used to prescribe for her and we had lots of fall outs...because she was successfully fixing the system.*

> *So a lot of our relationship is about control. Our relationship is difficult - although I was the one who told her she had AIDS* (this is a crucial point in the illness careers of many with HIV as it suggests the beginning of the end). *It's a bit like a father-daughter relationship - she does not want me to know what is going on, but when the chips are down, she'll come to me. (Taped interview August 1994)*

One such 'fall out' happened in 1990 when Rhona went to a different hospital for maternity care and obtained prescriptions for drugs from here while she kept

her prescription from Dr Green. Rhona and her partner collected methadone on two prescriptions. When Dr Green realised this, he threatened her with the drug squad and he thinks this is one reason why she went to the CDPS for her drugs.

Paul, the CAST worker.

Paul from CAST had been seeing Rhona from late 1991. She was referred to CAST by the Infectious Diseases Unit ward nursing staff, who found Rhona's behaviour difficult to handle, particularly because she would continue quarrels or feuds with other patients when she was in hospital. The care order and access negotiations over Rhona's and her partner's child put a strain on Paul's relationship with Rhona, as she associated him with the Social Work Department's treatment of her. Paul, on his part, attended case conferences and meetings and tried to put Rhona's and her partner's views across. His involvement with Rhona at that time demanded exceptional diplomatic skills, as Rhona disagreed with her partner over whether or not they were to ask for full custody of the child. Rhona felt too ill to care for the child full time, while Scott wanted him back. Paul was thus not only caught in a dispute between Rhona and the Social Work Department, but also between Rhona and Scott and this dispute often escalated into physical fights in Paul's presence. The relationship nevertheless survived the traumas of the care order case, and Paul continued to see Rhona regularly. During the period of conflict he also encouraged Rhona's contact with the CDPS worker Kate.

Kate, Rhona's CDPS worker

Rhona, in an interview in February 1994 told me she had come to the CDPS so that she and everybody else could be clear about who made decisions as far as her prescriptions were concerned:

Rhona:

I was hitting doctors for drugs, and I was struck off, so I says: "Look, I'm going to get this in perspective ...I don't know who's giving me what. I don't know if it's the GP or the CDPS giving me my prescriptions. I'm going with the CDPS." (Taped interview February 1994)

Rhona was referred to the CDPS by her GP at the time. Paul also encouraged Kate to get involved. Kate described to me in July 1994 how she became involved in Rhona's support:

Kate:

I have been involved with Rhona as a counsellor since early 1992. Paul, her CAST worker, asked me to get involved because the relationship between him and Rhona was strained. She saw him as associated with the Social Work Department's treatment of them regarding their child. Paul wanted somebody to see Rhona even if he didn't. Rhona phoned also.

I saw Rhona regularly to begin with. She came to the Methadone clinic, she was assessed, and went through the programme. But after that, she never came to clinic appointments. It is possible that she came to the CDPS in order to get more drugs. She would get nowhere with Dr Green - he would not give her any increases.

I was seeing her for about a year. Dr Green withdrew from the methadone prescribing, because Rhona was with the CDPS. Then I started withdrawing a bit from the case. Paul's relationship with Rhona was 'repaired' and Dr Green was beginning to take over the methadone prescribing. He communicated very well with Rhona's GP, and I was left out of this communication a bit. CDPS has no direct access to the hospital, as I found out when I was filling in for Paul one time and tried to get Rhona into hospital. I got nowhere - in the end I phoned Rhona's GP who got her in with only a phone call - no bother. (Interview July 1994)

Dr Peters, Rhona's GP

Dr Peters did not find Rhona's drug taking or behaviour a problem.

Dr Peters:

> *One of the reasons why she is still with us is that we have a policy with*
> *people like Rhona, that only one doctor sees her.... I suppose like you, I get*
> *on with Rhona quite well - I like seeing her. It is fairly straight forward.....*
> *I see her about her prescriptions. She does not mess me about too much over*
> *that - there has been one or two incidents....We have no problems with*
> *Rhona's methadone. She does not try to cheat us - not like some people who*
> *come in with an endless stream of excuses why they need more or earlier*
> *methadone. We know she is topping up with stuff she buys, but that does*
> *not bother us too much. The few times where she has cheated, she is open*
> *about it when confronted - we don't make too much fuss about that.*
>
> *Rhona's methadone does not worry me - not with her prospects. This is not*
> *the main issue a the moment. The accepted wisdom is to see patients on*
> *methadone every month or two weeks to discuss the dose, but in Rhona's*
> *case, this does not seem much use.*
>
> *She is fairly good with appointments - people in her situation sometimes*
> *have difficulties in that respect. She has missed two or three ..(checks*
> *notes)..no - seven appointments in the last few months. That is not bad.*
> *She does not cause a lot of aggro - does not shout and abuse. (Taped*
> *interview October 1994)*

Rhona also saw her GP about other matters than her substitute drug
prescriptions. Her relationship to the practice was not uncomplicated, however.
She had attacked a receptionist once. Unluckily, it was Scott's receptionist, and
he was struck off. On another occasion she had called the doctor out because she
had a chest infection and a fever. She was visited by a doctor who did not know
her. According to Rhona, the doctor told her to pull herself together and gave
her some aspirin to control the fever. I did not ask this particular doctor of his
perception of what happened, but established that no other action was taken.

Paul visited her later in the day and found her very unwell. He told me he phoned the hospital and took her up in his car. According to Paul, she was admitted and found to have PCP pneumonia.

Rhona, often erroneously, saw Dr Peters as somebody who protected her from the hospital. For example, in September 1993 she had avoided hospital admission for a chest problem when, in fact, Dr Green had arranged for a community nurse to come to her home and give her nebuliser treatment. He also wrote to Rhona's GP and informed him of the arrangements. When Rhona spoke to me about the incident, however, she credited her GP, who, she said, had spoken words to the effect that:

> *"If you go into hospital, they would cut down your diazepam, your hash, your fags, and for what? To make you better so that you can die."*
> *(Fieldnotes September 1993)*

The Drug Reduction
Background to the drug reduction
Up until spring 1994 Rhona was on a daily prescription of 110 mls of methadone a day, but she felt she needed at least 150 mls. She had tried to get her prescription increased, but did not succeed, so she bought extra. She was quite open about this.

At the time of the drug reduction described here, there appeared to be some lack of clarity over where the final responsibility for Rhona's prescribing really lay, whether with the CDPS or her consultant. In a taped interview Rhona told me:

Rhona

> *I don't know who prescribes (decides) my medication.*

GH:

> *You don't?*

Rhona:

> *I don't know if it's the CDPS, my GP, Dr Green. I think it's the CDPS.*
> *I don't know - I really don't know. But they all seem to get involved when*
> *it's time and nobody knows _what is going on. (Taped interview February*
> *1994)*

After the drug reduction, I tried to check this out with the consultant and the CDPS worker. I found some confirmation of Rhona's confusion in that both Dr Green and Kate seemed to think the other's agency was making the decisions. Kate had told me:

> *Early 1993, there was a case conference, which resulted in a first detox.*
> *Rhona was taking far too much, she was buying far too much and was*
> *damaging her health. Dr Green took over the methadone prescribing, then.*
> *It often happens, that the City takes over the 'scripts, and the CDPS is*
> *never told. (Interview July 1994)*

I asked Dr Green in August 1994 if she was back with the hospital as the main prescriber:

Dr Green:

> *No, that is part of the problem. She is still being prescribed for by the*
> *CDPS, which I think is in many ways inappropriate. It causes problems -*
> *we do the medical bit, they do the drug management bit, but they do not*
> *come and see our patients when they are on the wards and causing problems*
> *because of their drug habits.*

GH:

> *And have you not asked to take over her methadone prescribing again? No -*
> *why not?*

Dr Green:

> *Because I have offered it to the patient - we don't want to be seen to control people. Anyway it would be a recipe for disaster - it probably works better this way, anyway, for both of us. But then the real irritant is - when we then get requests from the CDPS to sort out people's drug habits.*
>
> *I think it is a difficult relationship between us and the CDPS..... where they (CDPS) are doing the drug management bit and we are doing the HIV bit and I don't like it generally. I would rather either they looked after them or we looked after them, and that's one of the problems I find, you get splits. We should do all the medical management including the drugs because nobody from the CDPS comes and advises and sees the patient when they are stomping up and down the corridor (because of drugs). So yes, I don't know why the CDPS picked up the prescription (for Rhona) and our role. And Paul isn't actually connected with the CDPS, so that makes it even more difficult. (Taped interview August 1994)*

Towards the end of 1993 Paul, Rhona's CAST worker, and Kate, her CDPS worker, were feeling uncertain about what Rhona had been told by her consultant and GP about her drug prescription. They thought she was telling them different stories and setting the consultant up against the GP. Seeing Rhona at home and observing the effects of her drug taking behaviour, they felt unable to support and advise her appropriately.

November 1993: Paul decides to act.

In November 1993 Paul, the CAST worker, took the initiative to try and clarify things. He arranged a meeting between himself, Kate, Rhona and Dr Green to discuss her drug taking and its effects on her health. The GP was not invited. Paul gave his reasons for calling the meeting as follows:

Paul:

..because we were fed up listening to what Rhona was saying Dr Green was
saying and not knowing how much of it to believe. And also her GP was
saying things, so we felt we needed to have a meeting to be clear on
whether Dr Green advised an increase in her methadone and what the
implications were for an increase. We all knew she'd been taking extra. So
we wanted it out in the open. You know, she wants to split everybody - I'm
not saying that as bad - it's an accepted fact that Rhona will try and
manipulate people and try to get what she wants. We wanted to - not to
stop that, but just so that we all knew where we stood. We didn't want to
encourage Rhona to ask for an increase that was going to be detrimental to
her health, so we got the meeting together with Dr Green. (Taped
interview November 1993)

After the meetings was arranged, but before it took place, Rhona had been in hospital with breathing difficulties. When I saw her during this admission, she told me she was going to ask Dr Green for an increase in her methadone prescription from 110 to 150 mls per day. She was obviously withdrawing on her prescribed dose of 110 mls per day. The next day she left. According to Dr Green she had not asked for an increase, but simply arranged to leave. According to Paul she had been asked to leave because she asked for a 10 ml. increase. It was obvious to everybody then that she was taking far more than her prescribed dose.

The case conference, November 1993.
During this case conference, Rhona made the decision to go into hospital to try and reduce her methadone from 150 mls per day to her prescribed 110. These are Paul's and Dr Green's perceptions of how this happened;
Paul:

The meeting went very well. Dr Green was really good. He had given her a choice: either she wants to live as long as she can, or she can live for just now get an increase in her methadone and not particularly bother/care about her health long term, as long as long term can be. And he wanted her view on that. (Interview November 1993)

Dr Green:

What she wanted me to do was to recommend to the CDPS that I put her dose up to 150 mls per day. And I said "hang on - I have nothing to do with your methadone. CDPS prescribes it - why are you coming to me? Why are you asking me for this?" What I remember is that there was a sort of stand off from her about it all. What I was saying was "look - it does not bother me if you have 150 mls." but while she was there I took the opportunity to spend some time chatting to her about the effect of the 150 mls. was having on her health - saying- "well you are getting these recurring chest infections you have to think about it, what you want to do - do you want to deal with it or do you want to carry on." And I think I suppose I took the view: "why should anybody give you a prescription for 150 when you're on 110? If we gave you a prescription for 150, you'd be on 200".

I think at the end of that conversation there were a number of scenarios outlined - one of them that she would come in and sort out her drug habit. And I said "OK - we'll bring you down". But that was partly because there were some phone calls from Paul beforehand. - to do with that. And then I said - "all right, come in", which is what we did, and we got her down to 110. (Taped interview August 1994)

The reduction

She went into hospital late November and stayed till Christmas. She did manage to come down, in spite of difficulties. The first week-end after she was admitted, her partner phoned up in a panic and said he could not look after their child, who was on a regular week-end home visit from his foster parents.

The child wanted his mother. Rhona wanted to discharge herself. According to Paul, he went to Dr Green and suggested that Rhona should be allowed to go home at week-ends and look after her son. Dr Green came on to the ward to try and sort this out. He suggested to Rhona that she could go home for the week-end on the dose of methadone they had decided for that period and come back on Sunday night. She appreciated this: *'That man is fucking brilliant!'*

Rhona also told me about the support Dr Green was giving her when she was in hospital. She often got herself and other patients into trouble when she was in hospital, mostly over accusations of drug dealing, and during this admission she was not allowed to leave her room. The nurses were supposed to call on her regularly to talk to her, but according to Rhona they did not do as agreed. According to Rhona, Dr Green, however, spent time with her and she said she 'spilt her guts out to him.'

Paul, her CAST worker came in to see her both to support her during the detox and to help her work through problems in her relationship with her partner.

The outcome:
Rhona went out the week before Christmas. The holidays meant that it was difficult for her CAST worker and the CDPS worker to support her effectively after the drug reduction. However, Rhona wanted to be at home to prepare for her child's Christmas

I asked Dr Green about the support Rhona had been getting after she left hospital.
Dr Green:

Well, they (the patients) often reduce it to a medical situation. It is difficult to arrange support afterwards - they say they'll be allright. CAST would have been involved. Paul would have been involved....because he had to arrange the admission with me. Again, it's very difficult......we've done the technical bit, but it's actually quite difficult to get them (CDPS and CAST) to pick up the rest of it after that. (Taped interview August 1994)

I went to her house one day after Christmas and found Kate in her flat. Kate asked her if she had managed to stay on her dose of 110 mls a day.

Rhona said: "Have I heck! I was allowed to go home at week-ends. It was all Don's (Dr Green's) fault. It was stupid - just because Bob (her son) was on the phone crying for his mum and Don said I should go home."
(Fieldnotes January 1994)

Rhona told us she had had difficulties after she came home. She attributed a lot of these difficulties to the hospital, among other things to a prescription for Clonidine, a drug which is used to counteract withdrawal symptoms. This medication must be taken only under medical supervision and only for a short time because it affects bloodpressure. She did not feel right, and she went to Dr Peters, who, according to her, told her to come off the Clonidine straight away. Again, the GP appears as somebody who protects her from the hospital, but he had, in fact, prescribed the medication as directed in the letter the hospital staff had written to him about what treatment she would need from him on her return home from hospital.

Rhona also told Kate and myself that Dr Green might say she needs 110 mls per day - but she knew better and she knew 150 mls. was right for her.

Kate : "But you agreed with him at the case conference when I was there?"

Rhona: "Yes, but Dr Green does not really know! Anybody who says you
have only two months to live if you don't change your lifestyle, and here
you are two years later! The trouble is, Dr Green turned my head. He
sounded so convincing at the case conference - he manipulated me!"
(Fieldnotes January 1994)

A question emerges: who manipulated whom?

Postscript:

Rhona's wishes regarding her methadone prescription were in the end
accommodated. The GP later told me that in April 1994 Rhona's methadone
prescription from the City Hospital was increased to 140 mls. per day.

Mike

In contrast to Rhona, I never came across occasions when Mike had become the
object of discussion and argument between his service providers. I do not have
'stories' about him like the one I have presented about Rhona. This account gives
a general description of Mike's support network and describes three episodes
from his history of service use in more detail. One episode concerns how he
handled an unwelcome attempt by a dietician to interfere in and control his diet
and eating habits. This episode could have developed into a situation where he
became the object of exchange of opinions about him among his service
providers, but this did not happen. The second illustrates his use of services in
the way resources were activated on his behalf to investigate and control his
symptoms of peripheral neuropathy. The third concerns his relationship to his
GP.

Mike's service providers

The Consultant, Dr Campbell

Mike has been a long-standing user of the GUM Department, and this
relationship pre-dates his diagnosis with HIV infection. However, when first
diagnosed with HIV, Mike was sent by his GP to the Infectious Diseases Unit at

the City Hospital. Although the staff in this Unit were very helpful, Mike did not feel at ease with the place. In the waiting room were a few drug users, one of whom collapsed. 'This is crazy - I don't need this' Mike said to himself. After a few visits to the Infectious Diseases Unit, he transferred back to the GUM, where people knew him well and where he therefore felt he would get a good and personal service. In particular, he knew the consultant, Dr Campbell well - so well that he considered him 'a friend'.

When I first started seeing Mike in August 1993, there was no meeting in the GUM Department where patients were reviewed on a regular, systematic basis. Since then, two attempts have been made to establish such a meeting, but as discussed in the previous chapter it is not yet a regular event and might not be unless the relationships between the consultants and their staff change. There was thus no formal mechanism for Mike's consultant to liaise with other service providers in the Department, and there was a limited opportunity for Mike to be the topic of discussions between service providers. This can be traced back to the role of his consultant and his relationship to Mike. The scarcity of my data about the consultant's views on his relationship to Mike is in stark contrast to the strong feelings and opinions Dr Green expressed about Rhona in my story about her.

Counsellor

When he was attending the City Hospital, Mike met people from the counselling clinic there. He has continued seeing one of them after he left. She sees him regularly, in his home. This counsellor has no contact with his other service providers. In her words:

> I never liaise with anybody - neither with his consultant nor his GP. There does not seem to be a need for it. Nothing ever happens out of the ordinary which makes it necessary to inform others what I am doing. And he is a very private man. (Interview November 1993)

The GUM has its own psychologist working in the Department. These psychologists (there are now two who job-share) are members of the Regional psychology service for AIDS. The psychologists meet the clinical staff in the Department informally and liaise and discuss patients when necessary. The fact that Mike was not using the Department psychologist for emotional support meant that there was one less chance of communication between his important service providers.

Research nurse

From his time at the City, Mike also has continued to stay in touch with a researcher who works on a project on the effect of HIV on neurological and brain functions. He sees this researcher once a year. In Mike's words 'she looks after my brain once a year' and he has been helping her with the research. They also used to meet outside of this relationship. For example, Mike was putting on arts events for children, and the researcher's children used to enjoy going to these.

GP

Since he was diagnosed, Mike has changed his GP. He did not get on well with the first GP, among other things because this doctor did not handle the disclosure of a positive test result very well. Mike was left unsupported and traumatised to cope with the sudden knowledge that he was HIV positive. Consequently, he changed his GP in the summer of 1991.

Mike had not been seeing his GP very often, but when he did, over conditions like the flu, or a cough, or diarrhoea, he appreciated the service because it is accessible, it is quick, and efficient. The GP gets letters from the consultant after each out-patient visit, so he is up to date on the latest developments in his condition. Sometimes Mike takes the letters from the consultant to the GP himself.

The GP said about him:

He sees the consultant as his specialist 'key worker'. There is no doubt about that. I don't know this consultant - if he came into the room, I would not even recognise him.

I asked how that leaves him as a GP - the gatekeeper to secondary care?'

