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A SYSTEMS APPROACH TO MODELLING SERVICES FOR PEOPLE WITH DEMENTIA

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CONTENTS

LIST OF TABLES

LIST OF ILLUSTRATIONS

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DECLARATION

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ABSTRACT

Dementia is a condition whose causes are poorly understood, which cannot be cured and for which current treatments have marginal effects. It is estimated that some half a million people in the United Kingdom have it. There are important implications for the health and social care services that support them, and care of people with dementia has moved rapidly up the health and personal social services policy agenda in recent years.

The thesis has three objectives. The first objective is to understand the extent to which systems science approaches are appropriate and useful in a 'soft' domain, using the organisation of formal services for people with dementia as an example. The second objective is to assess the extent to which systems science approaches can be used to provide insights into the chosen domain. Although there have been some excellent studies the domain has not been extensively investigated, and the thesis provides an opportunity to develop understanding of the nature of service delivery. A case study approach, employing both qualitative (eg. influence diagrams, qualitative System Dynamics) and quantitative (Markov Cohort analysis) methods, is used to achieve the first two objectives.

The third objective is to understand the influence of two important elements of government community care policies, namely the flexibility and co-ordination of services, on the organisation of services for people with dementia. While the first two objectives focus on the detail of methods and patterns of service delivery, the focus here is on wider sytemic issues. Taking these three objectives together, the thesis hypothesis is: Can a systems science approach be applied in this apparently 'soft' domain, to produce new insights and knowledge?

It is concluded that both 'hard' and 'soft' approaches can provide useful insights into the nature of the domain. In contrast with some authors, it is argued that there is no simple relationship between research problems and systems science methods. Rather, thorough understanding of a domain is required, so that any one problem 'induces' the use of some methods rather than others.

The case study results confirm some of the observations made by other commentators about the domain, particularly in relation to the poor co-ordination of key aspects of service delivery for people with dementia. The results provide additional insights into the behaviour and attitudes of key decision-makers, which help to explain some of the observed problems in implementing successful community care policies on the ground. The policy analysis highlights the limits to the flexibility and co-ordination of services that can be achieved in the domain, given the current professional and organisational divisions between the services provided to people with dementia.

CHAPTER 1
INTRODUCTION

1.1 Introduction

The subject of this thesis is the movement of people with dementia from the community to long term institutional care. This movement involves an inherently complex set of pathways and decisions, with several parties typically involved. Aspects of the decision concerning entry have been investigated in the past, and these have enhanced understanding of the circumstances that surround decisions and some of the factors that make the use of particular patterns of care more likely. There are, though, many aspects of the decision-making process which are not well understood. The thesis explores the decision, using detailed data obtained from case study sites. Several different systems science approaches are used to characterise the domain and to help explain observed patterns of movement from community to institutional care.

These patterns have been substantially influenced by national policies. The National Health Service (NHS) and Community Care Act of 1990, and a sequence of important policy documents published over the last six years, still dominate the policy agenda in health and social services in this country. They have set in train profound changes in the funding and organisation of both services, and have lead to considerable analysis of the likely nature and destination of the new policies (Flynn et al., 1996; Lewis and Glennerster, 1996; Malin, 1994; Ovretveit, 1993). Sitting as it does at the boundary of the two services, the decision to enter institutional care serves as an indicator of the extent to which the new policies are consistent and co-ordinated, and enhance or diminish the lives of vulnerable members of society. Given the importance of these policies, the thesis also explores the extent to which two key concepts - namely the co-ordination and flexibility of service delivery - are likely to influence the design of services for people with dementia in coming years.

In order to deal with the complexity of the domain, appropriate methodologies and methods must be selected. The approach chosen in this thesis is to use a variety of tools, within a broad systems science framework, and is thus consistent with the eclectic stance advocated by Flood and Carson (1993). The following sections of this chapter define dementia, specify the objectives for the thesis, present the rationale for the methodology used, and outline the structure of the remainder of the thesis.

1.2 Dementia Defined

Dementia is a condition whose causes are poorly understood, which cannot be cured and for which current treatments of symptoms have at best marginal effects. Dementia affects a significant proportion of the population of elderly people in developed countries, and it is estimated that over half a million people in the United Kingdom have it. There are thus important implications for the health and social care resources required to support them, and care of people with dementia has moved rapidly up the policy agenda in recent years.

The term dementia refers to a constellation of signs and symptoms reflecting global impairment of higher intellectual functions. It involves progressive deterioration of the brain, the principal causes of which are Alzheimer's disease, strokes and alcoholism. Dementia thus refers to a cluster of organic disease processes which manifest themselves as changes in cognition and behaviour. Dementia is believed by most authors to be an irreversible condition, though some (for example Byrne, 1987) argue that there is a class of reversible dementias, due to problems with the thyroid and with vitamin B12 deficiency. Dementia can also be a consequence of other diseases, notably Creutzfeldt-Jacob Disease (see Keen, 1992: Chapter 1).

At present there is no convincing explanation for the origins of the changes that occur in dementia, although both genetic and environmental factors are implicated, and there is a great deal of research being undertaken into the biochemical basis of the disease processes. The Royal College of Physicians (1982) gave the following definition:

> "Dementia is the acquired global impairment of higher cortical functions including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills, all aspects of language and communication and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often progressive though not necessarily irreversible."

In most cases, particularly in Alzheimer's disease, onset is slow and takes months or years to develop. Many people never progress beyond a relatively mild form of dementia, and are conscious and quite able to hold conversations, even though some mental functions are impaired. In other people onset can be very rapid, from normality one week to severe dementia the next, where memory and other functions are grossly impaired. Whatever its time course, the presentation of dementia can be highly variable for any one person, particularly in the degree of confusion and memory loss on successive days. But in all cases, the clearest indicator of dementia is marked memory loss, particularly of recent events.

At the time of writing only one drug, Aricept, has been given a UK licence specifically for treatment of the symptoms of dementia, and this is proving too expensive for some health authorities to fund (Murray, 1997). However, a great deal of work is being undertaken by drug companies to develop new drugs, particularly for the treatment of memory loss, so more effective drugs may become available in the next few years.

Described from the point of view of the person with dementia, its principal characteristics include (King's Fund, 1986):

- Memory. The fade-out time of current memory become faster, so that it is difficult to hold material in the mind. Concentration is therefore affected and becomes poor. Inappropriate memories of long ago may appear as current events.
- Orientation. The ability to recall 'where and when it is' increasingly dominates existence. The clues as to who other people are become increasingly difficult to recall.
- Confusional states. Physical illness frequently occurs during the course of dementia and gives rise to greater temporary mental disturbance. Drugs and social and environmental changes may have similar effects.
- Dysphasia. An inability to recognise or name objects, including everyday objects such as pens and watches.
- Grasp. Greater difficulty is experienced in teasing out what is going on and what is being said. This is particularly so if events move too fast, with little repetition to aid memory, or if a whole series of concepts are rapidly introduced.
- Communication. On top of the stresses described above, there is a restricted power of communication, so that even if something is available in memory it is not expressed.
- Depression. The stress of the failing mental mechanisms may cause normal reactions such as anxiety or depression. Sometimes the reaction may become severe enough to cause serious agitation or even misinterpretations, delusions and hallucinations.
- Other characteristics. Some people with dementia may experience paralysis or abnormal body movements. Others may wander around

their environment - and those that do may be physically very fit for their age.

Dementia is distinguished from other conditions by the global nature of its effects: people have several of the above problems rather than any one alone. In addition to those listed, the massive changes in the brain can cause physical problems, notably with urinary and faecal incontinence and with mobility. These are all important problems, but it should be stressed that many people appear to outside observers to be quite happy in themselves.

Dementia can, though, look rather different to those who do the caring. The majority of people with dementia live in their own homes and are cared for by relatives or friends. The great majority of them want to do the caring, but it often involves full time commitment. The relentless and often physically demanding nature of caring can cause them stress and illness. The progressive nature of dementia means that satisfaction cannot be gained from improvements or remissions in the status of the person with dementia. The result is that dementia is also very much about those who do the caring.

It is also about formal health and social services, and the extent to which they can and should provide treatment and care. Providing services for people with dementia has proved to be one of the greatest challenges in community care. Dementia has consequences for both the health and social services, and general practitioners (GPs), social workers, home help organisers and many others can be involved. There are therefore many questions that can be asked about the organisation of these services, and the extent to which they are successful in supporting people with dementia and their carers.

1.3 Objectives For The Thesis

The domain of interest in this thesis includes the activities surrounding the movement of people with dementia from community settings to institutional care. The domain is investigated through different qualitative and quantitative modelling approaches, which focus on the organisation and delivery of formal health and social services. The model building process is used to explore both the modelling approaches themselves and the nature of the domain. There are three main objectives for the thesis.

The first objective concerns systems science approaches. The domain is a complex human system, and provides a test of the value of existing systems science methodologies and methods. There has been considerable debate about the extent to which 'hard', positivist approaches to modelling are appropriate in situations characterised by relationships between people - rather than situations dominated by problems of machine design. This can be traced back more than 30 years through a number of prominent authors including Ackoff (1974), Checkland (1980) and others (see Rosenhead, 1989). The objective, therefore, is to understand the extent to which systems science approaches are appropriate and useful in this 'soft' domain, and identify their strengths and weaknesses.

The second objective is to assess the extent to which systems science approaches can be used to describe and explain the patterns of service delivery within the domain. Although there have been some excellent published studies (for example Challis et al., 1995; Levin et al., 1983, 1989) the domain has not been extensively investigated, and the thesis provides an opportunity to further understanding of the nature of service delivery and the factors that might enhance or inhibit the provision of effective services. A case study approach, described below, is used to investigate the domain.

The third objective is to understand the influence of two important elements of government community care policies, namely the flexibility and co-ordination of services. While the first two objectives focus firmly on the detail of methods and patterns of service delivery, the focus here is on wider sytemic issues. In recent years great stress has been laid on concepts such as flexibility in service delivery and good co-ordination of health and personal social services. There have been some helpful general commentaries on the extent to which these concepts are internally consistent (eg. Lewis and Glennerster, 1996: Chapter 9; Morris, 1994), but they have not been applied to the domain of interest in this thesis. The thesis therefore presents an analysis of these two important planks of policy, and discusses their implications for the domain.

Taking these three objectives together, the thesis hypothesis is: Can a systems science approach be applied in this apparently 'soft' domain, so as to produce new insights and knowledge?

1.4 Methodology: Outline

The field of enquiry which is described as systems science, or sometimes just systems, is recognised by many of its practitioners as diverse, and the range of methodologies and methods employed is wide. Several authors have offered classification schemes which allow people to locate different approaches within a broad church (eg. Flood and Jackson, 1993).