You know what he is like. He makes an appointment and comes in. We respond - patient control, I suppose. Most patients with a chronic illness know more about it than you do. This happens with other diseases as well, for example diabete.'

I see myself as an on-tap medical support worker - 24 hours a day, every day. The hospital cannot offer that - at least I don't think they do. I suppose in some ways we don't have a great role for people like Mike. (Interview November 1993)

Acupuncturist

Mike also sees an acupuncturist who was recommended to him by a teacher of the Alexander technique. He sees the acupuncturist once every three to four weeks. Mike values the treatment and finds the acupuncturist supportive in a number of ways.

He is very helpful. He gives therapy. You can also talk to him about anything - your fears, your anxieties. He needs to know about that in order to give the physical treatment. (Interview February 1994)

Family, colleagues and friends

He is single and lived by himself until his health deteriorated and friends and relatives have spent time with him to help and care for him. He is involved in several social networks through work, through church and through charity work. He has a wide circle of friends and colleagues. His family, although they do not live in Scotland, is close knit and supportive of each other, and his

mother, sisters and brothers and their children are important to him. He did not tell them of his HIV infection until he was so ill he had to explain his physical deterioration. He did not want to worry his mother. When he told them, they had all guessed anyway, but they had not been able to support him fully until he disclosed that he had AIDS.

He was also careful about how and whom he told at work. As his health deteriorated he told a few close friends at work about his infection, and they helped and supported him in a number of ways. However, while he was still able to work he did not make his HIV positive status official. Doing this would jeopardise his job. Mike said in one of the earlier interviews I had with him:

> *I think, you know that it (telling his colleagues) would cause too many problems. So what people don't know about, then they can't get worried about which I think, for me, is the right way. I think that keeping the status quo going is really quite important, psychologically it is important for you to feel that there is nothing really changed except a possibility of getting more illnesses and not being able to fight them. I think life can go on as opposed to thinking 'oh, gosh, I've got a fatal disease and I'm going to drop dead any moment. (Taped interview October 1993)*

After this description of Mike and the networks in which he operated, I go on to describe how relationships within the system of services he had set up for himself were activated in specific situations.

Episode 1: Mike and the dietician: 'she had no right'

In Autumn 1993 Mike became the object of interest of the hospital dietician, who had noticed, or, in Mike's words 'it had been brought to her attention', that he was very thin. She told the nurses she wanted to see him about his diet. Although the dietician had only been doing her job, and may be said to have been doing it well, Mike was quite offended:

I eat regularly, and I eat good food which I have prepared myself. In a way,
I quite resent that the dietician needs to talk to me about the quality of my
diet. (Taped interview October 1993)

He said he did not have the time, but that he would see him on his next visit to
the out-patient clinic. But he managed to avoid it. His weight went back up, as
he knew it would. He had been working hard, and his weight had dropped
because of it.

We've had a bit of a gag with the nurses up there (the clinic) over this.
They have supported me in my avoidance of the dietician. (Interview
February 1994)

I discussed his reaction to the dietician with him and asked him why he had
behaved like he did. He said:

This person (the dietician) had no right to interfere like that. This kind of
intervention should come from Dr Campbell. He is in charge of my
treatment. (Interview November 1993)

Mike resented an 'outsider' interfering in his life and demanding of him that he
discuss his eating habits with her. Mike had not asked her, and thereby not
vested her with the authority, to look at his state of health. He invests this
authority in the doctors, more specifically Dr Campbell. We discussed an
apparent lack of concern for his reduced weight among the consultant and his
junior colleagues. Mike thought it possible that the doctors had noticed his loss
of weight, but had not considered this important enough to raise with him.
However, he also questioned the fact that Dr Campbell had not mentioned his
weight.
Mike:

How come the doctors did not take any interest in my weight? They are
different people, perhaps - or maybe the dietician had not talked to them? Is
there no meeting there where they review patients? (Interview February
1994)

At the time, there was no such meeting. I tried to find out later whether Mike's weight loss had been brought to the doctors' attention. Dr Campbell did not remember, and nothing was found about it in Mike's notes.

Episode 2: 'I feel thoroughly looked at'

During 1994, Mike developed symptoms of peripheral neuropathy which were causing him pain and discomfort, and which also decreased his mobility and made his working life difficult. A number of services were activated on his behalf or mobilised by him to help him control the symptoms and finding their cause. He appreciated the way this was done.

The symptoms started late 1993. He went to the hospital out-patient department where a registrar diagnosed peripheral neuropathy. This was communicated to his GP in a routine letter. When Mike went to see his GP about swollen ankles, the GP was able to associate the swelling with the neuropathy. He recommended an elastic stocking.

The symptoms grew worse during 1994 and by the end of the year his walking was affected. I saw Mike in January 1995, when he told me:

> *I have been to the hospital, and they got in touch with AA, the research nurse at the City who does my brain function tests. And she told us that a neurology specialist has a clinic at the City once a week, and she was able to help me fix an appointment with him quite quickly. So I am going to see him next week. It was a good thing that AA knew me and was able to help me with this appointment. If it had not been for her, I would have had to wait much longer.*

AA is doing a scan of my brain, and they are doing a scan of my spine (at
his own hospital department). I certainly feel that no stone is left unturned
to find the reason for my symptoms. I feel well and truly looked at, from
every angle. It is comforting, it is a great comfort. (Interview January
1995)

The way he described 'being looked at' brought to my mind 'the medical gaze'
and suggested a distinction between on the one hand, a controlling and on the
other, a caring 'gaze'. To Mike, the 'medical gaze' was clearly a comfort and it
was controlled by him.

In the previous chapter (chapter five) I described how Mike had told me of his
reactions to his consultant's absence from his friend's last period of illness in the
hospice. I asked him how he was getting on with Dr Campbell, remembering
that he was disappointed at the lack of attention he was giving his friend.

I have not seen him. He does not seem to be around very much. But I don't
need to. The junior doctors are quite good, and they will review my case
with Dr Campbell regularly. (Interview January 1995)

Episode 3: the GP

My conversation with Mike about the consultant's lack of concern for his dying
friend had lead to a discussion about the role of Mike's GP in his care. At this
time I had begun to formulate a theory about the value of the GP's marginal
position in the system of care.

Although he was not saying so explicitly, Mike seemed to be thinking about the
time when he would himself get ill. We discussed the options of
hospital/home/Milestone in general terms. He said he would like to consider
home as an option for some of the time, but did not know how to go about it. I
suggested he spoke to his GP, who would be able to arrange home nursing care

for him if needed. I took the opportunity to tell him about my ideas concerning the GP as somewhat outside the main hub of service provision, and that this detachment might be a real resource. I also suggested that his GP might be ready and very pleased to respond to requests for more involvement. Mike said he understood what I was saying.

> *"The GP is outside the intensity of people's relationships with hospital staff".*

He also said he might follow my suggestion and go to his GP, whom he had not seen for months.

> *"You do that"* I joked *"and help me test my hypothesis. Your GP will probably be very negative and unhelpful and prove me all wrong."*
> *(Fieldnotes September 1994)*

Three months later, I spoke to Mike on the phone. He told me he had been in hospital with meningitis, but that he was now better.

> *"My GP has been absolutely wonderful by the way'* he said. *'You should go and see him. He has still got your form."* (A form I had given the GP to record contacts with Mike and other service providers. I had not been to see the GP for a year, as I knew Mike had not consulted him very much). *(Fieldnotes November 1994)*

I went to see the GP. He had very little to say. Mike had been to see him six times over the last year - three times over the meningitis incident. He had not been in contact with any other of Mike's service providers, apart from routine letters from the GUM about out-patient visits.

> *I said: "Mike seems very pleased with your services."*

I held my breath while I waited for the response. Would he confirm or dispel my beginning of a theory?

"I don't know why" he said. "I've done nothing for him!" (Fieldnotes December 1994).

I fought off an impulse to give the GP a hug and left the surgery elated.

Comparison of the two cases - when an individual becomes a story

The cases describe two service users: Rhona is a 'typical' drug user in the way she is described as chaotic, manipulative and out of control while Mike is a 'typical' gay man in the way he is described as articulate and in control.

The image of Rhona as chaotic, manipulative and out of control came not only from her. It was also a product of the system of care into which she linked. This system was very complex, and the communications and interactions which took place within it 'processed' her as chaotic. She went in clear about what she wanted: more methadone, and came out as somebody who failed a drug reduction. The complexity of the situation around Rhona's drug reduction makes it difficult to see who was responsible for the decisions made. **The situation took over, nobody was in control**. Rhona was accused by everybody - apart from the GP - of being manipulative in the way she told different stories to different people in order to get her drugs. She, on her part, was genuinely confused as to who was responsible for her prescriptions, although she might well have played on this confusion to get more drugs. She also accused her consultant of manipulating her into a drug reduction. In an important sense, then, everybody in the study about Rhona were 'manipulated' by the complexity of the situation.

The image of Mike as in control comes about largely because he controlled the flow of information among his service providers. This was partly his doing, partly a result of a history which largely unfolded from his consultant's strategy of limiting the exchange of information about him and other patients. Thus, the

episode with the dietician did not escalate to an incident of exchanges of opinions about him among his service providers. Also, he used people in the City Hospital IDU for support, and there was no institutionalised contact between these service providers and the GUM.

Rhona was a rich source of anecdotes which circulated among people who knew her. The exchange of anecdotes made her into a public narrative, as it were. Mike, on the other hand, was never made into a story in that way. Continuing the comparison between them, I discuss the very different power dynamics which underlie the way Rhona became a story in the IDU setting, whereas Mike in the GUM setting was allowed to remain, in the words of his counsellor, 'a very private man'. I first discuss Rhona's lack of control over the process by which she was narrativised.

Rhona as a story, Mike as a 'non story'

In the introduction (chapter one) I made reference to Good's (1994) theories about narratives and narrative exchange as social practice. The way Rhona was made the object of stories suggests these theories as a way of linking the construction of stories about her to the social context of the City Hospital IDU. I will emphasise the following: 1) the stories draw on intricate networks of terms and ideas by which the reality of service provision in the IDU is constituted, 2) She was told differently by different people, according to each person's perspective and interests, and stories about her unfolded through the structural dynamics of the service setting. 3) Because the narratives were lived, narrators were the audience as well as the perfomers of the stories and the stories were used to make sense out of central dilemmas of provision.

Rhona was, of course, one of the narrators, but for the sake of presentation, I will discuss how others constructed her first and then move on to her own reaction to her narrativisation.

The story of 'the manipulative, chaotic drug user' (and the 'gay man in control') is central to a cultural repertoire of stories about service provision in Edinburgh service settings. The stories are woven around an intricate network of terms and ideas many of which spin out from a central idea of 'control' and various terms juxtaposed to 'control 'such as 'chaos' 'fraud' and 'manipulation'. In the three previous chapters I have attempted to uncover parts of these networks and ways in which they are underpinned by the structural dynamics in the settings I studied. Chapter three discussed 'control' and 'chaos' in the discharge of patients from the City Hospital IDU, chapter four 'self reliance' and 'manipulation' in welfare benefits. I have argued that the dichotomies which are made by juxtaposing opposing terms to the central one of 'control' are ambiguous and contested. One person's 'control' is another's 'manipulation'. Out of the ambiguities of these dichotomies and the way they are contested come many of the dilemmas and stresses of service provision.

Rhona became the focus of many of these ambiguities in that she was made into a dichotomy of 'manipulation' and 'self reliance'. There were two very definite opinions about her among service providers who knew her. It was difficult to be neutral about her and as far as I knew, only her GP was. The opinions held varied with the structural power and authority held by the person concerned. There were those who believed she was a congenital liar who stopped at very little in order to obtain what she wanted, mostly extra drugs. Her consultant held this opinion. There were, on the other hand, those to whom she was a heroine, a wonderfully complex character for whom her manipulation was a strategy of survival. Her CDPS worker, her welfare rights workers and, less intensely, her CAST worker belonged to this group, as indeed did I, her ethnographer.

During her failed drug reduction and its aftermath in my investigation of it, she was made the object of an argument between her consultant on the one hand, and, on the other, her CPN and CDPS worker. This argument was about much more than Rhona. It was about the relationships of authority between the three workers, about the appropriate explanations for certain kinds of behaviour,

about whose view of the situation was the 'right' and 'true' and about the right kind of management. In a sense, each of the three workers 'plotted' her as a story about the stresses and strains, the morality and immorality of substitute prescribing and harm reduction programmes. They all plotted her differently and contested each others' plots. I became part of the dynamics through which Rhona was 'told' as a story because I intervened in the contest about her and suggested other plots. I thus came to have a role in the way the story about her unfolded and my role in this respect drives my own narrative about her.

The story of Rhona's drug reduction progresses to the point where everybody's control is lost in the complexity of the situation. This lack of resolution is, in narrative terms, highly unsatisfactory. Stories need a beginning, dramatic tension and a resolution of these tensions by way of an end (Brooks 1984). The protagonists in this story created this end by apportioning blame. Thus, Rhona blamed the consultant, who blamed the CPN, who, in a letter to me, blamed the GP practice and their lack of involvement. And everybody, apart from the GP, blamed Rhona for being manipulative.

When I wrote the results of my investigations into the drug reduction as part of the report for the longitudinal study I tried to suggest an alternative ending in the way everybody was manipulated by the complexity of the situation (Huby, Porter and Bury 1995). Kate and Paul embraced my suggestions - Kate with considerable enthusiasm. She requested copies of the report for a meeting in the CDPS team to discuss the way they worked with drug users and related to the City Hospital IDU. Paul also found my account helpful. Both Paul and Kate had found working with Rhona difficult because they easily lost perspective and were carried away by the complexity of events and situations. Dr Green, however, did not move position. He responded with strong feelings:

> "It was very depressing reading - very depressing. If harm reduction is manipulation, then I might as well give up!" (Fieldnotes April 1995) .

He implied I did not fully realise Rhona's tendency to manipulate and that I had let myself be manipulated by her. One minute she was sweetness and innocence, the next she changed completely and was violent and aggressive. He suggested I stress the fact that Rhona had difficulties with authority, and that she automatically positioned herself as its victim. I tried to take his comments to heart in my final version, in that I stressed the positive outcome of his and others' input in her care. I also brought out more strongly Rhona's tendency to position herself as the innocent victim of authority. I did not, however, give in to his view of her as simply and callously manipulating everybody, including me. He accepted my final draft.

By that time, the argument between myself and Dr Green about Rhona already had a history. In the meeting described in chapter five I had used Rhona's situation as an example to illustrate how the system of communication itself produced complexities of service provision and processed patients as 'chaotic'. Rhona was instantly recognisable and I had shown her what I had written and asked her permission to use it in the meeting. She was very keen for me to do so. She even gave me back my interpretations in her own words and a wonderful soundbyte which I immediately put on an overhead and showed in the meeting.

> So all I can say is, I've reformed myself. I've stuck to the same doctor, the same chemist, the same GP, all because I don't want all different stories getting bounced back off walls, fae a tennis ball to a football. Cause it snowballs ...."Watch her for this"....Because I hate all this feedback from this one, that one, "you said this" I says "no!" that's why I would love to have one of them (points to tape recorder) you know, 'cause I forget things I've said. (Taped interview February 1994).

I did not know then, that Dr Green and Rhona had a complicated relationship dating back years which revolved precisely around the question of her manipulation and his control. What I thought was a good case example which illustrated my points well, was particularly provoking to him. He reacted by suggesting that I had somehow been taken in by Rhona's and other service

users' suggestions that they were innocent victims of unreasonable use of power. He concurred with my basic premise that there are as many truths as there are actors in the setting where he is in charge, but refused to move beyond an insistence that his view of the 'truth' must prevail because he had the ultimate responsibility.

There was no way I could 'win' my argument with Dr Green, because I was positioned as a pleader of patients' view to the consultant and per definition, whatever Rhona or other service users told me was their way of 'manipulating' me into believing their particular version of 'the truth'.

Each narrator thus told the story of Rhona differently according to his or her point of view, interest and motivation at the time. These in turn were linked to our situation and position in the system of service provision and research. The narrative was not only being told, it was also being lived. It unfolded in the interaction between us and was carried by the dynamics of our relationships. It changed with the occasion and context of the telling, it was spurred on by events or knowledge gained in previous encounters.

In Mike's case, the dynamics were simpler. He was never drawn into situations where he became the object of contests the way Rhona was. The one occasion when he might have been, his dispute with the dietician, died before it became plotted as a story. There was never any disagreement among his service providers or myself about who he was, what he did or why he did it. He was a 'non-story' because the power dynamics in the GUM allowed him to be. My feed-back to his consultant of what I had written about himself and Mike elicited no response whereby I was drawn into an exchange or contest of opinions about him.

I now turn to the question of how they themselves reacted to the way they were being told respectively as a story of manipulation and a 'non story' of self reliance. The different perceptions of Mike and Rhona mirror the distinction between 'object' and 'subject'. Mike was a 'subject' of his own history because he

was in control, while Rhona became an 'object', although far from docile, of the discourse which constructed her as a chaotic and manipulative drug user. So where were the 'real' Rhona and the 'real' Mike? Can I move beyond this distinction between 'object' and 'subject' in my presentation of them? Did my relationship with them allow me to see them as they were outside of the way they were being 'told' in the interactions among their service providers and researcher?

Docile object, meaningful subject or reflective agent?

'Rhona the manipulative drug user' was constructed in interaction among her ethnographer and her service providers. The stories about her were contested and debated to the point where it was impossible to begin to determine where Rhona ended and the gossip began. She seemed acutely aware of this in the comment to me about stories being bounced off walls. Mike came across as very sure of who he is. Yet, he is, indeed, a very private man, and I do not presume I knew him any better than I knew Rhona.

I often felt that Mike did not quite add up. How could somebody in his situation appear to be in such control all the time? It was not difficult to accept that he did not choose me as the audience for his innermost fears and insecurities, if he had any. I adopted a strategy with all my informants of emphasising their strength and resources rather than what they might have seen as their weaknesses, but all my other service user informants, no matter how private or reserved, occasionally showed distress, confusion, anger or fear. Mike never did, apart from hints that he might tell his acupuncturist about his fears and anxieties. I felt there were aspects to his story of which I never even got a glimpse. His GP had expressed similar thoughts about him. In the absence of tension or passion in the image he presented, he appeared almost shallow, and yet I knew he was not.

After having known him for two and a half years I found a clue to his own story. He once told me about his relationship to work and how he had decided not to disclose his infection to colleagues so that he would not be forced to stop working.

> *Therefore, certainly as far as my work is concerned, it is invaluable really, because it is so consumingly interesting and challenging all the time. I'm very fortunate that I've got something like that. (Taped interview October 1993)*

At the time, this came across as a sensible strategy. The full emotional and existential force behind the statement was made apparent to me when I went to see him defend a client in court. At this time, he had difficulties walking because the nerve endings in his legs were badly affected. He looked ill. His face was thin and gaunt, cheekbones protruding. *'Marked by death'* I thought and instantly felt guilty of harbouring such an ominous platitude about him. I was also worried because he looked too frail to perform such a demanding task. As soon as the proceedings started, however, he was transformed. His posture and expression changed dramatically as he absorbed himself in the case and the performance of his part. The case lasted for two days. After that I never felt the need to search for missing parts of him. His job was so obviously the space where he lived his story, a space without HIV.

Mike's networks were so dispersed that there were plenty of spaces where he could hide from our various controlling 'gazes'. Rhona however, was visible to all of us because of the information about her that circulated. There seemed no corner or dark place where she could hide, apart from possibly in her drug use, and from where she could live her own story rather than react to the stories made about her. I have no doubt that she managed this, however, and that her 'manipulation' was a vital part of this strategy.

'Wherever there is oppression, there is also resistance', according to Foucault. What service providers saw as 'manipulation' in some service users, for

example Rhona, can perhaps be seen by the social scientist analyst as a reaction or 'resistance' to medical power. However, Rhona was not simply and mechanically 'resisting' the power of the services with which she had to deal by manipulating them, although she was, no doubt, partly doing this. She was also plotting her own story amidst the many versions of her which were in circulation.

She often changed her story. For example, she blamed the consultant for her failed drug reduction after having praised him for his support during her efforts to come down. Dr Green reminded me of her sudden and dramatic change of face and personality. This was often seen as part of her 'manipulative' behaviour. However, respondents were all 'manipulating' me, the researcher, by telling me their preferred version of a story which was then sometimes contested. Many people's stories, including the consultant's, also changed from one situation to the next.

For Rhona, as for other research participants, this 'manipulation' was also a positive activity of identity building. She plotted her narrative with herself in different roles. She was sometimes the heroine, for example when she threw the ashtray at Dr Green, or when she obtained her Mobility Allowance through her superb performance at the tribunal (see chapter four). Sometimes she was the 'victim', for example when Dr Green 'chose the moment she was at her weakest to pick on her', or when she described to me how Social Services were telling lies about her ability as a mother. Other people switched roles between 'villain', 'gullible' and 'hero' as Rhona's switched between 'victim' and 'heroine'. She tried out different plots and their possible endings and implications.

She was, however, most often actively presenting herself as resourceful and strong - this was one of the most important plots around which she constructed her lived narrative which unfolded as she told it to herself, to me and to her family, friends and service providers.

Sometimes, she lost the grasp on her narrative and became depressed. She said to me shortly after the failed drug reduction:

> *"I am so depressed, Guro. Nothing is going for me - the flat is not decorated,*
> *the benefits not sorted out, Scott is depressed, lies in bed and does nothing.*
> *When is this all going to end?." (Fieldnotes January 1994)*

She said she wanted to do something with her life. I could not answer her. I felt acutely uncomfortable because it was obvious she would die within a year or so. I suggested her life had been both fascinating and worthwhile and I agreed to tape her story and help her tell it.

She brought the narrative on herself and re-established her plots. She quarrelled with Scott who threw a coffee table through the window. Rhona swore she was going to leave and go to a women's refuge, but she stayed. The air cleared, Scott got out of bed and interacted with her again, a neighbour came in to help her decorate her flat.

She provided the most fascinating and rich material for both the study and this thesis - at one time I contemplated writing the latter as a story about her. And still, thinking about her and reading over my notes from our conversations and interviews, I realise how little I knew her. Very few people did. One of her support workers said:

> *There is only so much you can do for Rhona. You think you are starting to*
> *get somewhere - that there are issues there you can work with - and then she*
> *withdraws. She has a lot of people around, she makes sure nobody gets too*
> *close, and calls on one or the other if there is a crisis. (Interview July 1994)*

She remained enigmatic, in spite of, or perhaps because of, all the information which circulated about her. She herself actively contributed to her enigma. She did so by picking up the two versions of her - Rhona the villain and Rhona the heroine - and blurring the distinction between them to the point where she vanished. In this sense, there was no doubt that she did manipulate me,

although, I am convinced, not in the callous and straightforward way the consultant implied.

She greeted me as a long lost friend every time I came to see her and she made me feel special. Once when she was admitted to hospital, she gave my name as one of her support persons to be notified on her admission and discharge. I was unable to determine how much of this was flattery, and how much was earnest affection. For example, she once said: *"You come here to the likes of us, Guro, and you fit in. How come?"* when I had done nothing more than banter about cheating the DSS. Was she being serious, or was she making fun of me? I never could tell.

In some contexts, for example when she was explaining her 'manipulative' behaviour as a response to doctors who were prescribing her drugs, she appeared convincingly as the victim of administrative confusion and incompetence. In another context, she picked up the rumour of her as 'manipulative' and played with it. Once I was seeing her in hospital, and she suddenly remembered she had forgotten to phone Scott and remind him to pick up their child from nursery. She panicked, she had to get home and sort this out. She winked at me and said: *'Who is here of the junior doctors? Who can I manipulate to let me go home?'* She was, of course, herself being manipulated by her relationship to Scott, in which she created him as helpless, incompetent and useless and he, in his turn, manipulated her in the way he was living up to this image. Although she sometimes talked of their relationship in that way, she was blind to this on that particular occasion. I tried to suggest that Scott was a grown man, and that she could reasonably expect him to remember this himself. She looked doubtful. She stayed on in hospital in the end, although probably not as a result of my arguments.

Tsing observed how the powerless among whom she did her fieldwork copied and embraced the rhetoric of state domination and subtly distorted it 'just enough to confuse one's vision'. She says:

'This blurring of vision, this uncanny displacement of the rhetoric of state rule (*or in Rhona's case, service provision*) in which one could never quite draw the line between subjection and objection, was key to constituting that local sphere that was worth living in, protecting and continually reimagining'

(Tsing, 1994, p280)

Rhona blurred our vision to the point where we lost sight of the object and the subject of a discourse on 'manipulation'. She did this sometimes knowingly, sometimes unwittingly, usually playfully. In the blurred boundaries between the villain and the heroine she created a space for herself, even in the full glare of a 'gaze' that constituted her as the example and the embodiment of dilemmas of harm reduction and substitute prescribing.

I do not presume to know who she was in, or how she used this space. The idea or ideal of a perfectly equitable and reciprocally validating exchange of knowledge between an ethnographer and an informant is appealing, but masks the power differentials which usually structure this relationship and certainly structured my own and Rhona's. To Rhona, I was somebody with authority although I occasionally 'fitted in with the likes of them' and she appreciated my efforts to listen without judgement. We were, however, never intimate.

Failing to recognise this power differential takes away, rather than gives voice to, subjects of research, by 'domesticating' their accounts into a liberal and academic discourse which, although well meaning, speaks to the ethnographer's need for self-discovery and validation of a certain self rather than the freedom of the oppressed (Rafael 1994, in commentary on Tsing).

Rhona will not be domesticated. She remains our heroine.

Positions of marginality: the ethnographer and the GP roles compared

In this chapter, I have argued the importance of marginality, both in an analytical and structural sense. It is from a position of structural marginality that we can allow people space to choose who they want to be in their relationships to us. I have also implied similarities in my own role and in the role of the GPs in Rhona's and Mike's networks. There are, however, important differences in our roles, for the GPs were committed to action, while I was committed to reflection and analysis.

In chapter five I tried to describe how 'power' worked to structure the City Hospital IDU and the Royal Infirmary GUM respectively. In the City IDU information is widely available and contested. Here, consultants control by deciding what version of a story is valid, others with different versions either manipulate or are manipulated. In the GUM, 'manipulation' is not acknowledged because the flow of information is blocked by the consultants and management decisions are assumed to be made with reference to 'objective' clinical criteria. 'Power' in the person of his consultant, prevented information about Mike circulating, whereas in Rhona's case, the consultant was a key to its free availability and contest. I never became involved in telling Mike's story, whereas I was a protagonist in the telling of Rhona.

Both Rhona and Mike had complex and ambivalent relationships to their respective consultants. The relationships were emotionally highly charged and the most powerful of their service provider relationships. Rhona resented Dr Green's arrogance but also appreciated his support. Mike regarded his consultant as a friend but was also puzzled by his apparent lack of concern. In both cases, the consultants' role was important because they held the knowledge of their disease and its progression. In both cases, this relationship was central to the way their service provider networks were structured. Their networks were different, but they had one feature in common: their GPs' marginal roles were in different ways an antithesis to their consultants' powerful and central roles.

From their position of marginality, and in different ways, these two GPs provided for their patients space away from the complexity of hospital-centered care. For Rhona, this meant escape from a process whereby she was made into a story about manipulation and control. In Rhona's relationship to her GP she was in control - she could decide who she was. She negotiated, she did not manipulate. The GP was exposed to a very limited number of stories about her which might cause him to know her differently than he did. The occasions when she did misuse the system, by failing to turn up for appointments or take more drugs than prescribed, the GP did not 'see' it. For example, he did not realise she had failed to attend a significant number of times until he looked in the notes, and he did not emphasise the few times when she had 'cheated' about her drugs:

> *She does not mess me about too much over that - there's been one or two*
> *incidents. (Taped interview October 1994)*

Mike had this degree of control in his relationship to all his service providers. He nevertheless appreciated his GP because their relationship was simple. The GP gave Mike a quick and efficient service on Mike's terms. Their relationship was less complicated and less emotionally charged than his relationship to the consultant. For Mike, it meant escape from the ambivalent relationship he had to his consultant.

In their different ways, then, the GPs, because of their marginal position within both Rhona's and Mike's support networks, were a valuable resource. However, neither GP fully realised that Rhona's or Mike's relationship to him was of value because it created a space away from the intensity of hospital-centered activity, where they had some degree of control over the interaction.

As an ethnographer I provided both Rhona and Mike with a similar space because of my marginal position in their networks of relationships. My position was different from that of the GPs in that I did not have to act upon any of the

information they gave me. I simply listened. When I did act, for example in feeding back my suggestions about Rhona to her consultant, the outcome of my actions was important to me first and foremost as data upon which I could reflect and from which I could theorise. My lack of commitment to action and outcomes allowed me a personal space from where to reflect on my relationships to my respondents and ways in which this conditioned what they told me and ways in which they told it.

In the next and final chapter, I will continue these reflections on ethnographer-respondent relationships in a summary of the arguments I have developed so far. In the concluding remarks to my story I will pick up the contrast between reflection and action, theory and practice.

Chapter 8:   The Power of Silence:

Issues in the ethnographer - respondent relationship

Giving the service users a voice

The previous chapter ended by raising questions about the relationship between action and reflection, practice and research. I also raised issues of power and authority in ethnographer-respondent relationships. In this chapter I will develop the latter theme in more detail.

These issues are crucial in considering the project's aim of studying users' experience and opinions of services so that their views may inform provision and development. The present chapter ends my story by summarising the argument developed so far in the context of a critique of 'service user satisfaction studies'. This is an area of growing importance within health services research as 'the consumer' becomes an increasingly important, if shadowy figure, in the political/rhetorical landscape of the British National Health Service after the 1980's and 90's market-model reforms (Secretaries of State for Health, Wales, Northern Ireland and Scotland 1989, Leavy, Wilkin and Metcalfe 1989). 'Consumer satisfaction' is now an outcome measure in evaluation and audits of service. Research into users' experience and perceptions of health services has become an important part of health services research with the potential of feeding into policy (Baker 1991). However, this field of research raises a number of issues which are central to the argument developed in this thesis about the social conditions for the production and contestation of knowledge. My methodology has involved collecting material on the context and situations in which people articulated their experience to me. This gives me the opportunity to comment on the authority and role of ethnography in presenting people's views of themselves and ways in which they relate to for example health services.

My story has moved from a consideration of structure to a discussion of how individuals relate to and operate within structural constraints. Parallel to this movement has been a shift in my own relationships to the field of study. I have tried to present myself as somebody who started out as an 'outsider' looking at and trying to make sense of the systems of care I was studying. The discharge study was carried out by myself and Edwin, the sociologist. During this part of the study our personal follow-up and interviews with both service users and providers made us form closer relationships with study participants, and we increasingly became part of the social system under study. Sometimes we were ourselves party to events recorded. However, the analysis of the data from this study was predominantly quantitative. Analysis of qualitative material was largely descriptive rather than analytical. Fieldwork for the next phase was from the outset defined as qualitative, long-term participant observation and carried out by myself alone. The role as an outsider and an objective recorder of people's behaviour and experience was abandoned. This happened partly by design, partly as a result of events like the meeting described in chapter five. With this movement from observation and recording to immersion and participation followed a deepening of my relationships to study participants, both service users and providers. This shift in methodology allows me to address the question whether and to what extent ethnography can provide insights into individual experience. The answer has to be negative. Rather, ethnography's contributions are made in the borderland between the individual and the social and is itself part of the activity whereby individual experience becomes social discourse and collective 'fact'. This perspective opens up for reflections around the power and limitations of ethnography.

This perspective was not always in accord with expectations of our study and the material it produced. Service providers participating in our research looked to the project for answers to questions about the value and appropriateness of their service. These questions were more than mere window-dressing aiming to present an image of a consumer friendly service. I described in chapter two how the system of Lothian HIV/AIDS services developed as an experiment in open and democratic service delivery where the user of services was given a voice.

Service providers' commitment to this ideal was genuine. Their commitment translated, with a very few exceptions, into full co-operation and support for the study. They were also aware of the complexity of problems they were asked to manage and knew that the political and economic context of individual problems which clients presented were often beyond their influence. One said:

> *"We feel the world upon our shoulders - there's so little we as service providers can do!"* *(Fieldnotes November 1994)*

In this situation, it is small wonder that many wanted clear and unambiguous answers from us as to the effects of their interventions on service users' lives. The project did not always meet these expectations. Rather, our increasingly open-ended methods allowed us to make explicit the social context in which statements of service user evaluations were elicited, and this approach also accessed the structural/situational aspects of communication in settings under study. As my own relationships with study participants evolved, issues of power and authority in determining our own and various service providers' rights to represent service users' needs and opinions emerged.

Research and the production of discourse: a critique of studies of health services users' satisfaction

Research into health service users' satisfaction with services often assumes that valid articulations of 'experience' or 'opinions of service' exist among respondents in verbal form for the researcher to take away through interviews or questionnaires. Such studies often take the form of surveys aiming to measure satisfaction with a service. The development of instruments of measurement which are sensitive to differences in opinion is not unproblematic. For example, surveys generally produce a high rate of satisfaction with health services (e.g. Cartwright 1964 for general practice, Carstairs 1970 for Scottish Hospitals). The validity of questionnaires are also an issue. The construction and wording of survey questionnaires influence the detail of respondents' comments, and

respondents' age, gender and social class also influence response. Work has been done to refine and develop survey instruments of satisfaction and to clarify the interpretation of results (Locker and Hunt 1978, Cartwright 1964, Fitzpatrick 1991). However, within the quantitative paradigm, conceptual problems remain in using survey research methods due to difficulties in defining 'satisfaction' as a social/psychological entity (Linder-Pelz 1982).

Given the conceptual and methodological problems associated with survey research of 'satisfaction' some advocate qualitative methods in studying service users' perceptions of a service (Calnan 1988a, Fitzpatrick and Hopkins 1983). Such studies suggest that given the opportunity to express themselves on their own terms, service users are able to critically evaluate several aspects of care (Calnan 1988b).

It is necessary to contextualise this material, however, because people's evaluations of services are grounded in factors outside the service encounters themselves. Everyday experience and ideas of illness, health and health services influence views on services (Calnan 1988a, Fitzpatrick and Hopkins 1983, Hopton, Howie, Porter 1993). Williams (1994) argues that in order to appropriately interpret service users' comments on a service, it is necessary to consider the position from which they are speaking and their view as to their role as evaluators of a service. Service users may not all see themselves as 'consumers' with a right to pass critical comment and they may not all possess the language in which to do so. If this is the case, then studies of 'consumer satisfaction' of services will fail their purpose. It is possible that, rather than reflecting people's experience, studies (be they qualitative or quantitative) which presuppose a unidimensional view or clearly articulated opinion of health services among users may construct a kind of service user evaluation which fits with bureaucratic procedures of service audit. This research may thus distort the expression of opinion and paradoxically deny people as consumers the means of influencing services (Williams 1994).

Accessing 'experience' through statements we as researchers ask people to make is   problematic for a number of reasons. First of all, not all experience is verbalised. 'Experience' is also affective and sensual and lived out in daily life without being intellectualised. Rather, research activity of any kind sets in motion complex cognitive, emotional and behavioural processes in both the researcher and the researched. Research **creates,** rather than simplistically reflects, social reality. Ingrid Rudie (1994) describes her relationships to two women whom she knew during fieldwork. As the three women compared and reflected upon their different lives and existence, each woman's experience changed as a consequence. Rudie coins the phrase 'the inventive edge' to describe the process whereby individuals in social interaction reflect on practice and experience and change these reflections into language. Experience is created, re-created and changed in such interchanges - and research is instrumental in this change.

Secondly, the language available for us to elicit and for respondents to express experience is not a culturally or politically neutral medium which reflects social or individual reality, or even realities. Rather, language as part of discourse **shapes** realities by 'carving the world up' in specific ways thus creating the objects, feelings, events and, in this case, 'needs' to be communicated, and also their 'truth' or legitimacy' (Foucault 1981). As Foucault's work demonstrates, realities and the language which expresses them change with shifts in structure and institutional arrangements wherein discourse is rooted. As researchers we engage in this production of discourse.

In the 1970's the sociologist Ken Plummer (Plummer 1995) embarked on a research project which aimed to investigate the experiences of people who were defined as 'sexually different'. He set forth with a taperecorder and a research assistant and proceeded to collect a variety of life histories from people with very different sexual orientations who were all willing to give him their story. After a while, however, Plummer realised that he was not getting anywhere near people's individual experiences. Rather, the stories he collected were highly stylised and obviously part of a convention of 'telling the sexual story'. He had

become part of a media and research industry fuelled by the fascination of
sexual difference and the wish to know its individual 'truths'. This 'industry'
included therapy, academic research and popular research in the genre of Shere
Hite and Nancy Friday. Media events like chat shows were important
ingredients in shaping and driving the trend. Prominent among the latter was
the Oprah Winfrey show with Oprah herself disclosing her childhood experience
of sexual abuse at the hand of male family members.

Plummer found himself part of a flurry of social activity which assembled stories
around lives, without actually grasping them. He slotted into the role of a
'coaxer' of stories and joined the agony aunts, the chat show host(esse)s, the
popular journalists and researchers who probe for the 'the personal narrative'
about sexual difference and its experience. He says about this storytelling:

> Out of this activity emerged the 'story products': 'the objects which
> harbour the meanings that have to be handled through interaction.
> These congeal or freeze already preconstituted moments of a life
> from the story teller and the coaxer and await handling of a reader or
> consumer
>
> (Plummer 1995 p. 21).