The complexity of the domain offers both constraints and opportunities for research. The constraints include the uncertainties surrounding the identification of dementia, its variable presentation and time course and the fact that personal circumstances and local services are far from uniform. There is little, on the face of it, that can easily be standardised about the provision of services. But there are opportunities too, which stem from the fact that the domain has become increasingly important over recent years.

As a result, it has received attention from a variety of perspectives, and these provide a useful starting point for this study.

At the outset it was not clear that any one approach was ideally suited to the domain. Accordingly, three different approaches were explored. In the first, detailed empirical studies were undertaken, which were designed to explore the domain from different perspectives. These studies were used as the foundation for later model-building processes, with fieldwork and model-building feeding off one another in an iterative process. The approach is designed to avoid one of the major criticisms of systems science - and also of Operational Research (OR) - namely the inappropriate application of particular methodologies or techniques. Burrell and Morgan state:

> "The selection of a particular type of analogy to represent a system in advance of a detailed analysis of its structure and mode of operation is akin to prescription in advance of diagnosis. This has been the principal problem with systems analysis in social science." (Burrell and Morgan, 1985: 68)

In the first instance, then, a conservative approach to modelling the domain was taken. The characteristics of professionals involved in decisions, and their attitudes towards one another, were obtained through detailed interviews. Quantitative data about the services received by people with dementia and their entry to institutional care in a case study area were analysed. The case study was conducted as a summative study, and one moreover where the researcher was essentially independent of the main actors, and did not seek to alter local practices.

The second approach used particular systems approaches as overall frameworks for investigation of the domain: to avoid Burrell and Morgan's criticism, these were only chosen after initial fieldwork has been completed. In this thesis the domain of interest is analysed using different frameworks including cybernetics (Beer, 1979, 1981) and soft systems methodology (SSM: Checkland and Scholes, 1991). The recent history of systems science has seen a shift from 'hard' to 'soft' systems approaches. In this thesis both are found to be useful, and it is suggested that 'hard' approaches can be used to advantage in apparently unstructured domains.

The third approach is linked to, but distinct from, the second. Rather than model a specific domain, important general features are abstracted and relationships between them explored: this is the policy analysis designed to achieve the third objective of the thesis. Van Gigch (1993) describes this more abstract modelling process as meta-modelling, though it is also consistent with some of the thinking of 'soft' systems and OR practitioners. It might be described as 'systems thinking as guide', in contrast to the 'systems thinking as framework' in the second approach. The turbulent backdrop of new community care policies makes this a necessary step in understanding the nature of the domain of interest: it is necessary to understand both the 'foreground' of detail revealed in the case study and the policy 'background'.

There are also two sub-themes running through the thesis. One is concerned with the relative value of different modelling approaches in complex domains, and the extent to which abstraction from a specific domain actually leads to understanding of the detail of that domain. The second theme concerns the extent to which systems science can offer a single integrated methodology or a useful 'toolkit' of methodologies and methods. These sub-themes highlight particular issues that cut across the three main themes.

The methodology described here does not, inevitably, address all of the questions that might be addressed. In order to ensure coherence, the thesis focuses on issues relating to the organisation of services, rather than on individuals or their carers. People with dementia are ever-present, in the sense that they are the people who move through the systems being studied. Much of the analysis and discussion is, though, about the people who provide services and the systems within which they work.

One consequence is that it is not possible to make any judgements about the merits of different combinations of services: the thesis does not, for example, investigate the relative merits of living in one's own home or in an institution. This is because the thesis does not attempt to link patterns of service delivery to measures of outcome for people with dementia. Rather, it characterises the systemic nature of the formal services provided within the domain, identifies the many different pathways of care available, and seeks to understand the factors that led to the particular form of the systems observed.

1.5 Structure Of The Thesis

The following chapters of this thesis explore different approaches to modelling the decision to enter institutional care. Chapter 2 has two purposes. The first is to outline the general methodological approach used in the thesis, and the chapter expands on the outline in the last section. The second is to identify and describe methodologies which are to be used in subsequent chapters.

Chapter 3 provides a general overview of the domain, from the perspectives of people who have dementia and their informal carers, and of the providers of health and social services. It gives background epidemiological information about dementia, which is important in designing studies and interpreting results in later chapters. Chapter 4 discusses the relevant literatures on the delivery of services and on government policies affecting those services. Chapter 5 presents an initial conceptualisation of the domain, based on the material presented in earlier chapters, using SSM (Checkland and Scholes, 1991).

In Chapter 6 the roles of the people who make decisions, including GPs and social workers, are investigated. The chapter presents case study material, which emphasises the extent to which decisions may be made on the basis of proximate 'crises' such as illness in a carer, rather than on the basis of individual client health or social needs.

Chapter 7 presents quantitative evidence of the movements of people with dementia within and between health and social services, based on fieldwork conducted in Kirklees in Yorkshire. A cohort study was conducted, which followed the movements of people with dementia over one year. A decision analytic approach was used to analyse their movements, and the referral decisions that led to those movements. Chapter 8 reports on a cross-sectional study, also undertaken in Kirklees, where the data were analysed using System Dynamics. The analysis includes information about the capacity of the local health and social services for people with dementia - for example the numbers of hospital beds available. The analysis therefore provides additional insights into the behaviour of the system, and the opportunity to model the system so that the effects of any changes in capacity or referral patterns could be explored.

The next two chapters discuss the third approach noted above, where essential features of the domain are abstracted and analysed in detail, in order to shed light on the way that it operates. Chapter 9 discusses flexibility, which is widely deemed to be a desirable property of community services, but which is poorly defined. Flexibility is defined, and the extent to which it is feasible or desirable in the domain is discussed.

Chapter 10 investigates collaboration in service delivery, in so far as it affects services for people with dementia. Community care policies depend in important measure for their success on effective collaboration across the traditional binary divide between health and social services. However, the two services have grown up with separate cultures and values, and have a patchy record of joint planning and financing, and effective collaboration will not be easily achieved.

Chapter 11 discusses the extent to which the different approaches presented in earlier chapters are useful in the domain of interest. Proposals are made about the most useful approach to modelling the domain. Chapter 12 is the conclusion of the thesis. It reflects on the extent to which different approaches have enhanced understanding of the domain.

CHAPTER 2

SELECTION OF APPROACHES AND METHODS

2.1 Introduction

The purpose of this chapter is to identify conceptual approaches and select methods which are appropriate to the objectives of the thesis. Noting Burrell and Morgan's quote in Chapter 1 about the risk of selecting the wrong analogies for studying problems, it is important to try to avoid mistakes here. Avoiding mistakes is difficult, though, because the frameworks currently available for matching systems science approaches and methods to problems are not well developed, and no framework is generally accepted. This chapter therefore considers:

- Which broad strands of systems science thinking are appropriate to the domain; and,
- How to tackle the problem of identifying approaches and methods. One selection framework, Total Systems Intervention (TSI: Flood and Jackson, 1993), is used here to explore the issues involved.

Arguably, the thesis is itself a test of the appropriateness of the approaches used in the domain

2.2 Systems Science And Systems Theory

The academic field of systems science is broad, and it is useful to start by identifying the part(s) of the field that might be relevant in the thesis - that might be used to provide the most useful insights. Systems science is generally presented as being a product of two distinct but related intellectual traditions, systems theory and cybernetics (Flood and Carson, 1993: Chapter 1). Systems theory was first proposed by von Bertalanffy in the 1940s (see his 1968 book, 'General Systems Theory'). Reacting against what he saw as an over-emphasis on reductionist thinking in science, he emphasised the importance of the arrangement of, and relations between, the constituent elements of any system. The interactions of the different elements led to new - emergent - properties that were products of the particular arrangement of elements, and not of the individual elements themselves. Cybernetics, derived from the Greek word for steersman (*kybernetes*), developed from the work of Claude Shannon and Norbert Wiener. It is concerned with identifying general laws of communication and control in complex systems.

Systems theory and cybernetics start from the same basic premise, which is that there are fundamental principles of organisation of any complex system, and these fundamental principles are independent of any domain. If there is a distinction between systems theories and cybernetics, it is that systems theories focus more on the *structures* of systems, whereas cybernetic theories focus more on how systems *function*. In the domain of interest here, these theories will be used as a source of concepts for understanding the actions of individuals and organisations.

These descriptions raise questions about the definitions of the terms 'system' and 'complexity'. Checkland and Scholes (1991: page 4) note that there are many definitions of 'system' available in the literature, but all take as given the notion of a set of elements mutually related such that the set constitutes a whole having properties as an entity. Checkland argues that:

> "The core notion is that of a whole in an environment which is delivering shocks to it. It may contain smaller wholes, and may itself be part of a larger whole. This gives us the idea of a layered or hierarchical structure. And if that whole has processes of communication and processes of control, then it might, in principle, adapt and survive in a changing environment." (Checkland, 1992:1025-6)

Here, the different wholes may include individuals who make decisions, parts of formal organisations (such as social services departments) or organisational relationships that cross formal (legal) organisational boundaries.

'Complexity' is the property of a system which has many elements, related to one another in ways that are not readily understood. As Winston (1992) has pointed out, complexity can be in the eye of the beholder. Some people see patterns in situations where others see many apparently unrelated parts - for example, some might perceive the parts of a car engine laid out on the ground as the elements of a single whole, whereas others see only a jumble, not even realising that the parts might make an engine.

Lane (1993) makes a further useful point, concerning the metaphors that are always used, consciously or unconsciously, in systems science. He notes that some authors (notably Stafford Beer, see Chapter 5) use biological metaphors to model social systems. Others, including systems theorists (von Bertalanffy, 1968), also use metaphors but draw them from a wider range of circumstances. Lane argues that whatever metaphor is used, the central concept is that of control. Control is concerned with linking inputs, decisions and outputs within a system, and the objective of control is, broadly, to optimise the performance of a system. Control of internal processes and of relationships with external environments is the basic mechanism whereby systems - of any kind - are able to survive and adapt.

Systems science is, then, a distinctive way of thinking about and addressing problems. It works from general assumptions about the nature of laws governing the structure and function of any complex system, and employs metaphors in the analysis of problems. Systems science is also associated with particular research approaches and methods. The list of these approaches and methods is long, but there are two useful distinctions that can be made.