As the context of interaction is in constant flux, so the meanings harboured by
the story products change. Plummer's own role as a sociologist in the 1970's
gave him the power to goad people into telling their story **in a certain way.**
Thus, the 1990's woman who has been raped tells a very different story from the
woman who was raped in 1950 - if the latter was allowed to tell her story at all.
For the 1950's woman the definitions into which she was slotted made her into a
'seductress', at worst a 'whore' whose story carried no legitimacy. Today the
social definition of a woman who has been raped is moving from a 'victim' of
male aggression to its 'survivor'. This story has considerable social currency. It
has an audience. Similarly, current gay 'coming out' stories are part of a process
of legitimising sexual orientation which was formerly stigmatised as abnormal
and pathological. For these stories too, audiences have emerged which
contribute to the meaning they convey and also to the social identity of the
tellers. Plummer was a child of his time in terms of 'theory, questions and style'

and the stories he coaxed were different from those elicited a century ago by for example, Krafft-Ebbing'.

> Whereas he looked for - and found - pathological tales, I looked for - and found - tales of normalcy

(Plummer 1995, p.21).

Literature on the changing nature of communication about death and dying in medical settings documents how discourses about death have changed during the last century. According to Aries (1981) medicine's '100 years' conspiracy of silence' about death was broken in the 1960's and there is now an emphasis on openness about death in interactions between medical personnel and their patients. Glaser and Strauss (1965) identify four possible types of 'awareness states' between service provider and user in the management of chronic terminal illness: closed awareness, suspicion awareness, mutual pretence and open awareness. Kubler Ross (1969) describes natural stages in the process of coming to terms with death and bereavement: denial, withdrawal, anger and acceptance. Thus, an ideal state of mutual awareness and acceptance is held up as a goal and possibility for medical staff in communication with dying and chronically ill patients in medical settings, including settings selected for this study. However, 'open awareness' and 'acceptance' of death is a complex experience which is often articulated differently by the dying, their relatives and the medical staff bringing the news of impending death (Timmermans 1994).

Armstrong (1987) argues that the new openness about death is not simply a matter of old truths and experience about death finally being liberated from repression by medical power. Rather, a new discourse about death has emerged, which has created new truths about death and dying. Before the 1960's the 'truth' about death was to be found in the physical properties of the body, while personal reactions to dying was a silent part of a great secret surrounding the event. The 'truth' is now sought in the psychological and interpersonal space surrounding the physical act of dying. With this have come ideas of 'right' and 'wrong' 'healthy' and 'unhealthy' ways of communicating about death. This regime of truth has brought with it new powers of medical

interrogation and control. Denial of death is no longer a natural part of the great secret, it is a state to be diagnosed, examined and corrected.

The question is, then, the woman who takes the blame for a rape, the gay man who genuinely wants to be heterosexual or who finds no comfort in 'coming out' the terminally ill who do not want to talk about their dying - is there an audience who want to know and hear their experience? Is there a language for them to express it? Are their stories legitimate? The criteria of acceptability are constantly changing, but the criteria are nevertheless social.

As researchers we trade in discourse and we are firmly a part of the histories whereby realities and perceptions of realities change. We are caught up in the social production of the very phenomena we then proceed to objectify as 'research aims' and 'findings' (Marcus 1994). Research is an inevitable part of institutional arrangements which produce certain discourses as 'legitimate' and 'right' whereas others are 'irrational' 'wrong' or 'deluded'. The questions we ask are to a large extent formulated for us both by the histories of our disciplines and our personal biographies. On one level, the answers we obtain when probing and questioning are also predetermined by history because the individuals from whom we solicit answers link into a historically contingent discourse. We analyse our material according to parameters of 'interesting' and 'uninteresting', 'relevant' and 'irrelevant' which are similarly historically determined.

Experience' of or 'satisfaction' with health services, together with their expression, are thus entangled in complex social dynamics. As researchers we can demonstrate and perhaps change these dynamics, but we can also reinforce them. The role taken by researchers in interaction with respondents, the use of language and the epistemological status given to statements respondents make is therefore not only of theoretical interest but have political consequences. For example, this project was originally designed to study the co-ordination of care between hospital and community-based services. The planned quantitative methodology for the discharge study, had it succeeded, would have

perpetuated the silence which surrounds the economic and structural production of material needs in a whole population. We would have reinforced the projection of 'needs' to the level of individual physical and emotional response to HIV.

Debates about the studies of 'consumer satisfaction' of health services have parallels to the debates about the sociological and anthropological enterprise outlined in the introduction. We have long since relinquished the idea that research and writing produce a 'true' and timeless account of a setting or a group of individuals. As a result we have come to confront epistemological issues around how to produce valid representations of others' experience of themselves and the world, and we have been forced to address political and ethical considerations in determining our right to do so. While this is undoubtedly a healthy development, in the process the ethnographer's voice can become only one among many and its authority to say anything beyond the personal has been challenged (Spencer 1989).

I return to Hastrup and Hervik's (1994 p 3) suggestion that 'no matter how much the anthropologist is part of the reality studied, it is still real'. The researcher's and the respondents' experience of disease, needs and the resources available to meet these may well be different, but physical deterioration and death, unpaid bills and damp walls, the meals cooked, the shopping brought and the comfort given by a neighbour or family member do have reality. The fact that this reality is contested means precisely that it is shared. This contest is embedded in the economic and political forces that structure the way people articulate their experience of themselves and their engagements with the world, and these structural dynamics are equally 'real'. The research process is one form of social interaction where this reality is negotiated, shared and thereby created and this process needs to be reflected in ethnographic field work and writing. For example, the gender, race, age, social class and personal history of the researcher, together with the circumstances of the research, determine the public roles and private selves assumed by the researcher in the field. This, in turn, affects the relationships established with informants and the kind of

knowledge being produced (Okely and Callaway 1992). The validity claims of
ethnography stem from our ability to relate what people say to the
social/political position from which they are saying it:

> The conditions of production of anthropological knowledge - who
> told whom? what? when? and why? - are themselves data of
> considerable importance
>
> (Spencer 1989, p 157).

'Experience' is thus not an entity which can be described out of the context and
situation in which it is articulated - a context of which the research is a part. The
challenge and responsibility of the researcher is to capture the expression of
experience without removing it from the flow of time and the situation and
context where people have some control over its articulation. I will argue that
the task lies in teasing out the individual and the structural in firmly anchored
social and historical given contexts. However, understanding the way
respondents themselves articulate the relationship between their personal
experience and the wider social forces which influence this experience is by no
means easy (Abu-Lughod 1990). In the following, I will suggest that due
attention to silence is vital.

The issue of silence

As the study progressed it became clear that what respondents chose <u>not</u> to say
about their situation and their use of services, both to me and to their service
providers, was as important as the statements they did make. Given my
growing relationships to study participants, it was possible to see how
discussions with service users about their experiences of services became
entangled in strategies not only of coping with their illness, but also of
negotiating the complex and pervasive system of care on which they had come
to rely. I have tried to describe how this system helped contain the effects of the
infection, but also controlled people's lives, both practically and in terms of the
expression of who they were. Respecting and interpreting study participants'

silence appropriately, and in a way which informed service delivery, became a major concern, both ethically and methodologically. In the following I describe my own relationship to three study participants and I quote a nurse's description of her relationship to a patient. These descriptions present examples of different kinds of 'silence' and the issues involved in interpreting these.

Silence as researcher's problem: Mick's avoidance of me.

A common occurrence for both service providers and researchers was the 'failure' of service users to turn up to appointments. Such absences were sometimes interpreted as a lack of ability to organise time, or as a failure to cope. Sometimes, however, such absences were interpreted both by some service providers and by me, as strong statements about a person's experience of the services or the research as intruding and controlling. This episode took place during the discharge study:

> *I went to see Mick and his wife in order to get their story of service use since Mick left hospital three weeks ago. When I spoke to them in hospital they were very obliging and willing to help in the discharge study by telling us about their service use and experience of services after discharge. When given the choice of filling in the diary or me coming out to see them and talk to them, they chose the latter. They gave me their phone number for me to phone and arrange a time one week after Mick had left hospital. I had to call off our first appointment , but I arranged another without any apparent difficulty. I phoned up just before leaving for their house, to make sure my visit was still convenient.*

When I arrived, Mick's wife told me he had just gone to get baby milk, but that "He will be back in a few minutes". My heart sank - I was sure he had left in order to avoid me. However, I accepted the invitation to come in and wait. Mick's wife offered me a coffee and a seat in her lounge. I met two other visitors already there: the family's social worker and a friend who was homeless and sleeping on their floor for a few nights. The wife was talking to the social worker and seeing to me while her two small children were running about. After a while the social worker left. Shortly afterwards Mick's drugs worker turned up. He had come to see Mick, as well. He waited half an hour. Mick's wife made him a coffee. The children were still running about, seeking attention. One was being potty trained. I admired her cool. I knew I would have cracked long ago had I been in her place. After waiting an hour I left. Mick's wife was very apologetic. She said Mick had some bad news a few days ago. "But it's time he starts facing up to things" she said. I felt bad. I knew my visit had deprived both of them of the opportunity, the space and the quiet in which to do so. (Fieldnotes October 1992)

Seeking care for HIV infection in some of the settings I have described meant laying oneself open to the scrutiny and sometimes intrusion of a variety of people: doctors, nurses, social workers, psychologists, counsellors and researchers. One community liaison nurse based at the City Hospital IDU said:

"These people - their life is not their own."

The networks in which service providers, service users and researchers operated were close knit, and there was a frequent exchange of information about people and events. People were highly 'visible' in many settings, particularly the City Hospital IDU. For service users, this meant that problems were noted and addressed. However, the constant attention of care workers and researchers was also a form of surveillance and control, whereby everyday behaviour and

lifestyles were scrutinised and evaluated in terms of 'appropriate' and 'inappropriate' ways of coping.

The way experience was or was not articulated was made the subject of such evaluations. There was an emphasis among some staff on 'the confessional' or on 'telling it' as a way of coping with feelings of distress. However, service providers and users did not always hold the same view as to the nature of a legitimate or appropriate confession. Rhona once told me:

> *When I am crying on the ward they (the nurses) tell me: "let it out Rhona, you'll feel better!" ...... Let it all out!!!!! They don't know what they're letting themselves in for: there's 15 years of abuse in here - the heroin, the prostitution, the rape - if I let it all out, they'd be in danger - I'd smash the place up! (Interview, January 1994).*

Nursing staff often experienced practical difficulties from patients' refusal to talk about the diagnosis of AIDS and the implications of their dying in ways which were immediately accessible to the nurses, as the following example illustrates.

'Chicken again?' Refusal to confront death
The following are extracts from an interview with a health advisor in the GUM. She was talking about a man, Jo, who had been attending the GUM regularly and who had been an in-patient both at the Royal Infirmary and the City Hospital IDU. He was dead at the time of our conversation. Jo avoided all situations where his diagnosis and physical deterioration might be brought up in conversation. This had caused practical problems for GUM staff and concern among the staff in the City Hospital IDU. In a taped interview in January 1994 I asked the health advisor how his refusal to communicate had affected the GUM in-patient staff and how they had handled it:
HV:

They didn't talk to him very much (staff at the Royal Infirmary in-patient wards). They used to talk about food. If anybody wanted to get near to him in terms of "how are things" and "what are you thinking about" and "how are you doing with this" it was awful (he would reply) - "oh, it's chicken again" or something - something quite banal........He threw you off course, I mean, if you're trying to get down to some serious discussion, where do you go from there? You can hardly say "but we're talking about something really serious but what are you bringing food into it?" It was his way of saying "don't talk about it". And you've got to accept that. And they also, it was somebody put him into a side ward, they gave him a room of his own, (but) he wouldn't go into a side room.

The ward in question had one big room with rows of beds for about 20 patients and a few small rooms with two to four beds. The man's refusal to go into a little room caused practical problems. The health advisor continued:

He had terrible diarrhoea on more than one occasion. (In the little side ward) he had a commode by his bed and he was the second room near the corridor going into the ward and the toilet was beside the other bed (in the side ward) You could quickly get out of bed and go to the toilet. He wouldn't go (in the side ward). ....he had to get out of bed, get another commode, or go to the bathroom. And, of course, he had an accident on more than one occasion, was acutely embarrassed at that but he wouldn't go into a little ward on his own. But that was another way of saying "I'm not going to deal with this"........ He was in that ward five weeks when he was in last. So, you know, "I can't be on my own with other people, so therefore you can't come and talk to me about that". .... nobody would like to embarrass him or in any way draw attention to him other than what was (happening already) because he was losing weight, not able to eat very well, had a drip up overnight occasionally, because they fed him overnight - tube feeds. But he used that to his own advantage in that he wouldn't allow himself to be moved.

.....You can't impose what you think should be upon what this man wants to happen in his life. I mean I can acknowledge that perfectly well to be quite honest because I got to know him and knew that there was no way you were going to make him be different because you thought it would be healthy for him to be different. It was the way he was - and accept the way he was and go along with that but draw attention sometimes to things which needed to be talked about. Because I remember, benefits was one of the things - his mortgage, he was very concerned about his mortgage. So as it happened, his father, his father's 'friend' (in inverted commas) who lived with his dad for a long time - she worked in the DHSS. So we got the ball rolling with certain things but she completed it at the other end which was really good because that sort of got things sorted out. But I don't know what he would have done otherwise. I mean, I brought that up with him, I said "what about such and such". And he said, "I don't know."

He also spent some time in the City Hospital IDU ward. The staff there found his silence problematic and contacted the GUM health advisor to ask her how to approach him. According to her:

......and then he went to the City (from Milestone) because he needed a blood transfusion and he became ill and they kept him in and nursed him and then put him on an anti-depressant because they said he was depressed because he wouldn't speak - which he probably was depressed but he was so ill at that point in time that really all the anti-depressant appeared to do when I saw him, to be quite honest, was just make him less able to communicate.

It was fine (them contacting me). I didn't mind at all. It was good to be able to say to them, "that's OK". Because, people (working in the IDU ward), you know, they felt really bad at not being able to talk to him and I think they saw it as they were not doing the right thing. You're doing something wrong because you've got a patient who doesn't respond to you. And I said, "it's just the way he is. You're not doing something that's either wrong or right. This man chooses not to want to regard, not to acknowledge his diagnosis, to acknowledge whatever's left of his life. That's his choice and if he doesn't want to speak he doesn't want to feel bad about that.... Accept that as a situation you're in with this man. And you could get along a lot better with him if you accept that rather than try and fight against it and think you've got to make him talk about it..." He was frightened to death of dying. Everybody is, but he ....

One of the problems Jo had was not having told his family about his HIV infection. This left large areas to silence because what had not been named could not be spoken. According to the health advisor things got better when his family was told.

He didn't want to tell his Dad because he didn't want to upset his Dad and I think, at the same time, he didn't want his Dad to think badly of him. He didn't want his family to turn away from him. And that was just the way he dealt with death and what was going on with him in his life.......And at the end of the day I said what can we do to acknowledge or get your family to know about it and I remember that (he asked us) "tell my Dad." I remember that Dr Campbell (the consultant) went up to the ward. We arranged a time, his dad came in and Dr Campbell made me sit in the room, insisted, and told his father what was wrong with him. And he (the consultant) said it was so much of a relief when his dad said: "we thought that was what was wrong with him but we needed someone to tell us". We thought that for months and months and months nobody suspected. Yet when they told their brother and there was a good friend of his, a girl called ... who used to come and see him, when they were told eventually they all said the same thing, "we knew that was what was wrong with him but he never would admit it".

I think the family were so relieved when they knew - they could deal with it rather than be in the dark. They didn't shun him. They did go up to Milestone (to see him). They took him home for a while, for him to be with them all. What he thought would happen was not really what did happen. And it's such a shame that he had not been able to be more open about it earlier. Maybe life would have been quite different for him, because he seemed quite isolated..... But then I think he made himself quite isolated.

He never told them and I think he found that quite difficult but he was a lot better after that in one sense. The nurses in the City Hospital IDU actually said to me afterwards when he had told his father eventually that he was a bit better after that. That he was easier to talk to. Presumably because no-one was under any sort of illusions of what was going on. It was out in the open in a sense. But he was difficult to communicate with (even after his family had been told). The nurses, everybody found that (Taped interview, January 1994).

What did Jo's pre-occupation with the food served in hospital 'really' mean? How do we interpret his refusal to stay on his own in a private room? Emotions have their own unspeakable force, the intensity of which is not necessarily reflected in the form in which they are expressed - be they ritual, symbols or language. Rosaldo (1989), who worked among the Illongot in the Philippines, describes how he struggled to understand how Illongot men associated the grief of bereavement with a rage that could only be alleviated by head hunting. This association was described in the barest of terms, as a fact which needed no elaboration or explanation. The full force of this association only made sense to him when he was himself faced with the death of a close family member. The aim of ethnography has been termed 'thick description' (Geertz 1973) of the way research participants interpret, construct and assign meaning to their physical and social environment. However, with Rosaldo, we are forced to ask:

> Do people in fact always describe most thickly what matters most to them?

> (Rosaldo 1989, p 2)

Jo's failure to communicate about his death then raises a host of questions. He caused practical difficulties in his refusal to stay in a private room. However, had he not felt a pressure on him to talk about his disease he might have accepted to be alone. He made life difficult for himself and his family by not telling them. However, they knew and were there for him even before AIDS had been spoken of. Was his death and dying then, in palliative care jargon, a 'bad' death? If so, was this because he refused to talk, or because he was pressurised to talk?

I identify with the nursing staff on this issue. I experienced my own relationships to dying study participants as an impossible balance act between saying too little and saying too much, as the next example illustrates:

Confronting or avoiding painful issues. My knowledge of Anne

As health service users we evaluate providers' authority, skills and interest in our treatment and adapt our response to them accordingly. We tell different things to different providers and use them differently. The service users recruited to this study were no exception. They also evaluated my own role and personality and made decisions about what to disclose to me, and what to keep from me. At times I was chosen as the audience for people's most intimate thoughts and reflections. Other times I was faced with ethical dilemmas around asking people to verbalize experience and thereby making it immediate in a way the respondent might find distressing and I might not have been able to contain. This consideration, together with the potential of the research as intrusion and control, meant that I sometimes erred on the side of caution in terms of inviting confessions.

This example continues the story about Anne, who appeared at the end of chapter three as the person who first made me aware of the importance of welfare benefits and housing assistance as an unmet need. She participated both in the discharge study and in the initial stages of the follow up study, although she died before the latter got fully underway. I have described how she responded to my questions concerning her service use and her experience of services during the discharge study, together with the investigations she allowed me to do into the processing of her welfare benefit application. During the first two months of my acquaintance with her, her benefit problems were gradually being sorted out. Her DLA came through, with a substantial sum in back payment. She and her husband used some of the back payments to install a phone, which made it easier for her husband to get her into hospital if she took ill in the middle of the night. They bought a new automatic washing machine which made housework easier for her. However, their flat remained damp and cold and unsuitable for somebody with chest problems, the main clinical manifestation of her infection.

On a particular occasion in the summer 1993, our last, formal interview, she told me that they had persuaded their housing association to put in central

heating in their flat. A counsellor helped them with this. We discussed these developments at length and the progress being made. She remained characteristically optimistic and cheerful.

> *Hopefully, things will be sorted out in a wee while, now she said.*
> *(Interview August 1993)*

That account was constructed on the basis of her verbal responses to my questions in the discharge study diaries. There is another account of my relationship with her which is constructed from everything we did not talk about. The following account is constructed on the basis of my field notes and memories of her:

> *I popped in to see Anne on the ward. She is getting so thin. She was*
> *sitting hunched over in a chair by the open window. She told me that "Dr*
> *Smith (her consultant) has said I haven'e got HIV any more- it's AIDS,*
> *now". She looked really frightened. I did not ask her how she felt about it.*
> *Should I have? (Fieldnotes November 1992)*

During my last interview with her, when she talked about her central heating being arranged and how everything would be all right in a wee while, her eyes told another story. *"I know you don't mean this"* I thought to myself. I sensed so strongly that the heating of her flat, important though it was, was not the most pressing concern she had at that time. I am also sure that she did not really expect to feel the benefits of her central heating. She died shortly before the system was put in. I saw her briefly in hospital before she went home to die (autumn 1993). She was sitting propped up in bed, with an oxygen mask over her face.

> *"They have pumped my lung up," she said. "They have done what they*
> *can. Hopefully, it will be all right, now." (Fieldnotes September 1993).*

Like the health advisor did with Jo's refusal to talk, I interpreted Anne's silence about her feelings concerning her illness and her visible physical deterioration as

part of her way of coping with her situation, both in terms of her illness, and in terms of the system of care on which she relied. She did not talk about what I felt very strongly was her distress to any of her service providers, either. She saw a counsellor who is skilled at helping people deal with their feelings about death, and the counsellor had told me she spent very little time talking with Anne about her emotional coping strategies. Most of the time she helped her with practical tasks such as the heating, although she knew there were emotional issues to be worked through.

Once or twice Anne gave me openings to talk about what was happening to her, and she might have wanted me to listen to her. However, I did not respond. I tried to show her I cared by helping her in practical ways, but I did not press her or follow her lead on the topic of her approaching death. My response was part of my own general strategy of coping with what I at times found a very stressful field work situation. I invited confessions only in cases where I felt certain I could respond to people's statements of distress in positive and constructive ways. Ethical considerations around roles of research and roles of support are encountered in settings other than HIV care. (Huby 1992).

I was able to maintain this detachment because all the service user participants in my study had access to professional help. Service providers generally appreciated this detachment. The comprehensive system of care available to people was not only a solution to, but also a cause of, ethical and emotional issues I faced during field work. I have described how problems of co-ordination were caused by a large number of service providers, together with blurring of professional boundaries. A blurring of my own research and counselling/provider roles in this context would have added to the complexity of co-ordination in individual cases. Moreover, I had neither the skills nor the resources to help Anne with her possible distress about dying. I would need professional help and back-up and there would be few ways I could use the information obtained as counsellor to her practical benefit without adding to the complexity of service provision.

Nevertheless, my reluctance to get involved no doubt closed off avenues of data collection as far as emotional issues in service use and relationship to service providers is concerned. It is, however, by no means certain if this would have got me any closer to the 'real' and private experience of Anne's and others' experience. As I have suggested, private and personal emotions and experience are not necessarily and straightforwardly expressed in language (see also Good 1994 ch. 6). Studying and making sense of emotions and ways of coping with distress therefore raises problems of communication and interpretation. Respondents may use the relationship to a researcher as an intimate and culturally safe escape from official discourse and the way this restrains the expression of private emotions (Wikan 1987). However, the researcher cannot assume that the words used evoke the same experience in the teller of the story, the researcher listening, and the audience reading the researcher's account of the story (Good 1994, p 140). Private experience is also enveloped in public forms of expression. For example, Foster in his study of family support and informal caring in Edinburgh families where one or more members had HIV found that the language in which people express their experience of HIV is poorly developed. Rather than talking about this experience directly, people use public narrative and stories to give expression to personal emotions and experience (Foster, forthcoming).

My discussions with Anne about her material circumstances were thus within a 'safe' emotional territory. She was silent on other issues. Was this her carefully reflected way of coping with her situation? Was there a language available to her, public or private, in which to articulate her feelings? Were there other ways and other relationships available to her in which she communicated and shared her experience?

My fragmented and incomplete insight into Anne's experience of her situation mirrored the relationship service providers had to some of their clients, as the following example illustrates.

Silence as a service provider problem: Neil's consultant

The following describes Neil, who chose me as the audience for detailed reflections on his approaching death, whereas a service provider, in this case a consultant, was excluded. When I asked him to describe his relationship with his service providers, he explained why he employed a strategy of avoidance with his consultant. Later on I interviewed the consultant who described the effect of Neil's behaviour on his work as a doctor.

Neil's community nurse, who came to see him in his home regularly, knew about his wish to avoid open discussions about his condition with the consultant. She had told his consultant not to tell him that he had AIDS. She made sure it was written all over his hospital nursing notes, so that out-patient and ward nurses would not tell him, either. This is what Neil told me in a taped interview in February 1994 about his relationship with the consultant:

Neil: ....

You go in and see the consultant, right, he reduces you to tears, almost.

Guro Huby:

He does?

Neil:

Aye, but he's only doing his job, but it's the way he comes out with things, you know what I'm talking about?

GH:

In what way?

Neil:

I just dinnae ken. It's just ...he's no being nasty, he's just telling you the truth, he's telling you this, that and the next thing, he's asking you questions, he's just got this thing that he almost reduces me to tears every time I go into his room, ken, because - that's what I'm saying to you - I ken what he's, what he's trying to tell me with the questions that he's asking, ken, he's no wanting to tell me straight, if there's something serious wrong.

GH:

He's not?

Neil:

No, because he's asked me that. He actually asked me my opinion.

GH:

Oh, right.

Neil:

"Do you want to know if anything serious was wrong" I says "no, I dinnae think I would." Because I would probably panic, ken whit I mean. So, like, but when he asked me a question, I can tell what he's getting on about, ken whit I mean. And then I go home and check whatever out that he's been talking about. And then I know that I'm that wee bit closer, ken, sort of thing.

GH:

Well, would it not be better then if he just told you, since you know so much?

Neil:

See, I dinnae ken, because like if I dinnae ken, right then I can just go on thinking how I'm thinking and then I know I'm going to get really ill one day and I'll have to go to the hospital but that's that because I'll probably not know much about it anyway when that day comes, ken whit I mean. But I think if I was to go to the hospital one day and he was to say: "Neil, you're thingmied, you've got AIDS, now. You've got a wee touch of this and touch of that", I'd probably just go out and dae myself in or something, ken whit I mean. Because I wouldn't want my family to go through sort of two or three months period it would take me to die, ken whit I mean. (Taped interview, February 1994)

Neil was taking AZT which was prescribed for him by his consultant. The consultant needed to see Neil regularly in the hospital out-patient department so that he could check for side effects to his AZT. However, Neil very rarely turned up for his regular appointments. In the end, the community nurse offered to take blood samples during her routine visits to Neil so that the safety of AZT could be checked. The following interview extract illustrates the consultant's reactions to Neil's use of him as a service provider:

Consultant:

> He is the most maladjusted person as far as his HIV is concerned . He has had 19 DNA's (failed appointments). You know - over the last six months - I sat down and made a count. .....He really has pushed and pushed the limits of what a patient is. As if he feels that I have no other patients than him. I have told him time and time before - "I expect you to behave like a patient. I cannot have you fill up my appointments and then defaulting, because somebody else could have seen me in that time" so we had a long chat about it. He still does not turn up. I'm not giving him any more appointments. I am not going to push myself on him, if he wants an appointment he has to phone up and it's up to him if he wants to take it up or not. (Taped interview, August 1994)

Neil, on his part, had a reflected approach to his hospital visits:

Neil:

> But I hate going to hospital. Because it brings everything back to reality, ken what I mean. You realise you have got HIV. You are going to die, ken, all that comes flooding into your head when you go to the hospital. Then you're getting blood taken, you're giving urine samples, everything, ken. And the just, I don't know, when I'm in the hoose I don't think like that, ken what I mean. I just get on with it sort of thing. (Taped interview, February 1994)

Neil was able to talk to his nurse and to the researcher - a comparative stranger - about his thoughts on death, while he chose to avoid the consultant. While he refused an open awareness state with the latter he was fully aware and accepting of his approaching death in other situations. This avoidance was causing considerable problems for his doctor who, not unreasonably, interpreted this as unwillingness to face up to his situation. However, based on statements Neil made to me, his behaviour towards the consultant can be interpreted as powerful, rational and well reflected statements from him about his experience of the service system. I interpreted Mick's avoidance of me in a similar way, while I lack the information with which to interpret Anne's silence about her reactions to her physical decline.

Providing answers: A research dialogue

I note, that I as a researcher found myself facing similar problems to those of a service provider as far as interpreting service users experience about their service provision was concerned. How, then can research inform service provision in any meaningful way? The following dialogue between myself and the chief psychologist based at the City Hospital illustrates the difficulties. Clare had read my paper on the organisation and communication among staff in the City Hospital IDU setting before we circulated it to all staff. She had responded very enthusiastically and in detail.

In the paper we had cited the example of a woman, Pat and the way she was being discussed in a multidisciplinary meeting. We wanted to illustrate how people's coping abilities were sometimes overlooked by service providers, and potential distress and need for counselling and emotional support emphasised.

Pat had sorted out her family's benefits herself, by dealing directly with the DSS. Shortly before her partner became seriously ill and dying, she managed to jump the housing queue by contacting her local councillor, who helped her get a ground floor housing association flat. She then nursed her dying partner.

Her service providers, particularly the nurses, were worried about her ability to cope and anticipated problems after her partner's death. This is how she was described in a meeting:

> "Pat - yes, she *is* doing well, but she is doing too much! She is taking on too much and may not be able to cope much longer. We have offered her counselling, but she will not accept it." *(Fieldnotes, January 1993)*

We wrote in the paper:

> Was this woman denying and suppressing her own grief and her own need? Is an emphasis on practical, material problems a way of hiding from emotional issues which should be worked through and addressed? These questions may be particularly pertinent in a field such as HIV and AIDS, where so many services are on offer, and where one way of making decisions is to 'vote with one's feet.' Who has the knowledge, the power and the right to define and articulate this woman's needs?
>
> (Quality of care for people with HIV/AIDS in Lothian, 1994)

In response to the paper, Clare wrote:

> This (case) is very important. It occurs to me that *you* are not commenting or making judgements. Is that what you intend? This case is not unusual, and I'll bet loads of people had promised help in the matter. She was more effective herself in the end.
>
> You're posing a question and dodging making an answer - or even giving the different possible answers. Of course it is better for her to have sorted it out herself. (They are often much better at it because they are more assertive and less polite than the providers).
>
> How dare people say she is doing too much? How paternalistic/(unfortunately) maternalistic! That quote from the meeting leaves me gasping - although I can see that, in some circumstances, I might have made it myself.
>
> More questions - be brave and give some potential answers. *(Letter in fieldnotes, February 1994)*

Eight months later, she reminded me that I still had not given her the answers.
Clare:

> *You have been studying us for two years, Guro. Surely you must be able to come up with some answers now!*

Guro:

> *But I have given you all the findings I've got! What do you want to know?!!*

Clare:

> **We want to know if we're doing the right thing!** *(Interview November 1994)*

Clare deals competently and on a daily basis with confusing, ambiguous and complex situations. She had supported our research project in numerous ways. Not unreasonably, she would have liked me to render her own and others' behaviour and experience explicit, accessible and rational. This I could not and would not do. I knew no more about service users' 'real' experience of the service system than she herself did. Besides, Clare knew as well as I that there were no easy answers. She was challenging my steadfast refusal to commit myself to one. Her challenge was partly made in jest, but it was also very earnest.

Statements about experience, which become the object of our academic descriptions and analyses, are never clear, explicit or unambiguous because they are made in social situations produced by complex, intersecting and competing relationships of power and interests. This social complexity comes through in the stories respondents told us about their experience. This complexity often masked, rather than revealed, private experience, however. Like Ken Plummer, I was participating in the exchange of stories around people's experience, but I was rarely grasping it. The problems can be seen as conceptually inherent in the relationship between experience, language and power.

Experience, power and language

Articulations of experience as studied in this project took place in settings in which relationships are structured by professional power and authority. Power has been suggested as an important dimension in communication between service providers and patients in medical settings. For example, in settings where persons in authority, often the consultant, take on the role of the sole communicator of potentially distressing information, the relationships between patients and staff are often strained and difficult (Field 1992, James 1993). Power is also instrumental in producing the content of and expectations for, communication.

The service settings studied here illustrate the way a comprehensive system of services provides effective support to people with terminal illness, but that this support also involves some scrutiny and control over people's personal ways of managing HIV and its effects. From this perspective, acts of avoidance and silence documented here may be seen both as individuals' reactions to their illness and the system of care on which they have come to rely, and also as a political statement about this system. Lack of language which articulates and promotes a certain experience and point of view has been seen as a response to power. For example, anthropologists studying gender point to the political strategy in women's lack of a public language. Avoiding or refusing to engage in a debate where the stakes in power are unequal has been suggested as one way for powerless people to deal with power (Ardener 1975). Absence of a certain kind of language does not mean that arguments are not well reflected, however. Neil's response to the consultant and Mick's avoidance of me can reasonably be interpreted as conscious decisions to avoid a powerful and invasive system of medical intervention and research which disrupted their way of coping with their situation. Anne's silence must remain just that: her own silence which is not for us to interpret. In all cases, however, understanding and interpreting their reactions raises the problem of relating the personal and political in other people's way of engaging with the world - and with researchers. Abu Lughod (1990) puts it particularly well:

'...how might we develop theories that give people credit for resisting in a variety of creative ways the power of those who control so much of their lives, without either misattributing to them forms of consciousness that are not part of their experience, ...or devaluing their practices as prepolitical, primitive, even misguided.'

(Abu-Lughod 1990, p. 47).

Like the doctors and nurses communicating about death with their patients, ethnographers tread a fine line between liberating experience and suppressing or controlling it. In writing the story about the project and the way we reached our findings, the silences, ambiguities and lack of clarity are vital in opening up the account and enabling readers to engage with respondents. In conclusion, I will suggest that part of the answer to Abu-Lughod's question consists in a consideration of silence.

Ending my story: the power of silence

In daily life, experience is lived out in embodied practice. It is rarely intellectualised and verbalised. By changing embodied, sub-conscious instantaneous and multidimensional experience into sequential, verbal form, experience is changed. There is room for creativity, reflection and personal and social change in this process (Bloch 1991) but epistemological issues arise around the researcher's translation of their own and informants' experience into text (Hastrup and Hervik 1994). In this translation, what people do not say is as important as the statements they do make. Returning to the visual imagery of Foucault's Birth of the Clinic, research in its role as 'coaxer' of stories is instrumental in opening up or closing off the 'dark spaces' of existence which, although charged with meaning and significance, are silent because no legitimate language exists for their expression. The task is to make these silences speak.

In the introduction to this thesis I referred to theories on the narrative as fuelled by our search for meaning and experience, both of which constantly elude us. I

also referred to modern literature's search for plots and literary forms which avoid the finality of meaning but open up the possibilities of multiplicities of meanings to be created as the story unfolds. I discussed the current debates about ethnographic writing as a reflection of these literary debates. I have addressed the issues by designing a conventional plot for my story in that it is anchored in a storyline which moves with a sequence of time. I suggest that this is necessary in order to demonstrate the conditions and contexts in which I engaged my respondents in dialogue and coaxed their stories.

I am now faced with the task of ending my story and I seek an ending which does not confer finality. I refer back to Conrad's (1924, quoted in Brooks 1984) critique of conventional endings in the turn of the century novels and the complacency which the finality of these endings create. He discusses the work of Henry James and his way of ending his stories in ways which leaves room for no such complacency. The following quote from Conrad's essay on James seems peculiarly relevant to my own ethnography:

> You remain with the sense of the life still going on; and even the subtle presence of the dead is felt in that silence that comes upon the artist-creation when the last word has been read.
>
> (Conrad 1924, quote in Brooks 1984 p. 262).

Brook goes on:

> The presence of the dead - certain ghosts..... are never laid to rest.
>
> (Brooks 1984 p262)

Brook discusses Conrad's 'Heart of Darkness' and the particular ghost to which he refers belongs to Kurz, the enigmatic explorer whom the narrator follows up the African river in order to find out from him what a man will see if he peers over the edge of human understanding and convention. Brooks suggests that Kurz's answer as he goes over the edge: 'the horror!!!' is inconclusive. He suggests therefore that the narrator in Heart of Darkness is destined to tell and retell his life's story as it relates to Kurtz's ghost. If I replace Kurtz's name with for example Rhona's, Anne's or Neil's, it is clear that for all that I have written about these people, their stories are, of course, not told. They will be told again

and again by me and by all the others who knew them and they will change in the retelling. Continuing the analogy to Brook's discussion of Heart of Darkness, we will never lay their ghosts to rest:

> The effort to narrate one's life story as it relates to their (the ghosts') numinous and baleful presence is never done. One must tell and tell again, hoping that one's repetition will in turn be repeated, that one's voice will re-echo.

(Brooks 1984 p263)

Therefore I will end my story with silence. This is entirely appropriate for a story that treads a wary path within debates about ethnographic authority and aims to demonstrate this authority without making unfounded claims to 'truth'. I have tried to be explicit about the reality of the context and the encounters within which I elicited my material and the theoretical conventions from where I have interpreted this. In so doing, I have acknowledged the limits of my account and suggested silent spaces which are beyond its authority.

Silence is part of the art of storytelling, and if I have told my story well, then these silent spaces will speak in terms of their potential for other accounts and other voices which, although they may not (yet) be articulated and heard, determine their own legitimacy. Karen Blixen, under the pseudonym Isak Dinesen, writes on silence in her story 'The blank page' (Dinesen 1957, Penguin Books 1986). She speaks through the toothless mouth of 'an old coffee brown, black-veiled woman' who 'sat at the ancient city gates' and 'made her living by telling stories'. The old woman had been taught the art of storytelling by her mother's mother, 'the black eyed dancer, often embraced, who in the end-wrinkled like a winter apple and crouching behind the mercy of the veil - took it upon herself to teach her daughter's daughter the art of storytelling. Her own mother's mother had taught it to her'. I take it to be highly significant that Blixen portrays the art of storytelling as passed on from one marginal to another - from grandmother to granddaughter in a line of dancers whom I imagine to be outside of the good society of women at the time. In the previous chapter I have tried to demonstrate the marginality of the ethnographer as her strength in opening up the story to possibilities beyond the spoken conventions of the time.