The first distinction is between 'hard' and 'soft' approaches to structuring problems (see Pruzan, 1988). The distinction will be discussed later in the thesis in relation to the domain, so suffice it to say here that 'hard' approaches are those that are applied in situations which are taken to be well-defined and which can be described quantitatively, but 'hard' approaches are inadequate when applied to 'soft' situations, particularly those involving 'human activity systems' (Checkland, 1981). 'Soft' approaches are applied to problems that are not easily structured and cannot easily be quantified. Hard approaches include Cybernetics (see Chapter 5), systems analysis (pioneered by the RAND Corporation) and the quantitative statistical/scientific methods used in operational research and management science. Soft approaches include Soft Systems Methodology (see Chapter 5) and cognitive mapping (Chapter 6). Some systems science approaches are presented as having aspects of both hard and soft, including System Dynamics (Chapter 8). It is important to note that it is usually the investigator who decides whether a problem is 'hard' or 'soft', and it is quite possible for different investigators to decide on different approaches when presented with the same problem.

The second distinction is between different research traditions. The seminal work here is by Burrell and Morgan (1985), who classified social science approaches as being positivist, interpretative or critical, each embodying a particular set of beliefs about the relationships between an observer and the world 'out there'. Their simple classification led to an extensive critique in the social science literature but the distinctions, while not academically beyond dispute, are in practice useful and the terms are now commonly used in textbooks on methods (for example Silverman, 1993; Yin, 1994).

In similar vein, Dando and Bennett (1981) argued that there were three competing paradigms within the systems movement: official, reformist and revolutionary. The official paradigm might also be termed positivist or even 'classical' systems science, and refers to systems analysis and other approaches that were developed early on in the history of the field (that is, in the 1940s and 1950s), and persist as the dominant approach reported in some journals. Practitioners assume that there is a physical world 'out there' which can be accurately modelled, typically using mathematical techniques. The world is assumed by many practitioners to work according to the rules embodied in the models, so that manipulations that work in the models should also work in the real world.

The reformist paradigm is exemplified by SSM, which asserts that the world 'out there' cannot be directly captured by mathematical rules. Rather, modelling is used to capture a particular, and always partial, view of the world: models are contingent representations of a perceived world, and there is no single right or wrong representation. Research is generally conducted within the interpretative tradition. Revolutionary approaches - broadly equivalent to critical approaches identified by Burrell and Morgan - have a different set of concerns, which stem from the belief that the observer directly influences the system being studied. In some formulations the observer should exert influence in order to emancipate those within the system who are disadvantaged: a central concern is power relations and how to change them. Revolutionaries/critical theorists see the world as being constructed by our perceptions, and argue that we do not therefore have cognitive access to a world 'out there'. Because our perceptions are constructed, it is not possible to identify any 'objective truths' about the external environment, and the researcher is therefore operating in a relativist world.

Systems science is thus a broad church, within which there is a wide choice of approaches and methods. This plurality is potentially a source of strength, since it offers practitioners many options. Yet it also raises a practical problem for anyone seeking to use the ideas and techniques that the discipline offers, namely how to match approaches and methods to problems of interest.

2.3 The Domain: Hard or Soft?

In addition to the academic discipline(s) selected to study a problem, the choices made for any particular domain are inevitably influenced by practical considerations, including the researcher's skills and interests and the resources available. In many situations there can be disagreement about the most appropriate approach, and it often seems that selection comes down to personal beliefs - believers in controlled experiments conduct controlled experiments, and so on. Put more formally, the choice of methodology for any particular domain is undecidable: there is no single best approach (Checkland, 1992). At this point it is therefore relevant to record some personal beliefs - or prejudices - that will affect the lines of argument used in the thesis. Two seem important, and these are:

- A belief that systems science models, at least of the organisations and people in the domain of interest here, do not capture external reality but can be used to represent interesting aspects of the world 'out there'. This position is essentially that of Checkland, and points towards the use of research methods based in the interpretative tradition. In this thesis, the concept 'community care' is not a physical entity but a set of ideas, and a set moreover that is capable of widely differing interpretations by different people;
- A belief that complex systems can be understood using methods that are usually associated with both 'soft' and 'hard' approaches, and neither is inherently superior to the other. Rather, selection of methods should be

driven by pragmatic considerations, about the likely insights that might be gained by using them. It can be appropriate to bring variety of methods to bear on a single problem.

Stating that methodology is undecidable is not, however, the same as saying that any approach or method can be used at any time, and periodic attempts have been made to map research problems to available approaches, in order to maximise the probability that appropriate approaches are selected (Ackoff, 1971; Klir, 1985). To start the selection process for the thesis, it is necessary to sketch out some of the characteristics of the domain of interest. The domain will be described in detail in later chapters, and here it is sufficient to note the following points:

- The domain has not been extensively investigated, at least by researchers;
- However the system of interest is defined, it will include several distinct actors or stakeholders, including people with dementia, their carers, and health and social service professionals. Some operate within formal (legally constituted) organisations such as hospitals and social services departments, but others do not;
- The domain appears to combine features that can be measured (such as numbers of movements from the community to institutional care) and that cannot (including the internal mental processes of professionals who make decisions about treatment and care);
- The external environment, that the system has to respond to, is uncertain, particularly in relation to changing government policies and to ever-increasing financial pressures.

On the face of it, then, the domain would appear to be a candidate for a soft systems approach. It is also worth noting, however, that there are likely to be aspects of the domain that can readily be measured, so that hard approaches are not completely ruled out. Indeed, this observation suggests that the soft/hard distinction is not an absolute one, and that there may be opportunities to pursue soft and hard approaches within one study. In order to take this process further, TSI is now used to help draw out important features of the domain and to identify appropriate metaphors and approaches.

2.4 Total Systems Intervention (TSI)

Flood and Jackson (1991, 1993) have developed TSI, which they argue is developed from Critical Theory (Habermas, 1971), and hence sits within the critical approach identified by Burrell and Morgan (1985). It is important to distinguish two ways in which TSI can be used. Firstly, it can be used as an organising framework for a systems study: TSI is itself a methodology. Secondly, it can be used to identify one or more approaches for a study, as a way of matching specific methodologies and problems. It is used here as a matching device.

TSI has three phases. The authors stress that it is an iterative, interactive methodology, but for the sake of clarity it is presented here as three sequential steps. The first phase is 'creativity', and involves identification of relevant metaphors to help people think about a problem. These metaphors might include:

- The domain as a production line (a closed system);
- The domain as a culture or cultures (concerned with norms and values);
- The domain as a coalition (a pluralist political system);
- The domain as an economic system;
- The domain as a meta-system (a synthesis of different metaphors);
- The domain as a network.

A 'dominant' metaphor is usually selected - though Flood and Jackson stress that it is possible to retain more than one. The relative lack of knowledge

Chapter	*Systems Metaphors*	*Methods*
6	**Problem/Mess**	**Cognitive Maps,** **Inference Diagrams**
7	Production line	Markov Cohort
8	**Production line**	**System Dynamics**
9	Flexibility	Secondary analysis
10	**Collaboration**	**Secondary analysis**

Table 2.1
Systems Metaphors Used In Later Chapters

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and the complexity of the domain of interest merit considering different approaches here: see Table 2.1.

The second phase of TSI is 'choice', where appropriate approaches are selected. Flood and Jackson provide a classification to aid this process (Table 2.2). Approaches are identified as the product of two types of distinction, simple/complex and unitary/pluralist/coercive. Given the comments made in Section 2.3, the domain of interest here is best viewed as being pluralist and complex. It is pluralist because different actors will have their own values and objectives, and complex because it is not well understood and not obviously easy to model. According to Flood and Jackson, a methodology such as SSM would therefore be appropriate.

	Unitary	*Pluralist*	*Coercive*
Simple	**S-U**	**S-U**	**S-C**
	Operational Research, Systems analysis, Systems engineering	Social systems design, Strategic assumption surfacing and testing	Critical systems heuristics
Complex	**C-U**	**C-P**	**C-C**
	Cybernetics, General Systems Theory	SSM, Interactive planning	

KEY: S= simple, C= complex, U= unitary.

Table 2.2

Classification: System of Systems Methodologies

Source: Flood and Jackson (1993)

The third phase of TSI is 'implementation'. This is an extension of the second phase, where the chosen methodologies and methods are applied to a problem. As described, the third phase can employ one or more metaphors and tools. It thus has some relationship to SSM (Checkland, 1981; Checkland and Scholes, 1991), which also stresses the value of using different metaphors or perspectives in arriving at an understanding of a problem.

2.5 Critique of TSI

This result appears rather equivocal - on the one hand Table 2.2 points towards using SSM, but on the other arriving at SSM seems to have been a process driven by the author's own pre-existing beliefs rather than any serious analysis of the domain. A different observer might well have latched on to the fact that measurement is possible in the domain (see for example Levin et al., 1989) and chosen a complex-unitary approach, while another might have identified people with dementia and their carers as actors with little power in the face of health and social services professionals, and chosen a critical approach. In addition, it is possible to retain a number of metaphors throughout the process, and there is no clear guidance about when or how to select the 'right' metaphor.

What is the problem here? Checkland (see Checkland and Scholes, 1991: Chapter 1) emphasises the distinctions between observers, domains and the methodologies and methods used by observers to study domains. (He was by no means the first to do this: many philosophers have mulled over the nature of cognition and the relationship between observers and their environments.) A key point here is that the choice of tools depends on the observer's perceptions of a domain, rather than on any presumed 'objective' properties it may have. Flood and Jackson therefore seem to have failed to take account of the prejudices (right or wrong) of the investigator. They (Flood and Jackson, 1991: page 203) view the 'problem-context' as being simple or complex (or, unitary or pluralist or coercive) - so the observer has gone missing.

A second answer revolves around the general approach to modelling that Flood and Jackson believe is appropriate. The examples they give all implicitly seek to model systems as a whole, even though the models may not attempt to capture all variables of potential interest. As a result, they do not entertain the idea that any one system can be divided up and the - still complex - parts investigated using different approaches and methods.

A third answer to the question, related to the second, is that a system may look complex from the perspective of some actors and simple from others. For a person with dementia and her carer, the decision to enter an institution may be agonisingly difficult, but from a care manager's perspective clear-cut (note Winston's (1992) point made earlier). This goes to the heart of the reservation expressed about TSI above concerning its managerial bias: it takes a particular stakeholder's standpoint and defines a domain as simple or complex as viewed from there, rather than looking at the domain from a number of perspectives and choosing the 'best' - perhaps simplest, or perhaps most politically astute - way in.

There are other criticisms of TSI, which can be found in Lane (1993) and Mingers (1992). The thrust of the criticisms centres on the 'real' nature of TSI, which critics argue is in practice poorly defined. The problems highlighted here suggest that TSI has a strong positivist streak, in that it does not allow for alternative interpretations of whether a system is simple or complex, unitary or pluralist. In other words, TSI is itself more unitary than pluralist.

Crucially, TSI does not allow for the possibility that relatively unstructured domains still have structured elements, and so structured methods can be used to examine them. Here, several different methods are used to look at an apparently very 'soft' domain. There is, therefore, a need for an alternative classification and mapping, if only to allow a way forward for this thesis. An alternative may only require only one additional element, namely to allow that a system can usefully be viewed from different perspectives, and that the differences between perspectives are themselves interesting, and might even form part of the investigation. (Accounts of SSM hint at this is possibility, but then go on to insist that the user select one 'best' viewpoint.) This accommodates the point made earlier in the section: the domain of interest here may be complex from the viewpoint of an informal carer, while to a statistician it may be a mixture of 'simple' (systematic relationships which can be tested statistically) and 'complex' (unexplained variation), and to some professionals it may be

Type of problem	*Examples of methodologies and methods that might be used*
No obvious structure: no one actor comprehends the behaviour of the system, and so even the range of possible perspectives is not obvious at the outset	**SSM, interpretative social science approaches**
Some structure discernible, contained within a system that lacks obvious overall structure: some distinct perspectives can be identified	SSM, System Dynamics: methods may be positivist or interpretative
Domain appears well structured, and adoption of a particular, identifiable perspective will probably provide useful insights	**'Hard' systems methodologies, statistical analysis (positivist methods)**

Table 2.3

Simple Classification Of Methodologies And Methods For Complex Systems

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straightforward, at least in so far as the decisions they make are 'obvious' to them.

In the domain in this thesis, a revised, pragmatic classification might take the form in Table 2.3. With the addition of the possibility of retaining multiple perspectives, it becomes clear that the choice of methods and tools depends crucially on where one stands. So, if the perspective suggests that referral patterns are important, then statistical and other methods to study them should be used. If, on the other hand, the carer's perspective is adopted, then the perceived issues would probably lead to the selection of qualitative methods such as cognitive mapping.

2.6 Conclusions

It would be wrong to dismiss TSI completely because it has not provided a valid and reliable method of linking approaches and problems. There is a real problem over selection of metaphors and approaches for systems science studies, that neither TSI nor this chapter has solved. The way forward chosen here is pragmatic rather than theoretically grounded. The point of using TSI here is to make a simple but important point: there really is no simple way of linking approaches and problems. Selection is rooted in individual experience and belief: this is undoubtedly prone to error, and if TSI serves a purpose, even with its flaws, it is in prompting the investigator to reflect on his or her own practices.

Table 2.3 captures a second important point. Some aspects of services for people with dementia can be readily understood from reviews of the available literature - these will be drawn out in Chapters 3 and 4, the next two chapters. Other characteristics of the domain, and particularly the role of professionals in determining patterns of treatment and care, will need to be described and explained through empirical research: this is undertaken from Chapter 5 onwards, as listed in Table 2.1. Several approaches will be used, and their value reviewed in Chapters 11 and 12.

CHAPTER 3
THE DOMAIN - I: CLINICAL CHARACTERISTICS AND EPIDEMIOLOGY OF DEMENTIA

3.1 Introduction

Dementia was defined and described in Chapter 1. The focus of this chapter is twofold, on the clinical diagnosis of dementia and on its epidemiology. While dementia has important consequences for both health and social services, it is useful to start by examining evidence about the ability of clinicians to diagnose it in practice. GPs are the main point of contact for many people with dementia and their carers, so their performance in diagnosis is likely to influence their actions. Epidemiological evidence is assembled to provide background information about the importance of dementia as a source of demand for health and social services. The dominant theme of the chapter is the variability of dementia, and the difficulties this causes to service providers in identifying and managing it and to researchers in studying it.

3.2 Clinical Diagnosis Of Dementia

One important consequence of the nature of dementia is that it can be difficult to make a definitive diagnosis during life: its presentation is highly variable and onset can be very slow. Moreover, it exists in both sporadic and familial forms - the familial from indicating at least a genetic predisposition - and both genetic and environmental risk factors (Lendon et al., 1997). As noted in chapter 1, there is currently no convincing causal model of the disease processes associated with dementia, although there is substantial basic research currently under way, and understanding of the biochemistry of dementia has advanced rapidly over the last few years. Some of this work has led to identification of a protein, Apolipoprotein E-4 (Evans et al., 1997; Hofman et al., 1997), that is present only in the brains of people with dementia, and might therefore be used as a clinical indicator:

but this remains a test for the future. As a result of the difficulties of diagnosis based on biochemical tests, there have been a number of attempts to develop question-based instruments that can be used to diagnose dementia within research studies and in clinical settings (Pattie and Gilleard, 1979; McKhann et al., 1984; American Psychiatric Association, 1987). Yet in practice most doctors believe these instruments are unsatisfactory for routine clinical use, being both time-consuming and insufficiently sensitive, and they prefer to rely on their own clinical assessment (Amar et al., 1996).

A major issue in clinical practice is that the signs and symptoms of dementia overlap with depression, memory loss and other problems (Jorm et al., 1991: Buntinx et al., 1996). Depression, in particular, can be successfully treated medically if correctly identified. So while there are currently few options for active treatment of dementia, there are good clinical reasons to establish whether someone has dementia, depression or something else. In practice, then, dementia is often a diagnosis of exclusion. That is, many doctors and other health professionals will try to identify depression or some other condition that can be treated, and only presume the presence of dementia if other explanations are not found.

The difficulties of diagnosis during life contrast with the situation after someone dies, when post-mortem examination of the brain can identify dementia decisively. Brayne (1993) reviewed studies which link diagnosis of dementia during life and post-mortem findings - that is, post-mortem examination was the gold standard for assessment of earlier tests. She noted that these studies were difficult to perform, so the total number of studies was small (she identified eleven good studies in twenty years): they suggested reasonable - though not excellent - correlation (coefficients typically in the range 0.5 to 0.7), which varied with a number of factors including the type of test used and the population sampled.

The difficulty of diagnosing dementia accurately in research settings underlines the problems that clinicians face in practice. In a study of seven practices in Cambridge (O'Connor et al., 1988), for example, GPs were asked to rate all of their elderly patients for organic and functional psychiatric problems. In relation to dementia patients were to be rated as definitely not demented, possibly demented or definitely demented. Their ratings were compared with the results of independent assessments made by a panel of clinicians (so here the panel's judgement was used as a reference standard). The GPs correctly identified 65% of people with moderate or severe dementia as definitely demented. 22% of patients who were not demented but who were suffering from functional psychiatric disorders (notably depression) were incorrectly rated as possibly or definitely demented. Similar results were found by Iliffe et al (1991), and Macdonald (1986) also found that GPs underestimated the numbers of people with depression in their practices. This suggests that GPs miss dementia, and have difficulty in distinguishing between organic and functional problems. It seems reasonable to infer from this that missing dementia or depression in someone, or taking one for the other, increases the possibility that they do not receive health or social services appropriate to their needs.

In the O'Connor et al. study community nurses were also asked to rate the (smaller number of) elderly patients on their lists. They correctly identified 86% of all cases - that is, agreed with the panel in 86% of cases - and 96% of people with moderate or severe dementia. They did, though, misclassify more patients as demented who had a functional psychiatric problem than did GPs. O'Connor and colleagues point out that community nurses may have an important part to play in identifying cases, alerting GPs and supporting families.

In principle, the performance of GPs and community nurses does not matter too much if services are designed to support observable signs and symptoms: that is, if they take a pragmatic approach, and respond to individual circumstances. Indeed, the more general term confusion is used by many people in health and social services, and in some research settings - particularly in observational studies where there is no formal intervention and the objective is to study services with a heterogeneous set of problems. (Whether or not appropriate services are in fact provided to demented/confused people will be discussed in Chapter 4.) The point to be made here is that the difficulty of diagnosing dementia during life adds to the general picture of uncertainty about the domain of interest. Not surprisingly, it also makes epidemiological studies difficult to undertake.

3.3 Epidemiological Evidence

3.3.1 Background

Dementia is an important component of more general demographic trends in the UK and other developed countries, where changes in the structure of populations suggest that financing health care, social care and pensions will pose serious challenges in the first quarter of the next century (OECD, 1988; World Health Organisation, 1986, 1994). The most important change will be an increase in the proportion of retired people in relation to those of working age.

Two important issues need to be addressed. First, some authors have questioned whether there is in fact any critical distinction between dementia and the processes of normal ageing. It is now generally agreed that dementia is distinct from normal ageing. The two main arguments in support of this view are that there are many older people who remain cognitively intact and show no obvious deterioration in intellect into their eighties and nineties, and that conversely dementia is found in people in their fifties. During the last decade it has become clear that young people

Age range	*1993 (base year)*	*1996*	*2001*	*% change 1993-2001*
Total	48532.7	49066.9	50023.3	+3.1
65-69	2236.7	2193.0	2117.7	-5.3
70-74	2071.2	2009.5	1932.3	-6.7
75-79	1448.7	1528.6	1631.5	+12.6
80-84	1092.4	1106.4	1108.3	+1.5
85+	839.5	931.2	1052.6	+25.4

Table 3.1

Population Projections For England, 1993-2001 (thousands)

Source: OPCS (1993)

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with AIDS and HIV infections can have dementia, often called AIDS Dementia Complex (ADC) or AIDS-related Dementia, and the strain of Creutzfeldt-Jacob Disease which may result from eating contaminated beef can affect people of any age including children. These developments dramatically emphasises the distinction between dementia and ageing processes.

The second issue concerns the numbers of people with dementia. The total population of England at the 1991 census was 44.876 million, some 7.553 million of whom were 65 years of age and over (Chadwick-Healey, 1991). (These figures are of course subject to error, not least because some people did not respond to the census in order to avoid the Community Charge - more usually referred to as the Poll Tax. They are, though, the most accurate whole population figures available.) Projections of population changes to 2001 are shown in Table 3.1. While the number of people over the age of 65 is projected to fall slightly over the next few years, the numbers of those in the upper age groups will continue to grow rapidly. Early next century the numbers of people over the age of 65 will again climb, leading to additional pressures on health and social services (OECD, 1988; Gillion, 1991). The picture is therefore one of a fairly stable population of people of 65 years and over, but of an increase of people in the older age bands. Any disease whose prevalence increases with chronological age will therefore become more prevalent in coming years.

Measurement of the numbers of people with dementia has proved difficult, not least because of the problems of identifying dementia during life, and analysis of data therefore requires care. But the figures presented below suggest that the numbers of people with dementia has been increasing over the last two decades, and this trend will continue at least for the remainder of this century and a few years into the next.