The old woman in Dinesens's story says:

> With my grandmother,' she said, 'I went through a hard school. "Be loyal to the story," the old hag would say to me. "Be eternally and unswervingly loyal to the story'.........'Where the storyteller is loyal, eternally and unswervingly loyal to the story, there, in the end, silence will speak. Where the story has been betrayed, silence is but emptiness. But we, the faithful, when we have spoken our last word, will hear the voice of silence.
>
> (Dinesen, 1986, p. 100).

I have tried to remain true to my story by not claiming too much.

Ethnography makes explicit the possibility for other stories told by different voices and has a potential role in coaxing these. In riding the tension between the stated and the unsaid, silence and language, private and public, present and future, ethnography derives its power.

Concluding remarks: reflections on 'action' and 'research'

I have told a story about a project which was set up to improve co-ordination of services for people with HIV in Lothian. The project was, from the start, defined as 'action research' in that the material produced was to be used by people providing or managing services to gain insight into the effect of their action and to change their practice if our findings suggested that there were gaps or inefficiencies in the system of provision. 'Applied' research enjoys a special and somewhat contentious standing within the profession of anthropology. It might therefore have been appropriate to discuss more explicitly the status of the project as 'action' or 'applied research', but the ethnography has taken me down different paths. By way of conclusion therefore I want to make more explicit reference to the 'applied' nature of the research which produced my ethnography.

Of course, we found that the relationship between, on the one hand, intellectual knowledge and, on the other, experience and action was a complex one and our research findings were not always directly translated into action. My ethnography highlights two main reasons for this. First of all, what we identified as 'gaps' in provision, for example welfare rights, were not always seen as such by the users of our research. The aims of provision with reference to which 'gaps' were defined were themselves contested by the different service providers taking part in or using the research and the project became caught up in this contest. Secondly, people 'saw' and accepted those of our findings which their experience and social position let them 'see'.

The ethnography comments throughout on the complex relationship between research and action. I will conclude with further reflections on this relationship and in the process comment briefly on the tradition of 'action' or 'applied' research' in social anthropology. I will argue that the complexity of the relationship between 'research' and 'action' applies to anthropologists as well as

to their subjects of research. Furthermore, I will suggest that this is an area where anthropologists may apply the tools of reflexivity to some advantage because we may explore some of the boundaries which at present structure and restrict debates within the profession, for example, the boundary between 'pure' and 'applied' research. Having devoted my story to the deconstruction of boundaries in the service cultures which I was studying it seems appropriate to turn the tools of reflexivity inwards and examine some of our own.

Summary and conclusion to the thesis

I have described the progress of the project in terms of the methods of investigation we used and how our research practice changed from quantitative description to qualitative interpretation. I have described and discussed the findings we made underway and I have endeavoured to demonstrate the value of a theoretically informed interpretation in deepening the understanding of these findings.

This interpretation has drawn also on my own experience of the social system I was studying. I shared my study participants' experience of the complexity of this system and my knowledge of it was, like my study participants', at the time incomplete and fragmented. It still is, even with the benefit of two years' reflection and distance. In particular, I still have no definite answers to give as to the effects of different forms and styles of service provision on different service users' lives and experience.

However, although my own and service providers' problems in terms of interpreting the system of service provision were similar, the position from which we reacted to these problems was different. As a researcher, I am obliged to strive for detachment and reflection, while the service provider is obliged to achievement and action. It is the understanding of my own subjective interpretation of service user experience, and the way I arrived at this, which can most responsibly contribute to service provision in this setting.

Paradoxically, findings from the study suggest that, in order to understand service user experience and apply this understanding in practice, the providers need to avert their scrutiny away from the client/patient and direct it upon themselves, their own practice and the motives and perspectives which underpin this. They also need to reflect upon how their position in a system of surveillance conditions their subjective understanding of the persons they are trying to help and how this understanding informs their practice, both in terms of interaction with service users and communication and co-ordination with other service providers involved in their care. In the course of such reflection, issues of power and authority both in service user-provider relationships and in relationships between providers, need to be addressed.

An ideal in service organisation in the settings I have described has been to give everybody involved, particularly service users, a voice. Our findings suggest that meeting this aim requires less attention to the content of communication than to the way communication is organised. Effective communication is not simply a matter of personal skills, but also of engineering systems of interaction where people are heard and where people are given the opportunity to speak for themselves without research as an interposing medium.

In the final meeting of the Project Advisory Group, I continued my discussion with Clare, the psychologist who had asked me for clear answers about the effect of her own and others' action, and I asked her what action she saw stemming from our research reports. She said:

> *"Of course I know why you cannot give me clear answers.............I think I will go back and encourage people to look again at how we organise our patient meetings." (Fieldnotes August 1995)*

The extent to which systems of communication have changed as a result of our findings is, however, not clear. This project illustrates the tendency within evaluation research and 'needs assessment' to define relevant 'needs' as that

which is provided by an existing system of formal services. The system in this case was hierarchical in the way some services and some needs were given prominence while others, for example welfare benefits, were marginalised.

My argument throughout has been that experience is formed and articulated in everyday action. Changing the perception of 'need' among providers and funders of services will require structural changes in the service system which alters providers' daily practice and interaction with clients. Academic and research arguments do not necessarily have the political force to bring about the structural changes needed, and research has clear limits as far as achievements of practical change are concerned. Although these limits may be politically frustrating, they are academically and theoretically interesting in the way they highlight issues about the relationship between intellectual understanding and action. They also inform a consideration of the boundaries between 'pure' and 'applied' or 'action oriented' anthropology'.

Action research in social anthropology

Action-research, or 'applied' or 'policy oriented' anthropology' is sometimes seen as a step-child of the discipline because of its lack of theoretical sophistication. As such, it has an uncertain status within the discipline. For example, a senior honour's essay title for the 1994/5 Edinburgh University Department of Social Anthropology course in Vocational Anthropology read: 'Applied anthropology has often been criticised as theoretically unsophisticated, praxis-oriented and ethically problematic. Yet the application of anthropology to practical problems is an important part of the discipline's future. Discuss.'

I have recognised both the value and contstraints of anthropology in solving practical problems, and I want to discuss the view of applied anthropology as 'theoretically unsophisticated'. This view of applied anthropology has considerable justification, for research commissioned by parties with clear stakes in a field of contested interests faces political constraints on what and the way in

which, information can be accessed and what can be said. Furthermore, the language in which findings can be expressed has to be adapted to the lowest common denominator in terms of the audience's theoretical and methodological background. Finally, this research is often undertaken in short-term contracts where there is no time to develop the material theoretically. However, it may be argued that all anthropological research, whether 'pure' or 'applied' faces practical constraints in terms of time and resources. Both 'applied' and 'pure' research also involves variously intense and difficult negotiations with stakeholders, both in terms of the information which can be collected and the way in which it can be presented. The crucial question is the extent to which data on these practical circumstances are mined theoretically and analytically and here the boundaries between 'pure' and 'applied' do not necessarily apply. Each project should thus be judged on its own merits in terms of data access and research conditions which allow for theoretical development.

This particular project was invited by service providers in order to provide them with practice-relevant information. The people who invited me to study them were also open-minded and flexible and prepared to accept that the project did not always provide them with the answers they expected or wanted, although they did not necessarily accept the answers we provided. It was therefore possible for me to gain access to people occupying a variety of positions, wielding various degrees of structural power, within the organisation of service use and provision. This access gave me particular opportunities to relate perceptions of service organisation and the articulation of its experience to the structural position of the speaker. This methodological feature of the study holds considerable theoretical promise, and it is unlikely that I would have gained this access without being invited. HIV/AIDS in Lothian was, at the time, a heavily researched area, and important stakeholders with the power to regulate access were explicitly denying access to researchers in many service settings in order to protect themselves and their clients from intrusion. Paradoxically, then, it was perhaps the fact that it was an action-research project which, in this particular case, opens up many of the project's theoretical potentials.

Deconstructing boundaries: power, action and reflection

In particular, it has allowed me to explore the way 'power' - in its wider sense of producing social organisation and experience - is acted out in the shifting and fixing of social boundaries. I have also tried to make the point that the social analyst is inevitably taking part in this play, because we have to act through the medium of language and human communication. Thus anthropologists, as well as our research participants, act in the world and contribute to the production of the social phenomena which we make the object of study. We are subject to the conditions of communication and interaction and although we may posses an intellectual understanding of these conditions, it is quite another matter to translate this understanding into our own action.

To act in the world, we have to use power - in its wider, productive meaning - and we have in a sense to be blind to its working. To be effective in terms of action, we have to act through a social position and we harness its power by building up and maintaining the position of others with whom we interact. To act effectively, we have to put ourselves behind and commit ourselves to a position. We cannot easily do this unless we become 'blind' to other ways of defining ourselves and others which threatens this commitment This is a social and shared phenomenon, not simply a matter of personal obstinacy and lack of ability to reflect.

For example, the consultant who refused to 'see' other ways in which he could relate to the welfare rights workers is an open, flexible and profoundly compassionate man. His patients respect him and his staff admire him. He has achieved a tremendous amount in terms of developing services for people with HIV and promoting research which will improve their clinical care. He has been efficient to a large extent because he is committed to his position as a consultant. This position confers responsibilities as well as power. He is seen to protect his staff from the threats of 'chaos' seen to inhere in drug users. He is also protecting the service from punitive government action by defining drug users

and welfare rights workers as 'manipulative' and by being seen to restrict their 'manipulation'. Had he been more open to other ways of 'seeing' drug users and welfare rights workers, for example, he might not have been effective in these respects.

In chapter seven, I compared my own and the GPs' positions of marginality in Mike's and Rhona's networks of services. I suggested that the GPs were not aware that their marginality was of value to their patients, or how it was of value. Neither was their marginality their intention. For example, Rhona's GP did not take part in the meeting about her drug reduction because he was not invited. Had he known about it, he would have attended. This lack of insight is not necessarily a result of lack of reflexivity or anthropological training, however. The GPs related to Mike and Rhona as patients and this conditioned their actions towards them in specific ways.

Intellectual understanding does not directly affect action towards others. For example, I recently discussed Foucault's 'Birth of the Clinic' with a GP who works in the Department where I did the research. He had enjoyed the book and said the concept of 'the gaze' was immediately relevant to him. I asked him if the book had changed the way he acted towards his patients. He doubted this. He compared himself to one of his colleagues who was very different from him in the way he diagnosed patients' symptoms. Whereas the colleague would write down the medical terms for a symptom, he would write down broad descriptions of it in lay terms such as 'cough' ,'pain'. He had started doing this because he knew that medical terms were just another way of classifying and naming the world which bore no direct relationship to a reality. However, he doubted that the difference in the way they described patients' symptoms was reflected in the action they took. For example, he suspected that they both prescribed anti-biotics in the same way. He was planning a small project with this particular colleague and others to investigate this. Intellectual curiosity and ability to reflect is not a prerogative of anthropologists and other social scientists, but is present also among people who are involved in action, more than research.

Anthropologists also act in the world. I have described the variety of points of view which were contested among the people taking part in my study as eminently 'rational' on their own terms. In any social field, there will be a variety of points of view, and the question arises as to which point of view the social scientist chooses to invest herself in terms of action. In terms of our own action, we are as conditioned by our social positions as anybody else, and we are often blind to the reasons why we want to chose a particular point of view. Becker (1967) had no hesitation in choosing the point of view of 'the underdog' as a political and ethical commitment. Gouldner (1973) pointed out that this choice fitted nicely in with Becker's and his contemporaries' strategy of challenging the positions and authority of their sociology elders. Gouldner suggests that a sociologist should be 'firmly on the side of suffering' by illuminating the relationships between different points of view, rather than supporting any of them. In sociological terms, this is also a point of view with certain implications in terms of the analyst's social position. On the basis of my ethnography, I will suggest that the content of our answers and our analyses may be less important than the insight into the process whereby we achieved them. This requires reflexivity, and a social positioning which allows us to be reflective. I will argue for marginality as the essence of such a positioning because it affords a privileged view of our own social conditioning as well as that of our research subjects.

McKeganey (1989) suggests that while medical sociology has been concerned with issues of power in doctor-patient relationships, and with patients' experience of illness, they have not taken seriously the study of doctors' points of view and experience. He suggests this as a fruitful future field. This requires us to explore the boundary between 'the medical profession' and 'social science'. As social scientists we have long made a living out of critiquing doctors' use and misuse of power. Currently, anthropologists' co-operation with doctors and medical professionals in interpreting and understanding patients' presentation of symptoms and experience of illness has been criticised as complicity to expansion of medical power (Singer 1989 and 1990, Scheper-Hughes 1990).

Good (1994) suggests, however, that the boundary between on the one hand a 'critical medical anthropology' and on the other an anthropology which acts as an instrument of 'medical power' is too facile because it stereotypes medical practitioners as 'dupes' of a hegemonic system of medical power and privileges the perspective of the analyst over the local knowledge and experience of practitioners. In practice, the boundaries between the oppressed (users of medical services) and the powerful (medical practitioners) are not that clearly drawn. Systems of healing in Western medicine are more a 'dance' with shifting configurations of interests, complicity and understanding than a 'battle' with clearly drawn and static battle lines. Good suggests that the boundary between a critical and an a-political interpretive anthropology may be fruitfully challenged to open up a field of enquiry which promises future theoretical developments. This may require a realignment of our relationships to medical practitioners and users of their services. Precisely because of its marginality, 'vocational anthropology' or 'action research' offers a unique opportunity to use the tools of reflexivity to theorise the role of anthropology and social research as agents in a political field, or, in more ambitious terms, to theorise the relationship between knowledge and power.

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INTERPRETING SILENCE, DOCUMENTING EXPERIENCE: AN ANTHROPOLOGICAL APPROACH TO THE STUDY OF HEALTH SERVICE USERS' EXPERIENCE WITH HIV/AIDS CARE IN LOTHIAN, SCOTLAND

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Abstract—This paper presents a critique of "health service user satisfaction studies" as a forum for users' voice and influence in health services evaluation and development. The study of service user experience is discussed from a social anthropological perspective, which explicitly theorises the relationship between the theoretical/epistemological foundation of health services evaluation and its political effects. It is argued that "experience" and its articulation are products of a social and political process in which research is implicated. "Experience" is thus not a static and absolute entity which can be measured or described out of the context in which data on experience are elicited and recorded—a context of which the researcher is a part. Validating findings on service user experience proceeds from a consideration of the way power and authority structure the situations where statements of experience are elicited and includes a critical appraisal of the researcher's role and ways in which this influenced interaction with study participants. The challenge and responsibility of the researcher is to capture the expression of experience without removing it from the flow of time and the situation and context where people have some control over its articulation. Attention to silence is suggested as a part of this strategy. An action research project concerned with coordination of services for people with HIV in Lothian, Scotland, is introduced. Material on users' experience of services is presented and discussed. In conclusion, the effects of research on the organisation and content of communication in the service settings studied are considered. © 1997 Elsevier Science Ltd

Key words—health services evaluation, AIDS/HIV, anthropology

INTRODUCTION: THEORETICAL AND POLITICAL ISSUES IN THE STUDY OF USER SATISFACTION WITH HEALTH SERVICES

"The consumer" has become a pivotal, if shadowy, figure in the political rhetorical landscape of the British National Health Service (NHS) after the market-model reforms of the 1980s and 1990s (Secretaries of State for Health, Wales, Northern Ireland and Scotland, 1989; Leavey *et al.*, 1989). "Consumer satisfaction" is now an outcome measure in evaluation and audits of service. Research into users' experience and perceptions of health services has become an important part of health service research with the potential of feeding into policy (Baker, 1991). However, this field of research raises a number of issues which are, on the one hand, theoretical/epistemological, and, on the other, political/ethical. They need to be explored in order to make research an effective avenue of service user influence. This paper attempts such an exploration, from a sociological and social anthropological perspective which explicitly theorises the relationship between the epistemological foundations and political effects of research in ways that enhance the practical value of research findings.

Accessing "experience" through statements we as researchers ask people to make is problematic. First of all, not all experience is verbalised. "Experience" is affective and sensual and lived out in daily life without being intellectualised. We cannot therefore assume that valid articulations of "experience" exist among respondents in verbal form for the researcher to take away through interviews or questionnaires. Rather, research activity of any kind sets in motion complex cognitive, emotional and behavioural processes in both the researcher and researched. Research *creates*, rather than simplistically reflects, social reality (Rudie, 1994).

Researchers' engagement in discourse is crucial in this process. The language available for researchers to elicit and for respondents to express experience is not a culturally or politically neutral medium which reflects social or individual reality, or even realities. Rather, language as part of discourse *shapes* realities by "carving the world up" in specific ways and thus creating the objects, feelings, events and, in this case, "needs" to be communicated, as well as their "truth" or legitimacy (Foucault, 1981).

As researchers, we trade in discourse and are caught up in the social production of the very phenomena we then proceed to objectify as

"research aims" and "findings" (Marcus, 1992). Research is an inevitable part of institutional arrangements which produce certain discourses as "dominant" in the sense of "right" or "rational", while others are "muted" by being termed "wrong", "irrelevant" or "irrational". A current concern in anthropology and sociology is the study of domination, and resistance to domination, in linguistic and social practices (Abu-Lughod, 1990). Asking users of health services to take part in research which evaluates these services means asking them to engage in a discourse and use of language which may not allow them to express their awareness of who they are, how they relate to the world and how they would wish to be seen by others.

"Experience" is thus not an entity which can be described out of the context and situation in which it is articulated—a context of which the research is a part. Research requires (a) the imaginative and critical use of language as a vehicle for expression of a variety of experience, (b) a critical awareness of the social position from which researchers engage participants of research, and (c) explicit use of this awareness in data collection and analysis. The challenge and responsibility of the researcher is to capture experience without removing it from the flow of time and the situation and context where people have some control over its articulation. Due attention to silence is here suggested as part of this strategy.

APPROACHES TO THE STUDY OF HEALTH SERVICE USERS' SATISFACTION

Studies of "service user experience" often take the form of surveys aiming to measure satisfaction with a service. Surveys generally produce a high rate of satisfaction with health services [e.g. Cartwright (1964) for general practice, Carstairs (1970) for Scottish hospitals]. The construction and wording of survey questionnaires influence the detail of respondents' comments, and respondents' age, gender and social class also influence response. Work has been done to refine and develop survey instruments of satisfaction and to clarify the interpretation of results (Locker and Hunt, 1978; Cartwright, 1964; Fitzpatrick, 1991). However, within the quantitative paradigm, conceptual problems remain in using survey research methods due to difficulties in defining "satisfaction" as a social/psychological entity (Linder-Pelz, 1982).