3.3.2 Prevalence and incidence of dementia

Prevalence data (the numbers of people who have a given condition at any one time) are valuable in identifying the population of people dementia that health and social services might need to support. Most studies have focused on people of 65 years and above. Ineichen (1987) reviewed studies of prevalence of dementia in older people (for the UK) and concluded that those using a restricted definition of dementia were the most useful. These studies suggested that 2.8%-2.9% of the population over 65 years of age had 'moderate' or 'severe' dementia (see Table 3.2 for definitions); a simple rule-of-thumb gives figures for those over and under 75 years of age (see Table 3.3). Within this group some half to two thirds of people have Alzheimer's disease, around 30% have vascular (or multi-infarct) dementia and 10% alcohol-related dementia. This suggests that the number of people with dementia in England lies between 211000 (2.8%) and 219000 (2.9%).

These figures are broadly confirmed by a more recent study in Cambridge (O'Connor et al., 1989), which found rates of 5.3% for moderate/severe dementia and 5.2% for mild dementia in a population aged 75 years and over. Two more studies, by Morgan et al. (1987) and by Livingston et al.

Mild dementia Difficulty in recalling recent information: limited or patchy disorientation to time and place; impaired problem solving, reasoning and the capacity to manage usual activities; diminished clarity of speech; defective knowledge of names of prominent figures; social facade and emotional responsiveness may be well retained but cognitive deficit present on testing.
Moderate dementia Severely impaired reasoning, problem solving and recall of recent events. Disorientated in time and place. Language unclear but not to a marked degree. Unable to manage housework, shopping, finances independently. Needs help with dressing and other self-care; may be occasionally incontinent. Testing reveals advanced deficits.
Severe dementia Incapable of recall, reasoning and self-care. Almost invariably incontinent, apathetic and inert. Totally incapable of independent existence.

Table 3.2

Sample Severity Rating Criteria For Research Projects

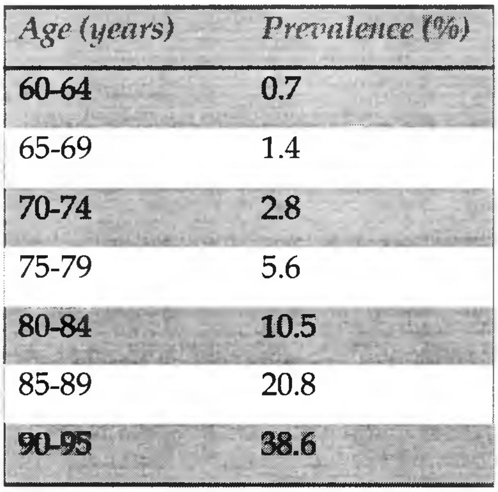
Source: O'Connor et al. (1989)

Age (years)	*Prevalence (%)*
65-74	**1**
75 and over	10

Table 3.3

Ineichen's Rule-Of-Thumb For The Prevalence Of Dementia

Source: Ineichen (1987)



Age (years)	*Prevalence (%)*
60-64	0.7
65-69	1.4
70-74	2.8
75-79	5.6
80-84	10.5
85-89	20.8
90-95	38.6

Table 3.4

Age-Specific Prevalence Of Dementia: Pooled Data From 22 Studies

Source: Jorm et al. (1987)

(1990) provide further confirmation of the broad picture, but they report slightly different rates.

Looking at evidence from other countries, however, complicates the picture. The results of 22 pooled studies from several countries (Jorm et al., 1987: Table 3.4), and those presented in a World Health Organisation report (WHO, 1986), suggest higher prevalences than those reported in most UK studies. More recent studies, using clinical indicators, in the Netherlands (Hofman et al., 1997) and the USA (Snowdon et al., 1997), suggest that prevalence may be slightly higher than reported elsewhere. In order to obtain an estimate of the total number of people with dementia for the UK - albeit based on international studies - the figures in Tables 3.1 and 3.4 (using the 85-9 year figure for all people over 85 years) gives an estimate of 458750 people with dementia in England.

Figures from studies using broader definitions of dementia range from 2.5% to 24.6%: such figures emphasise the difficulties of measurement of prevalence, particularly when the category 'mild dementia' is included. There is also disagreement about whether rates differ between men and women. Jorm (1990) argues that there are no significant differences, although there seem to be differences between regions within countries. In contrast, some UK studies report higher rates among women, as well as among institutionalised populations (see Livingston et al., 1990). The sources of the differences in results can be explained in part by differences in cut-off points for positive identification, and in the nature of the sample populations. But explanation of the origin of some differences remains elusive (Black et al., 1990), and this suggests a need for rigorously applied interviews and diagnostic criteria across studies (Henderson, 1986).

Any study of AIDS Dementia Complex would involve sampling of very different populations to those discussed in this thesis. Anecdotally, it appears that between ten and fifteen percent of people with HIV and AIDS may exhibit the signs and symptoms of ADC. Over the next few years the numbers of people in this group may grow significantly, so that population estimates for dementia in people under 65 years - and under 35 - can be expected to increase.

Incidence (that is, the numbers of people becoming demented over a specified period of time) also varies between studies. Incidence studies are important theoretically for understanding the effects of dementia on survival, in estimating lifetime risks of dementia, and the risk of dementia in relatives of demented people (where genetic factors are believed to be involved, as in some cases of Alzheimer's disease). But relatively few studies have been undertaken and at present understanding of incidence is poor (Jorm, 1990; Evans, 1997). Some authors suggest that rates may rise until around 75 years of age and then level off. Others (eg. Aronson et al.,

1991) found that incidence continued to increase with increasing age at least until the age of 85: they reported an overall incidence rate for all age groups of 3.4 per 1000 per year in an eight year period. Figures for the UK come from more recent studies. In a six year follow-up of elderly people living in the community in Liverpool, Copeland et al. (1992) reported an overall incidence of dementia in 690 survivors of 9.2 per 1000 per year. Morgan et al. (1993) found a very similar figure, 9.3 per 1000 per year in a four year follow-up study of 1042 people of 65 years and over. McGonigal et al. (1993), examining a population of people aged between 40 and 64 years, found a rate of 22.6 people per 100000 per year with probable Alzheimer's disease - emphasising the point that dementia is indeed found in people under 65 years, but in relatively small numbers.

3.3.3 Other measures

The effect of dementia on life expectancy has not been extensively studied. Dementia *appears* to be associated with reduced life expectancy, but the relationship is not clear cut: this occurs for a number of reasons, including difficulties of measuring survival after the onset of dementia (because a date of onset is difficult to identify), and because life expectancy for the whole population has been increasing, so masking the effects of the condition. Maule et al. (1984) found increased mortality, but Christie (1985) analysed data from longitudinal studies and found that survival time appeared to be lengthening. Nygaard and Laake (1990) found that the physical setting may have an effect, with institutional care being associated with an increased life expectancy.

The prevalences of the important problems experienced by people with dementia are useful indicators of potential demand for health and social services resources. Many people with dementia have urinary incontinence (Campbell et al., 1985; McGrother et al., 1990), although the majority of incontinent people are not demented (Table 3.5). These findings were

Factor present	*Prevalence (%)*	*Prevalence (numbers in sample)*
Dementia, locomotor problems, and incontinence	1.7	20
Dementia and incontinence	0.2	2
Locomotor problems and incontinence	6.7	80
Dementia and locomotor problems	1.7	20
Dementia alone	0.4	5
Locomotor problems alone	30.8	370
Incontinence alone	3.7	45
Any of the above	45.1	542

Table 3.5

Behavioural Disturbance And Mood Disorders In Alzheimer's Disease

Source: McGrother et al. (1991)

Problem	*Number (sample total 178 people)*	*Percentage of sample*
Urinary incontinence	83	46.6
Aggression	35	19.7
Wandering	35	19.7
Depression	41	23.0

Table 3.6

Problems Identified By Burns et al.

Sources: Burns et al. (1990a), Burns et al. (1990b) broadly confirmed in a study by Burns et al. (1990a, 1990b) of people with Alzheimer's disease: they also noted the numbers of people with a range of other problems (Table 3.6).

Some other figures offer insights into the scale and pattern of the potential demand on informal carers and for services. The numbers of people available as carers, which has been increasing over recent decades, appears set to decrease. Already, some one in four confused people have no close relative or helpful neighbour (Levin et al., 1983, 1989). As will be seen in the next chapter, these factors contribute to the demand for, and pattern of, services for people with dementia.

3.4 Conclusions

This chapter has highlighted the variability in the clinical presentation of dementia, and the numbers of people who have it. The focus has been on research data, but they point to important consequences for the identification and management of dementia in practice.

While this chapter has had a clinical flavour, it is important not to lose sight of the fact that the absence of a cure or effective treatment means that many of the problems posed by dementia are essentially social in nature. The challenges which people with dementia and their informal carers face vary between individuals and over time, but are concerned mainly with coping with everyday life. It might be expected, therefore, that both health and social services may be needed to support people with dementia, and it is to these that we now turn.

CHAPTER 4
THE DOMAIN - II: POLICY AND THE ORGANISATION OF SERVICES

4.1 Introduction

The first three chapters have presented background information about dementia, focusing mainly on its clinical character and epidemiology. They have indicated that people with dementia typically require help and support in living their lives, and that this is provided by informal carers - usually relatives - and by statutory, private and voluntary services. This chapter discusses national community care policies, evidence about entry to instututional care and the organisation of community-based services.

While it would be wrong to say that the current organisation of local services mirrors the wishes of national policy makers, it is certainly the case that national policies have played a crucial role in shaping local services. The first part of the chapter therefore briefly reviews recent national policies affecting people with dementia, charting the problems identified in the 1980's and the government's responses to them. The sections that follow discuss the provision of institutional places and the (fairly limited) research evidence about the circumstances in which people with dementia enter them. Then, the range and nature of care provided for people with dementia in their own homes is reviewed, starting with the most numerous group, informal carers. Taken together the sections in this chapter stress three themes, namely the roles of individual service providers in providing treatment and support, organisational relationships within health and within social services, and relationships across organisational boundaries.

'First pass' models are presented in the chapter, to highlight issues that will be addressed in later chapters. These include the identification of the 'system of interest' and 'environment' in the thesis, and some of the key treatment and care pathways that people with dementia may take, and that may influence their entry to institutional care.

4.2 The Changing Policy Context

Government policies throughout the 1980s focused on elderly people as a single group, and not on specific sub-groups such as those with dementia or with serious physical disabilities. The numbers of elderly people grew rapidly throughout the decade, and this demographic trend put pressure on the resources available for health and social services, and eventually required a response from the government. A key feature of the government's early responses was the assertion that it would not be able to fund existing levels of provision in the longer term, and that individuals would increasingly have to fund their own care and pension arrangements. The policies included:

- Identification of elderly people as a 'priority' group for receipt of health and social services;
- The belief that elderly people should remain in their own homes for as long as possible, where they would be looked after by friends and relatives;
- The decision that costs associated with physical and mental disability would increasingly be borne by individuals;
- The numbers of long-stay hospital beds would be reduced, and places in local authority residential homes effectively frozen;
- A government-subsidised increase in privately run residential care (Department of Health and Social Security, 1981, 1986).

In practice, though, the broad desire for 'care in the community' embodied in these and other policies came under increasing strain (Parker, 1990). One problem was that the numbers of informal carers (family and friends) available was not sufficient for the task: many elderly people had no close relative to fulfil a caring role. Another was that support services were often inadequate, some commentators arguing that this was due in part to underfunding of social and community health services (Schorr, 1992). For people with dementia, Levin et al. (1989) found that the amount of formal help available was often inversely proportional to the severity of a person's problems, so that there appeared to be selection against those in greatest need. As a result, government statements going back over 30 years that people should remain in their own homes as long as possible were not being fulfilled (National Institute for Social Work, 1988).

A third problem was the increase in private residential and nursing care (see Table 4.1), and its associated costs. Decisions about social security payments made by the Department of Health and Social Security (DHSS) in the early 1980's created incentives for people to take up private home places: this led to payments jumping from £10M. in 1980 to over £2bn. by 1991 (Lewis and Glennerster, 1996). This tended to undermine the thrust of stated policies, particularly on maintaining people in their own homes. (Indeed, care in the community seemed to be defined by the government as anything that happened outside long-stay hospitals and local authority homes, making privately run homes notionally part of 'the community': community was evidently a negotiable term.)

Fourthly, there were continuing difficulties in achieving coordination between health and social services to optimise the use of resources:the binary divide had bedevilled planning since the inception of the welfare state. This was shown to be particularly problematic for people with dementia (Wright et al., 1988), with little coordination or collaboration between social services and health services. More generally, government attempts to encourage joint working by offering joint finance monies as an incentive to collaborate generally failed (Wistow et al., 1990), with health authorities often dominating decisions about how budgets were spent. This

Place of residence	*Age Group (years of age)*	*Number*
In households	**65-74**	**1329479**
	75+	1464173
In institutions	**65-74**	**50249**
	75+	299018

Table 4.1

People With Long-Term Illness In England In Households And Institutions

Source: 1991 Census (Chadwick-Healey, 1991)

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led to a 'co-ordinator's nightmare' (Norton et al., 1986) on the ground that characterised community care in the 1980s.

The gulf between the stated intentions and the reality of community care was highlighted in a number of reports, notably in two by the Audit Commission (1985, 1986). They made it difficult for the government to ignore the problems, not least because the amounts of public money involved in providing social services and social security payments ran into billions of pounds. The reports set the government on the path to reform, initially through commissioning Sir Roy Griffiths to prepare a report on community care. His report (Griffiths, 1988) set out a broad policy framework, based on a separation of the purchasing and provision of services, with local authorities acting as the purchasers (or 'enablers') of care. Budgets held by the Department of Social Security (DSS), notably those for the subsidy of private residential care, and the NHS (mainly for long stay hospital care), were to be transferred over a period of years to social services departments, which would be the single main purchaser in a locality. Further, he feared that that community care budgets would be vired to other uses within local government, and so argued that they were to be ring-fenced.

There followed a great deal of public discussion, the burden of which was that the reforms were broadly welcomed by social services directors and many voluntary groups. The government was less enthusiastic about giving local authorities the leading role, but in the end accepted the report and included most of its recommendations in the White Paper, Caring for People (Secretaries of State, 1989) and the subsequent NHS and Community Care Act of 1990. The main exception was that the government decided not to ring fence community care budgets, arguing that local authorities would allocate monies to community care in a responsible fashion.

The gestation period from the first Audit Commission report in 1985 to the legislation in 1990 meant that policy was developed against a changing backdrop. In this period there were innovations in the delivery of services, notably in the development of care management (see later in this Chapter) which can be interpreted as a response to perceived failings in coordination and accurate targeting of resources in usual methods of service delivery (Goldberg and Connelly, 1982). Devised and developed at the Personal Social Services Research Unit (PSSRU) at the University of Kent, care management involved the devolution of budgets to nominated individuals, who made assessments and coordinated services for clients. Sir Roy Griffiths was impressed by the PSSRU model, and recommended its widespread adoption, and his recommendation was included in Caring for People. In this case, at least, service developments were reflected in national policies.

The new community care arrangements were originally intended to come into effect in 1991, but the formal commencement of the new arrangements were in the event delayed until 1st April 1993. (The reasons for the delay have been debated, but there is a widespread view that the government delayed because community care - involving as it does larger local authority budgets - would lead to an increase in the community charge, then still in force. This would have been unacceptable in the period before a general election, due in 1992.) It was always intended that the new arrangements would be introduced over a period of years, in marked contrast to the desire for the rapid introduction of a quasi-market in the NHS. The government realised that historical allocations of resources in community care could not be changed rapidly, most obviously in the cases of long-stay hospital and residential home care, where the changes in funding would have profound consequences for individuals. Community care was thus to be evolutionary rather than revolutionary.

The new policies sought to introduce explicit incentives to improve the efficiency and effectiveness of health and social services. They concerned themselves principally with general mechanisms for financing and delivery of care, rather than with details for particular groups. The most important structural change was the separation of purchaser and provider roles. In addition, however, there were several relevant themes. The Social Services Inspectorate (SSI, 1992) identified four 'strategic dimensions' which underpinned the reforms. The first was a move away from supply-led to needs-led, purchaser-dominated services. Service providers were to make assessments of the needs of individuals. Service users were to have more influence over the services they received; that is, they should have more choice. The design of new services and assessment of population and individual needs were complex tasks: it was envisaged that care management, developed at PSSRU, would be the cornerstone of these processes.

The second dimension involved changes in the responsibilities of the NHS and local authorities, with the two charged with clarifying their roles in each locality. Knapp et al. (1993) pointed to four important drivers of change:

- The continuing shift from NHS to social services in responsibility for purchasing and provision of long term care;
- The continuing deinstitutionalisation of acute health care, with attendant NHS and social services consequences for care of ill people in their own homes;
- The changes in purchasing after April 1993, with social services departments taking over both DSS funds and responsibility for purchasing residential and nursing services;
- The emphasis on health gain would, they argued, compel the NHS to work with social services and other agencies.

The SSI's third dimension was the move to a mixed economy of care. There was a mixed economy, particularly of residential care, before Caring For People but its scope and scale would be much greater in future, and it should increasingly be characterised by a measure of competition between providers. Social services were required to contract out a proportion of their services (to the NHS, private and voluntary organisations), and to charge users for certain services such as day care and some domiciliary services, and many local authorities have introduced charges for specific services since April 1993. That is, explicit prices and charges were to be being introduced, designed to influence decisions about the purchase of services by statutory purchasers or individuals.

Baldwin and Lunt (1996) reviewed patterns of charging after three years. They found wide variations in charging policies, though most now charged for some services, and all undertook means-testing for home care services. The services charged for included home care, meals on wheels, adaptations to the home and meals at day care centres. Charging for attendance at day centres was rare. This meant that local authorities had established income streams from these services. The authors were cautious in their conclusions about the consequences of charging, but expressed concern about the erosion of the concept of universal entitlement to services: access depended on place of residence and ability to pay. This went against the policy requirement to undertake needs assessments, suggesting that there were contradictions within the new policy framework.

The SSI's fourth dimension was the shift from institutions towards care delivered in people's own homes. The term community care is now intended by the government to be synonymous with caring for people in their own homes. A major preoccupation of Caring For People is the interface between residential and home-based care, and its consequences for health services, particularly for the de-hospitalisation of long term hospital care. The subject area of this thesis is located mainly within this fourth dimension - though there are also echoes of the other three.

Lewis and Glennerster (1996) reviewed the progress of the new community care policy framework, based on research in five case study local authorities. They pointed out that many of the ideas were not new - though charging for domiciary services *was* new. The problems that had to be addressed were as much a product of the government's own polices, particularly in stimulating the private residential sector, as of the real increases in pressures on resources due to demographic change. Their key conclusions were that:

1. The rate of rise in the provision of private residential care was successfully curtailed in their case study areas;
2. The drive to promote a purchaser-provider split and independent (non-SSD) provision of care had more limited success, as social services

departments ran up against problems in stimlating real markets for most services, particularly for people with the greatest needs;

3. Problems due to shortages of resources were becoming apparent, though they were not as great as had been feared at the outset.

Overall, then, the picture is one of successful control of increasing private residential care costs, and a shift of focus towards community-based services, with charging for some of those services, and limited provision of community services by non-SSD organisations - and hence a limited 'mixed economy' of community-based services. The residential care sector remains the main source of private provision. (This is in marked contrast to serious problems with community care policies in other areas, notably services for people with schizophrenia, which have prompted another review of policies, and may lead to a renewed focus on institutional provision for some people.) Yet the new arrangements are still in their infancy, and seem likely to develop over the coming years. Knapp et al. argued that:

> "Markets will emerge by stealth. Consequently it is very difficult to know what form social care markets will take, or to predict with any confidence whether they will promote cost savings, quality, choice and equity." (Knapp et al., 1993: Page 20)

Knapp et al. also noted the importance of individual and organisational values in shaping the new arrangements. One of the limitations that emerged early on was the lack of shared values and objectives among the different people who cared for people with dementia.