Given the conceptual and methodological problems associated with survey research of "satisfaction", some advocate qualitative methods in studying service users' perceptions of a service (Calnan, 1988a; Fitzpatrick and Hopkins, 1983). Such studies suggest that, given the opportunity to express themselves on their own terms, service users

are able to critically evaluate several aspects of care (Calnan, 1988b).

People's evaluation of services are grounded in factors outside the service encounters themselves. Everyday experience and ideas of illness, health and health services influence views on services (Calnan, 1988a; Fitzpatrick and Hopkins, 1983; Hopton et al., 1993). Williams (1994) argues that in order to appropriately interpret service users' comments on a service, it is necessary to consider the position from which they are speaking and their view of their role as evaluators of a service. It is possible that, rather than reflecting people's experience, studies (be they qualitative or quantitative) which presuppose a unidimensional view or clearly articulated opinion of health services among users may construct a kind of service user evaluation which fits with bureacratic procedures of service audit. Research on service user satisfaction can thus distort the expression of opinion and paradoxically deny people as consumers the means of influencing services (Williams, 1994).

Debates about the studies of "consumer satisfaction" of health services have parallels to, and are taken further by, long-standing debates about the sociological and anthropological enterprise. Critiques of "realism" point out the fallacy of the idea that research and writing produce a "true" and timeless account of a setting or a group of individuals. As researchers, we not only grapple with epistemological issues around how to produce valid representations of others' experience of themselves and the world, we also confront political and ethical questions in determining our right, as researchers, to do so. In the process, experience may be deconstructed in textual critiques (e.g. Clifford and Marcus, 1986).

In a volume that sets out to restore confidence in the anthropological enterprise and the vital position of ethnographic fieldwork in comprehending the world, Hastrup and Hervik (1994) suggest that, "no matter how much the anthropologist is part of the reality studied, it is still real" (p. 3). The researcher's and the respondent's experience of, for example, disease needs and, in the context of this paper, the resources available to meet them, may well be different, but this does not mean that they have no reality. The research process is one forum of social interaction where this reality is negotiated, shared and thereby created. In daily life, experience is lived out in embodied practice. It is rarely intellectualised and verbalised. By changing embodied, subconscious instantaneous and multidimensional experience into sequential, verbal form, experience is changed. There is room for creativity, reflection and personal and social change in this process (Bloch, 1991), but epistemological issues arise around the researcher's translation of his/her own and his/her informants' experience into text (Hastrup and Hervik, 1994).

In order to address these issues, it is important to realise the implications of the historically situated nature of all research. The gender, race, age, social class and personal history of the researcher, together with the circumstances of the research, determine the public roles and private selves assumed by the researcher in the field. This, in turn, affects the relationships established with informants and the kind of knowledge being produced (Okely and Callaway, 1992). It follows that in health evaluative research the researcher must "write herself into" the texts produced in order to let the respondents' voices and evaluations through in the final research product.

Researchers need to recognise the reality of the social, economic and political forces that structure the way people articulate their experience of themselves and their engagements with the world and to reflect this in ethnographic fieldwork and writing. This means relating what people say to the social/political position from which they are saying it: "The conditions of production of anthropological knowledge—who told whom? what? when? and why?—are themselves data of considerable importance" (Spencer, 1989, p. 157). Recent work in medical anthropology is developing "the narrative" as a methodological and theoretical tool which advances knowledge about the articulation of experience and its interpretation in the context of structurally situated practice (Good, 1994). As social practice, narratives or stories can be seen as "configurations that conceal(ed) dynamic relations as well as representing a coherent ordering of experience" (Good, 1994, p. 161). These "dynamic relations" are here seen as social/political.

This perspective informs the analysis of material collected during the action research project "Quality of Care for People with HIV in Lothian (Scotland)", which was set up to document and evaluate coordination of services for people affected by HIV in the region.

"QUALITY OF CARE FOR PEOPLE WITH HIV IN LOTHIAN" PROJECT: HISTORY AND AIMS

One aim of the project was to document people's experience of services they used, so that people's views could inform evaluation of provision.

In Lothian, as in other areas of Britain, care for people with HIV is medically focused and centred in and upon specialist hospital departments. The project evolved out of an initiative by a small number of local general practitioners who worked in Edinburgh localities where the incidence of HIV spread by intravenous drug use was high (Robertson et al., 1986) and who had a special involvement in and commitment to primary care for people with HIV. There was a concern that a lack of primary care involvement would result in gaps and discontinuities in services across the hospi-

tal–community interface. The original focus of the project was thus the coordination of hospital-based and community-based services.

Service provision in this environment is stressful. HIV in Edinburgh is, in the majority of cases, associated with poverty and drug use in economically and structurally marginal localities. These factors impinge on service provision. One service provider said: "We feel the world upon our shoulders—there's so little we as service providers can do!"

Service providers in the settings studied looked to the project for answers to questions about the value and appropriateness of their service. Their commitment to and cooperation in the study suggested that these questions were more than mere window dressing aiming to present an image of a consumer friendly service. They really wanted to ensure that their services were appropriate.

Methods used for the study allowed us to make explicit the social context in which statements of service user evaluations were elicited, and this approach also accessed the structural/situational aspects of communication in settings under study. Our focus on the latter raised issues about the implementation of research results. The project did not always meet service providers' expectations about the outcomes of our research. Some wanted clear and unambiguous answers from us as to the effects of their interventions on service users' lives. We focused on the system by which they communicated with service users and among themselves. In so doing we addressed issues of power and authority in determining our own and various service providers' rights to represent service users' needs and defining the appropriate way of meeting these.

RESEARCH METHODS AND THE RESEARCH PROCESS

The project was conceptualised and carried out in discrete components, each component building on findings from the previous stage and allowing for discussion with and input from study participants between each stage. This discussion took place in feedback meetings, informal discussions and in regular meetings of a Project Advisory Group which consisted of service providers and two service user representatives.

The discharge study

Bearing in mind the original project focus on continuity of care across the hospital–community interface, the first stage of the research was planned as a quick, quantitative study of people with HIV infection discharged from hospital. We wanted to collect information on the services they used and received after leaving hospital and their views on these services. We also planned to collect information on communications between people's service providers during and after discharge. We intended to focus on the four weeks following discharge,

using weekly diaries where respondents were asked to record service use and views on provision. The diaries were posted to respondents who were asked to return them in prepaid envelopes. In order to elicit users' views on service coordination around hospital discharge, we asked users their opinions of the mix of services they received each week, as well as of the timing and spread of service provision.

The weekly diaries were rarely returned by post, and most of the data was collected by personal follow-up at home by one of the two researchers working on this part of the project. Most of the information on service provider communication and input in care was similarly collected by personal interviews. The study was extended by two months, and the prolonged contact with both service user and provider study participants produced, in addition to the quantitative data, qualitative information on the context and process of service use and the extent of contact and communication with service providers.

The data produced by the survey questions were inconclusive in that they indicated a high level of satisfaction with day-to-day service provision after discharge from hospital. However, the level of satisfaction was lower than that recorded in many other similar studies (Huby *et al.*, 1994). In the course of the study it became apparent that the diary questions were not sufficiently detailed to tap service user concerns about service coordination. These were explored through the open-ended interviews and conversations which increasingly became an important part of the discharge study.

This qualitative material forced us to re-evaluate the focus of the study. We had hypothesised that the main problem for service users was coordination across the hospital/community interface. However, the open-ended interviews with service users suggested that this was not a main issue for them. Of far greater concern was a lack of integration of welfare rights services into the medically focused system of care (Huby *et al.*, 1994). This finding is particularly interesting because interviews with a varied sample of service providers undertaken before the discharge study had not suggested welfare benefits as an overriding concern (Huby *et al.*, 1992, 1993). When questioned specifically about welfare benefit work during and after the discharge study, most service providers talked at length about the time and effort they spent in helping clients with their welfare benefits. However, it remained a "hidden" area of work, perhaps because it was not a part of most workers' job description.

Longitudinal study

The increased reliance on qualitative research strategies meant that, in important respects, the discharge study merged with the second stage of the project, a qualitative and longitudinal study of 16 people with HIV and their service providers. The service users were recruited through services, and four of them took part in the discharge study. Histories of service use and service contacts in this group were recorded for periods up to two years. In the case of 11 service users, selected episodes of their service contacts, and the resulting communications between their service providers, have been studied in detail as "extended case studies" (Mitchell, 1983) in order to capture the dynamics and process of the liaison.

The two main methods used in the longitudinal study were semistructured or open-ended interviews and participant observation. Some interviews were tape recorded and transcribed verbatim. Information from interviews or informal conversations in prearranged or chance encounters, telephone conversations, observation and participation in settings and events was recorded in field notes.

As the project moved from quantitative to qualitative research strategies, the material collected on experience changed. The discharge study was carried out by myself, the author, together with a colleague. Our personal follow-up and interviews with study participants, both service users and providers, meant that we formed closer relationships with study participants, and we increasingly became part of the social system under study. Sometimes we were ourselves party to events recorded. Fieldwork for the next phase was from the outset defined as qualitative, long-term participant observation and carried out by myself alone. The role as an outsider and an objective recorder of people's behaviour and experience was abandoned. This made it possible to collect material on the context and situations in which people articulated their experience to me as the researcher. This material produced insights that enhance the analysis and interpretation of service user statements about "satisfaction".

THE ISSUE OF SILENCE

More specifically, it became clear that what respondents chose *not* to say about their situation and their use of services, both to me and to their service providers, was as important as the statements they did make. Given my growing relationships to study participants, it was possible to see how discussions with service users about their experiences of services became entangled in strategies not only of coping with the illness, but also of negotiating the complex and pervasive system of care upon which they had come to rely. This system helped contain the effects of the infection, but also controlled people's lives, both practically and in terms of the expression of who they were. Respecting and interpreting study participants' silence appropriately, and in a way that informed service delivery, became a major concern, both ethically and methodologically. The following presents extracts from three cases that illustrate different

kinds of "silence" and the issues involved in interpreting these.

Silence as the researcher's problem 1: Mick's avoidance

A common occurrence for both service providers and researchers was the "failure" of service users to turn up to appointments. Such absences were sometimes interpreted as a lack of ability to organise time, or as a failure to cope. Sometimes, however, such absences were interpreted, both by some service providers and by me, as strong statements about a person's experience of the services or the research as intruding and controlling. The following presents extracts from my field diary during the discharge study:

I have come to see Mick and his wife in order to get their story of service use since Mick left hospital three weeks ago. When I spoke to them in hospital they were very obliging and willing to help in the discharge study by telling us about their service use and experience of services after discharge. When given the choice of filling in the diary or me coming out to see them and talk to them, they chose the latter. They gave me their phone number for me to phone and arrange a time one week after Mick had left hospital. I had to call off our first appointment, but I arranged another without any apparent difficulty. I phoned up just before leaving for their house, to make sure my visit was still convenient.

When I arrive, Mick's wife tells me he has just gone to get baby milk, but that he will be back in a few minutes. My heart sinks—I am sure he has left in order to avoid me. However, I accept the invitation to come in and wait. Mick's wife offers me a coffee and a seat in her lounge. I meet two other visitors already there: the family's social worker and a friend who is homeless and sleeping on their floor for a few nights. The wife is talking to the social worker and seeing to me while her two small children are running about. After a while the social worker leaves. Shortly afterwards Mick's drugs worker turns up. He has come to see Mick as well. He waits half an hour. Mick's wife gives him a coffee. The children are still running about, seeking attention. One is being potty trained. I admire her cool. I know I would have cracked long ago had I been in her place. After waiting an hour I leave. Mick's wife is very apologetic. She says Mick had some bad news a few days ago. "But it's time he starts facing up to things," she says. I feel bad. I know my visit has deprived both of them of the opportunity, the space and the quiet in which to do so (field notes, discharge study, October 1992).

The research was carried out in service settings characterised by a high level of commitment to quality care and intensity of involvement in clients' welfare by highly skilled and motivated care workers. There were also a number of researchers working in the settings, and this project added to the number. Seeking care for HIV infection in some settings meant laying oneself open to the scrutiny and sometimes intrusion of a variety of people. One nurse said: "These people—their life is not their own."

The networks in which service providers, service users and researchers operated were close knit, and there was a frequent exchange of information about people and events. People were highly "visible" in many settings, and for service users, this visibility meant that problems were picked up and dealt with. However, the constant attention of care workers and researchers was also a form of surveillance and control, whereby everyday behaviour and lifestyles were scrutinised and evaluated in terms of "appropriate" and "inappropriate" ways of coping.

The way experience was or was not articulated was made the subject of such evaluations. There was an emphasis among some staff on "the confessional" or on "telling it" as a way of coping with feelings of distress. However, service providers and users did not always hold the same view as to the nature of a legitimate or appropriate confession. One woman service user told me:

When I am crying on the ward they [the nurses] tell me: "let it out, Sue, you'll feel better!"...Let it all out!!!!! They don't know what they're letting themselves in for: there's 15 years of abuse in here—the heroin, the prostitution, the rape—if I let it all out, they'd be in danger—I'd smash the place up! (interview, longitudinal study, January 1994).

The nature of a "true" confession was not always challenged in such verbally articulate ways, as the following extracts from a case study illustrate.

Silence as the researcher's problem 2: confronting or avoiding painful issues: Anne

As health service users we evaluate providers' authority, skills and interest in our treatment and adapt our response to them accordingly. We tell different things to different providers and use them differently. The service users recruited to this study were no exception. They also evaluated my own role and personality and made decisions about what to disclose and what to keep from me. At times I was chosen as the audience for people's most intimate thoughts and reflections. Other times I was faced with ethical dilemmas around asking people to verbalise experience and thereby making it immediate in a way the respondent might find distressing and I might not be able to contain. This consideration, together with the potential of the research as intrusion and control, meant that I sometimes erred on the side of caution in terms of inviting confessions, as the following extract from a case study shows.

This case study concerns a woman given the name Anne. She participated both in the discharge study and in the initial stages of the follow-up study, although she died before the latter got fully underway. The data collected about ways in which she articulated her experience with the service system is presented from two sources: the first is constructed on the basis of notes from her verbal responses to my questions about her service use and her experience of services during the discharge study, together with the investigations she allowed me to do into the processing of her welfare benefit

application; the second is constructed on the basis of field notes.

I was seeing Anne from October 1992 (during the discharge study) until her death one year later. I asked her about the services she had seen on her discharge from hospital, and the kind of problems she was trying to address through services. She told me initially that she had no problems on returning home from her many stays in hospital. Everything was fine—she did not see anybody, and day-to-day services worked well for her. On probing, however, major problems regarding her benefits came to light, and our subsequent conversations revolved around her material/practical circumstances. Her application for Disability Living Allowance (DLA) had taken several months, as the Department of Social Security (DSS) had lost the original papers and a new application had to be submitted. She complained about what she saw as lack of communication and information from her welfare rights worker. When I investigated this I found that the welfare rights worker was still waiting for a reply from the DSS.

During the first two months of my acquaintance with her, these benefit problems were gradually being sorted out. Her DLA came through, with a substantial sum in back payment. She and her husband used some of the back payment to install a phone, which made it easier for her husband to get her into hospital if she took ill in the middle of the night. They bought a new automatic washing machine which made housework easier for her. However, their flat remained damp and cold and unsuitable for somebody with chest problems, the main clinical manifestation of her infection.

On a particular occasion in the summer 1993, our last, formal interview, she told me that they had persuaded their housing association to put in central heating in their flat. A counsellor helped them with this. We discussed these developments at length and the progress being made. She remained characteristically optimistic and cheerful. "Hopefully, things will be sorted out in a wee while now," she said.

On the face of it, this is a straightforward account of the problems she was facing, how services had helped her sort them out, and what she thought about the help she had been given. For this woman, medical services and day-to-day support after hospital discharge were not the most important issue. Her unmet needs were material, not medical, and this turned out to be a common feature of people's evaluation of services.

However, there is more to the story. The following account is constructed on the basis of my field notes and memories of her:

I popped in to see Anne on the ward. She is getting so thin. She was sitting hunched over in a chair by the open window. She told me that "Dr Smith [her consultant] has said I haven't got HIV any more—it's AIDS now." She looked really frightened. I did not ask her how she felt about it. Should I have? (field notes, discharge study, November 1992).

During my last interview with her, when she talked about her central heating being arranged and how everything would be all right in a wee while, her eyes told another story. "I know you don't mean this," I thought to myself. I sensed so strongly that the heating of her flat, important though it was, was not the most pressing concern she had at that time. I am also sure that she did not really expect to feel the benefits of her central heating. She died shortly

before the system was put in. I saw her briefly in hospital before she went home to die (autumn 1993). She was sitting propped up in bed, with an oxygen mask over her face. "They have pumped my lung up," she said. "They have done what they can. Hopefully, it will be all right now" (field notes, September 1993).

I interpreted Anne's silence about her feelings concerning her illness and her visible physical deterioration as part of her way of coping with her situation, in terms of both her illness and the system of care on which she relied. She did not talk about what I felt very strongly was her distress to any of her service providers either. She saw a counsellor who is skilled at helping people deal with their feelings about death, and the counsellor had told me she spent very little time talking with Anne about her emotional coping strategies. Most of the time she helped her with practical tasks such as the heating, although she knew there were emotional issues to be worked through.

I tried to show Anne I cared by helping her in practical ways, but I did not press her on the topic of her approaching death, although she once or twice gave me openings to do so and might have wanted me to listen to her. My response to Anne was part of my own general strategy of coping with what I at times found a very stressful fieldwork situation. I invited confessions only in cases where I felt certain I could respond to people's statements of distress in positive and constructive ways. I was able to maintain this detachment because all the service user participants in my study had access to professional help.

However, the comprehensive system of care available to people was not only a solution to, but also a cause of, ethical and emotional issues I faced during fieldwork. Problems of coordination were caused by a large number of service providers, together with blurring of professional boundaries. There were several service providers involved in one person's care and they held different versions of who the person really was and really needed. This complicated the work of service provision and the person's own voice often disappeared in the mêlée of service provider opinions about the right approach to management. A blurring of the research and counselling/provider role in this context seemed a daunting task. I had neither the skills nor the resources to help Anne with her possible distress about dying without professional help and back-up, and there would be few ways I could use the information obtained as counsellor to her practical benefit without adding to the complexity of service provision. The following incident is a case in point:

After Anne had been given the diagnosis of AIDS (a crucial point in the illness careers of many) she had been absent from home a few times when her counsellor and researcher (me) had been calling on her. We asked in the out-patient clinic if they had seen her. We were told that she had defaulted twice—"most unusual of her". We

asked the hospital-based district nurse if she had seen her, and we were told that she had been to Anne's home a couple of weeks previously to give her inhaled drugs against pneumonia, and that she had seemed OK, but that she and her husband "had been drinking". By now, all these stories begged the question: had she not been able to cope with her AIDS diagnosis? Was she in crisis somewhere?

I caught up with her a while later. She seemed fine. She said she had been ill with a chest infection and had had to call out her GP; that accounted for one of her missed out-patient appointments. The second appointment she had been busy helping a relative who had been ill. I did not ask her about the drinking. It was coming up to Christmas, and we were all drinking more than usual anyway (field notes, December 1992).

Nevertheless, the role adopted by the researcher *vis-à-vis* respondents influences and structures both the collection and interpretation of information (Gold, 1969; Bourdieu, 1990), and my reluctance to get involved no doubt closed off avenues of data collection as far as emotional issues in service use and relationship to service providers are concerned.

My discussions with Anne about her material circumstances were thus within a "safe" emotional territory. She was silent on other issues. Was this her carefully reflected way of coping with her situation? Was there a language available to her, public or private, in which to articulate her feelings? Were there other ways and other relationships available to her in which she communicated and shared her experience?

My fragmented and incomplete insight into Anne's experience of her situation mirrored the relationship service providers had to some of their clients, as the following extract from a case study illustrates.

Silence as a service provider problem: Neil's consultant

The following is an extract from a case study where I was chosen as the audience for detailed reflections on the person's approaching death, whereas a service provider, in this case a consultant, was excluded.

The case presents extracts from two tape recorded interviews, the first with a service user who will be called Neil. During this interview, when I asked him to describe his relationship with his service providers, he explained why he employed a strategy of avoidance with his consultant. The second interview was with Neil's consultant, who describes the effect of Neil's behaviour on his work as a doctor. Neil considered the consultant his most important service provider, and, as the only person who could avert his visibly approaching death, also the most powerful.

Neil's community nurse, who came to see him in his home regularly, knew about his wish to avoid open discussions about his condition with the consultant. She had told his consultant not to tell him that he had AIDS. She made sure it was written all over his hospital nursing notes, so that out-patient and ward nurses would not tell him either. This is what Neil told me about his relationship with the consultant:

Neil (N): ...You go in and see the consultant, right, he reduces you to tears, almost.

Guro Huby (GH): He does?

N: Aye, but he's only doing his job, but it's the way he comes out with things, you know what I'm talking about?

GH: In what way?

N: I just dinnae ken. It's just...he's no being nasty, he's just telling you the truth, he's telling you this, that and the next thing, he's asking you questions, he's just got this thing that he almost reduces me to tears every time I go into his room, ken, because—that's what I'm saying to you—I ken what he's, what he's trying to tell me with the questions that he's asking, ken, he's no wanting to tell me straight, if there's something serious wrong.

GH: He's not?

N: No, because he's asked me that. He actually asked me my opinion.

GH: Oh, right?

N: "Do you want to know if anything serious was wrong?" I says, "no, I dinnae think I would," because I would probably panic, ken whit I mean. So, like, but when he asked me a question, I can tell what he's getting on about, ken whit I mean. And then I go home and check whatever out that he's been talking about. And then I know that I'm that wee bit closer, ken, sort of thing.

GH: Well, would it not be better then if he just told you, since you know so much?

N: See, I dinnae ken, because like if I dinnae ken, right then I can just go on thinking how I'm thinking and then I know I'm going to get really ill one day and I'll have to go to the hospital but that's that because I'll probably not know much about it anyway when that day comes, ken whit I mean. But I think if I was to go to the hospital one day and he was to say: "Neil, you're thingmied, you've got AIDS now. You've got a wee touch of this and touch of that", I'd probably just go out and dae myself in or something, ken whit I mean. Because I wouldn't want my family to go through sort of two or three months period it would take me to die, ken whit I mean (interview, longitudinal study, February 1994).

Neil was taking AZT, which was prescribed for him by his consultant. The consultant needed to see Neil regularly in the hospital out-patient department so that he could check for side effects to his AZT. However, Neil very rarely turned up for his regular appointments. In the end, the community nurse offered to take blood samples during her routine visits to Neil so that the safety of AZT could be checked. The following interview extract illustrates the consultant's reactions to Neil's use of him as a service provider:

Consultant: He is the most maladjusted person as far as his HIV is concerned. He has had 19 DNAs (failed appointments). You know—over the last six months—I sat down and made a count...He really has pushed and pushed the limits of what a patient is. As if he feels that I have no other patients than him. I have told him time and time before—I expect you to behave like a patient. I can-

not have you fill up my appointments and then defaulting, because somebody else could have seen me in that time, so we had a long chat about it. He still does not turn up. I'm not giving him any more appointments. I am not going to push myself on him, if he wants an appointment he has to phone up and it's up to him if he wants to take it up or not (interview, longitudinal study, August 1994).

Neil, on his part, had a reflected approach to his hospital visits:

Neil: ...But I hate going to hospital. Because it brings everything back to reality, ken what I mean. You realise you have got HIV. You are going to die, ken, all that comes flooding into your head when you go to the hospital. Then you're getting blood taken, you're giving urine samples, everything, ken. And then just, I don't know, when I'm in the hoose I don't think like that, ken what I mean. I just get on with it sort of thing (interview, longitudinal study, February 1994).

Neil was able to talk to his nurse and to the researcher—a comparative stranger—about his thoughts on death, while he chose to avoid the consultant. This avoidance was causing considerable problems for his doctor who, not unreasonably, interpreted this as unwillingness to face up to his situation. However, based on statements Neil made to me, his behaviour towards the consultant can be interpreted as powerful, rational and well reflected statements from him about his experience of the service system. I interpreted Mick's avoidance of me in a similar way, while I lack the information with which to interpret Anne's silence about her reactions to her physical decline.

PROVIDING ANSWERS: A RESEARCH DIALOGUE

As a researcher, I found myself facing similar problems to those of a service provider as far as interpreting service users' experience about their service provision was concerned. How, then can research inform service provision in any meaningful way? The following dialogue between myself and a service provider participant in the study illustrates the difficulties.

As an action research project, this study was designed to help service providers offer a good quality service by feeding back material on service provision and coordination and its effects on service users' lives. The effects of this feedback was also captured. An example of this feedback process illustrates some of the issues involved in representing service users' experience to providers of services.

Based on the qualitative material collected during the discharge study, we prepared an informal discussion paper about the culture of service provision in a particular service setting. This paper was circulated among the relevant service providers. One of the arguments was that the large number of service providers in the setting, together with a high rate of information exchange and an ethos of liaison between services, paradoxically prevented a "person-centred approach" to service provision.

The service user's voice and expression of experience were at worst blocked out of, at best distorted by, the exchanges of information between service providers.

We cited the example of a woman, Pat, and the way she was being discussed in a multidisciplinary meeting. We wanted to illustrate how people's coping abilities were sometimes overlooked by service providers, and potential distress and need for counselling and emotional support emphasised.

Pat had sorted out her family's benefits herself by dealing directly with the DSS. Shortly before her partner became seriously ill, she managed to jump the housing queue by contacting her local councillor, who helped her get a ground floor housing association flat. She then nursed her dying partner. Her service providers, particularly the nurses, were worried about her ability to cope and anticipated problems after her partner's death. This is how she was described in a meeting:

Pat—yes, she is doing well, but she is doing too much! She is taking on too much and may not be able to cope much longer. We have offered her counselling, but she will not accept it (field notes, discharge study, January 1993).

We wrote in the paper:

Was this woman denying and suppressing her own grief and her own need? Is an emphasis on practical, material problems a way of hiding from emotional issues which should be worked through and addressed? These questions may be particularly pertinent in a field such as HIV and AIDS, where so many services are on offer, and where one way of making decisions is to "vote with one's feet." Who has the knowledge, the power and the right to define and articulate this woman's needs?

In response to the paper, a service provider (female) wrote:

This [case] is very important. It occurs to me that you are not commenting or making judgements. Is that what you intend? This case is not unusual, and I'll bet loads of people had promised help in the matter. She was more effective herself in the end.

You're posing a question and dodging making an answer—or even giving the different possible answers. Of course it is better for her to have sorted it out herself. (They are often much better at it because they are more assertive and less polite than the providers).

How dare people say she is doing too much. How paternalistic/(unfortunately) maternalistic! That quote from the meeting leaves me gasping—although I can see that, in some circumstances, I might have made it myself.

More questions—be brave and give some potential answers (letter, February 1994).

Eight months later, this service provider reminded me that I still had not given her the answers.

Service provider (SP): You have been studying us for two years, Guro. Surely you must be able to come up with some answers now!

GH: But I have given you all the findings I've got! What do you want to know?!!

SP: We want to know if we're doing the right thing!

This service provider deals competently and on a daily basis with confusing, ambiguous and complex situations. She had supported our research project in numerous ways. Not unreasonably, she would have liked me to render her own and others' behaviour and experience explicit, accessible and rational. This I could not do, for I knew no more about service users' "real" experience of the service system than she herself did. When it came to providing answers, I was clearly failing her.

Statements about experience, which become the object of our academic descriptions and analyses, are never clear, explicit or unambiguous because they are made in social situations produced by complex, intersecting and competing relationships of power and interests. In this project, statements of experience were elicited from both service users and a variety of service providers all occupying different structural positions in the system of service use and provision. This methodology, together with the perspective on "narrative" outlined earlier (Good, 1994), allows us to see this social complexity coming through in the stories respondents told us about their experience. Several issues, both political and epistemological, must be addressed and the relationship between them considered before appropriate answers can be given to the service providers in this setting about the effect of service provision on service users' lives.

DISCUSSION: THE EPISTEMOLOGY AND POLITICS OF INTERPRETING STATEMENTS OF EXPERIENCE

In the introduction to this paper, the dynamics of power were suggested as determinants of the language in which information is encoded and, on a deeper level, as producing discourses which structure experience and the significance of objects and events to which experience attaches. "Experience" of or "satisfaction" with health services, together with their expression, are thus entangled in complex social dynamics. The role of a research project in enforcing or illuminating these dynamics must be critically appraised. The role taken on by researchers in interaction with respondents, the use of language and the epistemological status given to statements respondents make are therefore not only of theoretical interest, but they have political consequences as well (Good, 1994). For example, this project was originally designed to study the coordination of care between hospital- and community-based services. The planned quantitative methodology for the discharge study, had it succeeded, would have perpetuated the silence that surrounds the economic and structural production of material needs in a whole population and reinforced the projection of "needs" to the level of individual physical and emotional response to HIV.

The structure/agency debate within anthropology and sociology has a long history and has been vital in fuelling theoretical and methodological development. Teasing out the personal and the structural in people's expressions of experience is particularly important in an action research project where the aim is to change services in ways which improve people's satisfaction. However, understanding the way respondents themselves articulate the relationship between their personal experience and the wider social forces which influence this experience is by no means unproblematic. The problems can be seen as conceptually inherent in the relationships between experience, language and power.

Experience and language

Private and personal emotions and experience are not necessarily and straightforwardly expressed in language (Good, 1994). Studying and making sense of emotions and ways of coping with distress therefore raise problems of communication and interpretation. Thus, Foster (forthcoming), in his study of family support and informal caring in Edinburgh families where one or more members has HIV, found that the language in which people express their experience of HIV is poorly developed. Rather than talking about this experience directly, people use public narrative and stories to give expression to personal emotions and experience (Foster, forthcoming). Respondents may use the relationship to a researcher as an intimate and culturally safe escape from official discourse and the way this restrains the expression of private emotions (Wikan, 1987), but the researcher cannot assume that the words used evoke the same experience in the teller of the story, the researcher listening, and the audience reading the researcher's account of the story (Good, 1994, p. 140).

Emotions have their own unspeakable force, the intensity of which is not necessarily reflected in the form in which they are expressed—be they ritual, symbols or language. Rosaldo (1989), who worked among the Illongot in the Philippines, describes how he struggled to understand how Illongot men associated the grief of bereavement with a rage that could only be alleviated by head hunting. This association was described in the barest of terms, as a fact which needed no elaboration or explanation. The full force of this association only made sense to him when he was himself faced with the death of a close family member. The aim of ethnography has been termed "thick description" (Geertz, 1973) of the way research participants interpret, construct and assign meaning to their physical and social environment. However, with Rosaldo, we are forced to ask whether people in fact always describe most thickly what matters most to them (Rosaldo, 1989, p. 2).

Language and power

Articulations of experience as studied in this project took place in settings in which relationships are structured by professional power and authority. Power has been suggested as an important dimension in communication between service providers and patients in medical settings. For example, in settings where persons in authority, often the consultant, take on the role of the sole communicator of potentially distressing information, the relationships between patients and staff are often strained and difficult (Field, 1992; James, 1993).

Power dynamics also affect the content of communication. Literature on the changing nature of communication about death and dying in medical settings documents how discourse about death has changed during the last century. According to Aries (1981) medicine's "100 years' conspiracy of silence" about death was broken in the 1960s, and there is now an emphasis on openness about death in interactions between medical personnel and their patients. Glaser and Strauss (1965) identify four possible types of "awareness states" between service provider and user in the management of chronic terminal illness: closed awareness, suspicion awareness, mutual pretence and open awareness. Kubler-Ross (1969) describes natural stages in the process of coming to terms with death and bereavement: denial, withdrawal, anger, and acceptance. Thus, an ideal state of mutual awareness and acceptance is held up as a goal and possibility for medical staff in communication with dying and chronically ill patients in medical settings, including settings selected for this study. However, "open awareness" and "acceptance" of death are complex experiences which are often articulated differently by the dying, their relatives and the medical staff bringing the news of impending death (Timmermans, 1994). Thus Neil, who explicitly avoided open awareness with his consultant and was seen by the latter as not coping, was fully aware and accepting of his approaching death in other situations.

Armstrong (1987) argues that the new openness about death is not simply a matter of old truths and experience about death finally being liberated from repression by medical power. Rather, a new discourse about death has emerged, which has created new truths about death and dying. Before the 1960s the "truth" about death was to be found in the physical properties of the body, while personal reactions to dying were a silent part of a great secret surrounding the event. The "truth" is now sought in the psychological and interpersonal space surrounding the physical act of dying. With this have come ideas of "right" and "wrong", "healthy" and "unhealthy" ways of communicating about death. This regime of truth has brought with it new powers of medical interrogation and control. Denial of death is no longer a natural part of the great secret; it is a state to be diagnosed, examined and corrected.

The service settings studied here illustrate the way a comprehensive system of services provides effective support to people with terminal illness, but that this support also involves some scrutiny and control over people's personal ways of managing HIV and its effects. From this perspective, acts of avoidance and silence documented here may be seen both as individuals' reactions to their illness and the system of care on which they have come to rely, and also as a political statement about this system.

Lack of language that articulates and promotes a certain experience and point of view has been seen as a response to power. For example, anthropologists studying gender point to the political strategy in women's lack of a public language. Avoiding or refusing to engage in a debate where the stakes in power are unequal has been suggested as one way for powerless people to deal with power (Ardener, 1975). Absence of a certain kind of language does not mean that arguments are not well reflected, however. Neil's response to the consultant and Mick's avoidance of me can reasonably be interpreted as conscious decisions to avoid a powerful and invasive system of medical intervention and research which disrupted their way of coping with their situation. Anne's silence must remain just that: her own silence which is not for us to interpret.

In all cases, however, understanding and interpreting their reactions raise the problem of relating the personal and political in other people's ways of engaging with the world—and with researchers. Abu-Lughod (1990) puts it particularly well:

...how might we develop theories that give people credit for resisting in a variety of creative ways the power of those who control so much of their lives, without either misattributing to them forms of consciousness that are not part of their experience...or devaluing their practices as prepolitical, primitive, even misguided (Abu-Lughod, 1990, p. 47).

These are questions at the forefront of theoretical and methodological development within anthropology and sociology. Meanwhile, like the doctors communicating about death with their patients, researchers tread a fine line between liberating experience and suppressing or controlling it. In writing the story about the project and the way we reached our findings, the silences, ambiguities and lack of clarity are vital in opening up the account and enabling readers to engage with respondents. Researchers and service providers alike face the challenge of recognising the power of silence.

CONCLUSION: IMPLEMENTING RESEARCH FINDINGS

Service providers participating in evaluation research often expect clear and unambiguous statements of service user experience. The dilemma

facing researchers is that the language of policy and action is precisely the language which often masks or distorts a service user perspective.

In important respects my knowledge of service user experience was as incomplete and fragmented as that of service providers. However, although my own problems and those of service providers were similar in terms of interpreting service user experience, the position from which we reacted to these problems was different. As a researcher, I am obliged to strive for detachment and reflection, while the service provider strives for involvement and action. It is my own subjective understanding of service user experience, and the way I arrived at this, which can most responsibly contribute to service provision in this setting.

Paradoxically, findings from the study suggest that, in order to understand service user experience and apply this understanding in practice, the providers need to avert their scrutiny away from the client/patient and direct it upon themselves, their own motives and perspectives, and the way their position in a system of surveillance conditions their understanding of the persons they are trying to help. How do service providers reach their own subjective understanding of a service user? How does this understanding inform interaction with the service user concerned, and how does this understanding affect communication and coordination with other service providers involved in his/her care? In the course of such reflection, issues of power and authority, both in service user–provider relationships and in interprofessional relationships between providers, need to be addressed.

Effective communication between service user and provider is not simply a matter of personal skills, but also of engineering systems of communications where people are heard. The research has had some effect in changing systems of communication. Thus, in the final meeting of the Project Advisory Group, I continued my discussion with the service provider who had asked me for clear answers, and I asked her what action she saw stemming from our research reports. She said:

Of course I know why you cannot give me clear answers...I think I will go back and encourage people to look again at how we organise our patient meetings.

This reorganisation of meetings is still ongoing and its outcome remains to be seen.

This project illustrates the tendency within evaluation research and "needs assessment" to define relevant "needs" as those which are provided by an existing system of formal services. The system in this case was hierarchical in the way some services and some needs were given prominence, while others, e.g. welfare benefits, were marginalised. Partly as a result of our findings from the discharge study, and our dissemination of them, a part-time welfare rights post has been funded, and a hospital social work post has been "unfrozen". However, welfare benefits services remain peripheral to the medically focused service system.

This paper is written from the perspective that experience is formed and articulated in everyday action. Changing the perception of "need" among providers and funders of services may require structural changes in the service system which alter providers' daily practice and interaction with clients. Academic and research arguments do not necessarily have the political force to bring about the structural changes needed. This issue needs to be addressed if research is to be an effective avenue for users' influence on health services.

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