Figure 4.1 is a high level representation of the domain and its environment. The discussion in this section has focused on the environment within which people with dementia, their carers, and health and social service personnel make decisions. It has emphasised the major policy themes of shifting the patterns of resource flows from statutory services to individuals, and from

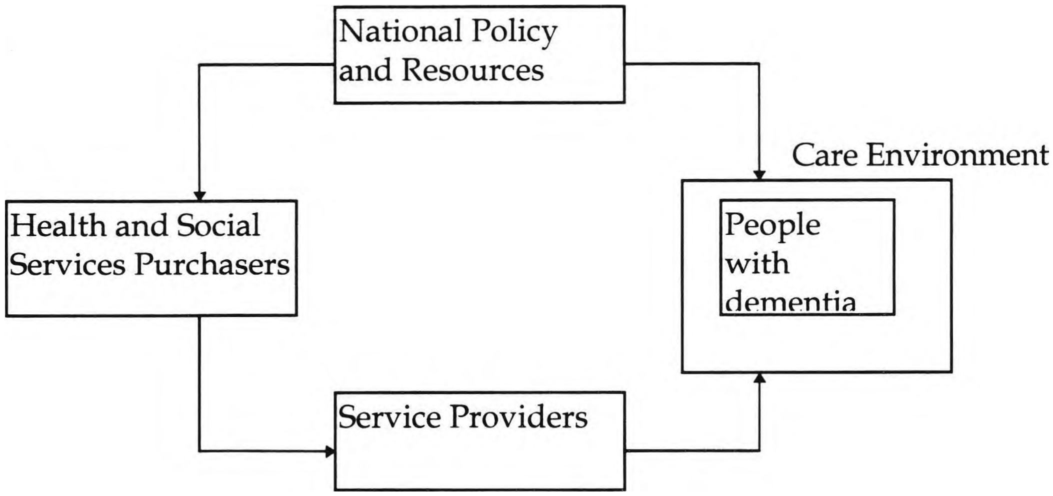

Figure 4.1

High Level Diagram Of The Domain And Its Environment

Arrows represent resource flows between:

- National resources-care environment: DSS payments
- National resources-purchasers: annual budgets to purchasers
- Purchasers-providers: annual budgets to providers (NHS, SSD, private, voluntary organisations)
- Service providers-care environment: care and treatment to people with dementia and carers

the DSS and NHS to local authorities. Figure 4.1 draws out these points: the following sections will develop understanding of the 'service providers' and 'care environment' parts of the Figure.

This section has also emphasised the importance of the resource flows. There are substantial practical difficulties in studying the costs of resource flows in this domain, particularly at the level of the resources available to individual people with dementia, and accordingly they were not included in the empirical work reported in later chapters. Background information about the resource costs of dementia is included in the Appendix.

4.3 The Provision Of Institutional Care

4.3.1 Introduction

The government policies outlined above stemmed in part from the perception that the well-being of residents in institutions was typically poor. In the early years - the 1960's and 1970's - it was believed that community-based care would be both better for individuals and cheaper for the state. Yet in the early 1980's the government had also stimulated - albeit inadvertently - a large increase in the provision of private residential care. The balance of provision of care has therefore changed over time, from mixes where hospital-type care was important early in the century, to a mixed economy with private nursing home provision now. Figure 4.2 shows the main institutional options for people with dementia at present. The merits of different types of institution are reviewed here, since they are part of the context for decisions about entry to institutional care.

4.3.2 Long Stay Hospitals And NHS Nursing Homes

For much of this century the principal institutional option has been long stay hospital care, often in geographically isolated mental hospitals. They have long been regarded as falling far short of any definition of acceptable care regimes or physical environments. During the 1980's there was a

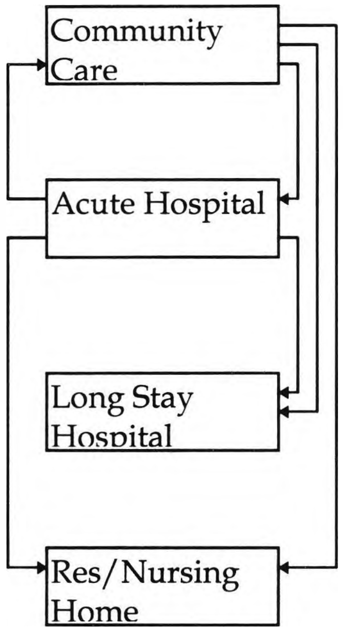

Figure 4.2
Main Institutional Options For People With Dementia In The UK

Arrows represent possible routes between settings for people with dementia

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concerted effort to close down these 'old long stay' hospitals, and many have now been closed or have far smaller populations than before. Former residents with dementia have typically been discharged into alternative forms of long stay care in acute hospital, local authority or other accommodation.

In some areas the old long stay beds have been partially replaced with beds on acute hospital sites, so that some people with dementia continue to live in hospital settings. By and large these are people who are deemed to have problems which require constant nursing care, or are regarded as disruptive by owners of other institutions - whether private or local authority homes. The disruption may take the form of aggression towards staff and other people, or persistent shouting or wandering. In recent years the NHS has also experimented with nursing home care (Donaldson and Bond, 1991), which is intended for people who require a significant amount of health care. Such homes remain few in number - there is a handful throughout the whole NHS - and seem unlikely to become more numerous in the short term.

4.3.3 Residential And Nursing Homes

The major alternatives to hospital-based provision are in private and local authority accommodation. The voluntary residential care sector has had a very small role in caring for people with dementia over the last decade. The most common form of provision in this sector has traditionally been by members of religious orders. Their role in the care of people with dementia has not been investigated, and is not addressed in this thesis.

Private sector provision grew enormously in the 1980s, fuelled by social security subsidies (see Department of Health, 1994; and Figure 4.2). It offers a range of accommodation, from residential (primarily non-health care) to nursing homes, where the latter are managed by a registered nurse. During the 1980's private sector homes tended not to admit people with dementia, though in practice some people became demented after admission to a home and continued to live there. More recently, however, owners have viewed people with dementia more favourably and some are willing to admit them. The reasons for this change have not been investigated, but may be due to the fact that people with dementia now form a substantial 'market'.

Local authority residential care has its origins in the welfare legislation of the 1940s. Local authority homes were originally intended for use by people with few health care needs, but came to be filled with people with a range of chronic illnesses (Gosney et al., 1991). As with private homes, admission policies often specifically exclude people with dementia, though residents might become demented once admitted. During the 1980s local authorities came under pressure to find places, with increasing numbers of people with dementia on the one hand and an effective (central government directed) freeze on building new housing on the other. The provision of local authority places fell during the decade, roughly in line with the rise of the private sector. Local authorities in many areas responded by designating particular homes or parts of homes for people with dementia. The decline of local authority provision appears to have been accelerated by the new community care policies, though there are no figures available for changes over the last three years. (In the case study area, described in Chapter 6, there was still substantial local authority provision in 1997.)

4.3.4 Evidence About The Quality of Residential And Nursing Home Care

The shortcomings of residential and nursing home care, for elderly people in general, have been comprehensively investigated in qualitative studies and are discussed elsewhere (for example Booth, 1985; Peace et al., 1982). These problems include lack of attention to people's emotional needs evidenced through loss of privacy and dignity, loss of self-determination, and loss of control over one's own finances. That is, day-to-day experiences are often poor.

What is less clear is how these experiences might affect long-term outcomes. Well-controlled quantitative studies, which might be used to identify long-term outcomes of residential care, have proved difficult to conduct, and evidence is scanty. Judge and Sinclair (1983) argued that quantitative evidence would be difficult to obtain because of the small numbers of people entering any one home in a reasonable time period for research, case mix variations, and the variability between homes. At the time of writing there is little convincing evidence either way, though Lindesay et al. (1991) hint that survival may be longer in 'high quality' institutional care specifically designed for people wit dementia than in 'low quality' long-stay hospital wards.

Consumer evidence that elderly people prefer their own homes comes both from people in residential care (Peace et al., 1982) and people still living in their own homes (Salvage et al., 1989; Sinclair, 1988). The preferences of carers for those they care for are also usually in favour of living in one's own home (Levin et al., 1983). There are difficulties in asking people with dementia about their preferences, but one study suggests that they too prefer to remain at home (National Consumer Council,1990). Others have argued that the negative analyses presented here overstate the problem (Elkan and Kelly, 1991; Foster, 1991), and ignore the positive contribution that residential care can make for some groups of people. These different views emphasise the point that there is no general consensus on the value of residential care for people with dementia.

4.3.5 Other Schemes

There are also a number of innovative residential schemes for people with dementia, whose development has typically been motivated by the desire to overcome perceived problems with hospital and residential/nursing home care (Norman, 1987). There are examples of buildings designed for people with severe dementia, who have their own rooms with en suite washing facilities, where people are encouraged to perform as many normal daily activities for themselves as they can (Lindesay et al., 1991). There are also a number of very sheltered housing schemes, which are similar to sheltered housing, but with more intensive services available (Foster, 1994). Tinker (1989) found that these specialist schemes can be highly valued by some groups of people, for whom they are an attractive alternative to living at home.

4.3.6 A Mixed Economy

The variety of residential care is evidence that a 'mixed economy' of care has existed for more than a decade. As noted earlier in the Chapter, two of the central planks of Caring For People were the move towards a more mixed economy of care and a shift in the balance of care provision from residential (and hospital) to home-based care. Both now and in the future, then, the decision to enter an institution will be a bellweather of national policy.

The current broad consensus is that whatever the merits or otherwise of institutional care, there will always be some elderly people - including people with dementia - who require alternatives to living in their own homes. Some people really cannot be supported properly at home, perhaps because they have serious health problems, and there may be no informal carer, or a crisis where a carer becomes ill or dies. In practice, then, a key objective of service provision is to achieve an appropriate balance between community-based and institutional care. The balance has been struck at different points at different times. In addition, the provision of institutional care is far from uniform across the country (Forder et al., 1993). A mix of local and regional factors within both health and social services has therefore shaped local provision over time.

4.4 Entry To Institutional Care

The next questions concern the factors that lead to entry to institutional care and whether people enter when they need to. In terms of Figure 4.1, this section focuses on the different settings that constitute the 'care environment'. Most work on entry to institutional care in the UK has concentrated on risk factors for entry to local authority residential homes. Those who enter these homes often have:

- High cognitive impairment;
- Significant behavioural or inter-personal problems;
- No informal carer;
- Carers who were in favour of residential care (typically because they felt that they could not go on themselves, rather than seeing it as a positive choice);
- Carers in poor physical health, particularly with heart conditions;
- Packages of services which did not include respite care for carers;

(Levin et al., 1983; Sinclair et al., 1986; Sinclair, 1988). In many cases, there is a crisis, a breakdown in support, with the carer falling ill (perhaps unrelated to the stresses of caring) or needed community services not being provided. It is not known whether the risk factors for entry to private homes are similar to those for local authority homes - a significant issue given the recent rise of private provision.

There have been few studies of the appropriateness of moves to local authority and private homes. Sinclair et al. (1986) found that over half of elderly people who entered local authority might have been inappropriately admitted, and admission could have been prevented by action either at the point of application or at an earlier point in time. Butler et al. (1983) concluded that a significant minority of people in their study of sheltered housing would have been just as happy in well designed ordinary housing. It is not known, however, whether the same pattern would have been found for people with dementia.

Admission to hospital beds has not received such close attention. As beds in the old long stay hospitals have closed, they have often been replaced by beds on acute hospital sites (Philp et al., 1991), though there has been a net decrease in provision. Philp et al. suggest that the demographic effects of more people with dementia (and other problems for adults and elderly people) has slowed the rate at which beds - wherever located - can be closed.

Rationing of the remaining beds has been effected in many places through policies that only 'acutely ill' people should be admitted. In this context an acute hospital stay may be measured in weeks and months, but the intention is that people be discharged back into the community. Recent evidence suggests that resident populations have higher dependency, and staff have lower morale, than those in residential or nursing homes (Clark and Bowling, 1989; Lindesay et al., 1991; Philp et al., 1991). The lower morale is thought to be suggestive of a lower quality of care.

The one other potentially useful source of evidence about admission to institutions is research evidence from the USA, whose health and welfare systems are very different, but which may offer useful clues. There, the risk of admission to long-term nursing home care has been investigated (Morris, 1988; Shapiro and Tate, 1988; Weissert and Cready, 1988). These studies found similar risk factors to the UK studies of local authority homes, and in addition identified poverty, bed availability and being white as positive predictors of institutional care. These three factors may to some extent reflect the different financial environment in the US (poverty may lead to qualification for Medicare or Medicaid funding and so increased likelihood of admission), but may also be suggestive of factors important in some areas in the UK. Williams (1990) notes the particular problems faced by elderly people from ethnic minorities in gaining access to appropriate services in the UK, although it is not known if these problems extend to access to institutional care.

Having explored the evidence about institutional care, the focus now turns to services provided to people in their own homes. For the sake of clarity of labelling different types of care setting, this will be referred to from here on as community-based care or just community care. While the problems associated with using this term are recognised, its use helps to distinguish people's own homes from residential/nursing homes in the discussion throughout coming chapters.

4.5 Informal Carers

Continuing to explore Figure 4.1, the 'care environment' can also include informal carers. The term carer is a broad one. Many elderly people, including those with dementia, are cared for by relatives. It has been argued that this often means women, whether wives, sisters or daughters (Finch and Groves, 1980), though it has been pointed out during the course of the fieldwork for this thesis that many men are carers too. Whether men or women, the important point is that carers are the most important supporters of people with dementia, both in terms of their numbers and the continuity of support they provide. Where a person with dementia has a carer, this relationship is central to any model of services.

Following a review of carers for all kinds of people with illness or disability, the House of Commons Social Services Committee (Social Services Committee, 1990) concluded that:

> "For too long carers have been the unrecognised partners in our welfare system. Their services have been taken for granted. They have been regarded as a resource, but not as people with their own needs. With the greater dependence to be placed by Government upon care in the community it is time to bring the carers into the mainstream ... and give them the recognition which they deserve. That recognition will inevitably cost money, but it is long overdue".
> (HC Social Services Committee, Page 2)

Indeed, the recognition of the importance of informal care probably stems from increasing awareness of its major contribution to the economy, and in particular the costs of providing other forms of care when it is not available (Glendinning, 1992).

People may live in their own homes, move into the relative's home, or live nearby. In some cases people are cared for by friends or more distant relatives: this typically involves the carer and cared for living in their own homes, with carers making regular visits. Informal carers play a vital role in the lives of people with dementia, and in almost all cases want to do so, even though the mental and physical burden can be considerable and they are themselves usually elderly. Where they are close relatives, they may see their role as a simple extension of their familial relationship to the demented person.

By no means all elderly people have someone who can care for them. About one in three people over 75 years of age have no close relative; and almost half live on their own. Figures for people who have dementia appear to be broadly similar, with one study finding that some three out of four lived with others or had a helpful relative nearby (Levin et al., 1983): so one in four did not. Even where there is a carer, it is often the case that the person cares alone, since there are no other relatives. So caring often falls on individuals, who do not have their own informal support network.

From the point of view of those caring for people with dementia, there are a number of problems that have to be coped with. Levin et al (1983) found that carers faced problems in four main areas:

- Practical - giving the elderly person regular help with household and personal care, for example, getting their relatives up, washed and dressed, toiletting them, making sure they ate, putting them to bed.

- Behaviour of the elderly person - for example, incontinence, repetitive questions, aggression, wandering, unsafe acts, night disturbance.
- Inter-personal - for example, sadness at the change in their relatives, losing their tempers with them and tension in their households.
- Social - for example, restrictions on getting out, seeing family and friends, having a holiday, going out to work.

The importance of these points was confirmed by O'Connor et al. (1990). The list emphasises the point that dementia poses problems which are at least as much social as medical. For people with more serious problems, that require constant support, the caregiving is relentless and can last for many years. Carers can easily become worn down both mentally and physically. This suggests that formal support could help with practical tasks, advice and providing periods of respite from caring.

4.6 Formal Services Which Support Carers

In practice, some services seek to care directly for individuals, while others are intended to support both people with dementia and their carers - and so relieve the burden on carers. (The provision of practical help to carers was one of the stated objectives of Caring for People (Secretaries of State, 1989). It commented that such help had not hitherto been developed in most places.) However, as Twigg et al. (1990) have pointed out there is uncertainty about the role of carers in relation to some services: sometimes it appears that services help carers to support people in ways that take account of carer's needs, but at other times it appears that carers are simply being exploited. Twigg et al. do, though, point to services which are wholly or partially focused on the needs of carers. These include:

- Help with personal and domestic care (although households where there is a carer tend to be selected against for these services);

- Medical services, particularly district nursing (though help with personal care tasks is typically available only intermittently);
- Respite care in hospitals, residential homes or day centres;
- Sitting services, where a helper substitutes for the carer. Most schemes are organised by the voluntary sector, and tend to be day rather than night services;
- Carer support groups of various kinds including self-help groups or groups organised by professionals.

These services have seldom been subjected to rigorous evaluation in terms of their impact on carers, although such evidence as is available suggests that each is effective, or could be effective if appropriately organised. In the single most comprehensive study of carers, Levin et al. (1983) found that the home help and respite care services were particularly highly valued.

Using a different approach, there have been several attempts to enhance carers' skills in coping, using techniques such as meditation, counselling and training in stress management (eg. Levine et al., 1983; Brodaty and Gresham, 1989). Results suggest that such interventions can be successful in reducing the psychological burden on carers, although in most studies outcomes for carers and cared for were not rigorously evaluated. There is no evidence that this kind of support can or should substitute for practical forms of support from outside. Rather, they can be a useful adjunct to them.

This discussion highlights uncertainty about the identity of decision-makers in, and objectives for, community-based services for people with dementia. It is not always clear whether services are designed to support people with dementia, their carers, or both. In contrast with many acute hospital services, therefore, it is not easy to identify a service objective such as ‘health improvement’ or ‘person cured’, a single locus for any formal support, or a single key decision-maker - since there are several different services that might be provided.

4.7 Health Services For People With Dementia

In general, health and social services for people with dementia are organised and delivered separately. As noted in Chapter 1, the extent of formal coordination between the two varies across the UK, but has traditionally been poor. The separate services are outlined first, before relationships between them are explored.

4.7.1 General Practitioners And Health Service Referrals

By their nature, health services tend to be provided for people with dementia rather than their informal carers. In most cases the first point of contact with health services is the general practitioner (GP). GPs may provide certain services themselves, especially medical services for depression or conditions unrelated to dementia. (Since 1991 GPs have been required to undertake an annual screening of people of 75 years and over. This will cover some, but by no means all, people with dementia. It is worth noting that carers may not be in the screening target group, and so cases of carer stress and depression will not be picked up in the screening.)

People with dementia may be referred by their GPs on to one or more other services. GPs may refer to other NHS professionals, including:

- Community psychiatric nurses (CPNs), who are trained in dealing with mental health problems and so are in a position to advise carers. Increasingly, CPNs are the principal NHS carers for people with dementia;
- District nurses, who can provide a range of practical services. This typically includes bathing (though this is less common than it once was), medical procedures such as changing dressings and giving

advice to carers. In some areas they provide 'twilight nursing' (ie 5pm to 9pm) services for people with intensive care needs. Nursing auxiliaries may offer similar support;

- Psychiatrists of old age, who in many areas are now based in community units and are increasingly interested in social as well as narrower health issues;
- Consultants in the care of the elderly, who are generally based in hospitals. They typically refer people with dementia on to psychiatrists of old age;
- To therapists, chiropodists or other professionals for other health problems.

Each of these groups can help people with dementia, most often by providing practical advice about a health-related problem, or in the case of consultants arrange for support to be provided.

One study found that GPs referred people to seven services, though the bulk of referrals were to three of them: almost half of patients identified as confused had been referred to district nurses, and most of the remainder to a psychiatrist or social worker (Levin et al., 1989). The study also found that many GPs 'miss' dementia, confirming evidence cited in Chapter 3, and that where referrals did occur they tended to be on medical rather than social grounds.

A major issue for health services concerns the level of service available. Bisset and MacPherson (1996) found that many GPs were concerned about the quality and quantity of services, and believed that there were gaps in service provision. By and large, however, the issue is not the kind of support that is received, but rather that there is not enough of it. This is most obviously the case for district nurses (Sinclair and Williams, 1990a), who may visit only weekly or fortnightly: the authors felt that the kind of practical assistance they provide would be more effective if available more often.

4.8 Acute Hospital Services: Admission And Discharge

There is evidence that a stay in hospital is an importnat indicator of subsequent admission to institutional care, and this is reviewed here. People may need to enter an acute hospital for treatment, which may or may not be related to their dementia. Over the last decade and more, hospital doctors have increasingly been willing and able to admit and treat elderly people. It is not clear, however, whether having dementia influences doctors' decisions, though anecdotal evidence suggests that people with dementia are admitted to hospital beds in a variety of specialties in many hospitals. It may be a matter of chance whether someone sees a psychiatrist of old age or a consultant in the care of the elderly - although the relevant Royal Colleges have developed ground rules to guide local practice and promote appropriate treatment and referral.

Discharge of someone with dementia may be to her own home, to that of a friend or relative, or to an institution. Research undertaken before the new assessment arrangements were introduced showed that hospitalisation was a key predictor of referral to a social services department. That is, hospitals serve as an important source of referrals to practical social support such as home helps. Caldock and Wenger (1988) found that one fifth of a community sample (in north Wales) had been in hospital since retirement. Sinclair et al. (1988) found that one fifth of referrals for home help in an area of north London were made by hospitals. It has also been shown that hospitalisation is a predictor of later institutional care in a long stay hospital bed or local authority home (Challis and Davies, 1986; Neill et al., 1988).

From the NHS point of view, many hospitals have long had problems with 'bed blocking' - people who are deemed not to need medical treatment but who are unable to leave, most often due to a lack of availability of support at home. Conversely, in practice many people are discharged without proper assessment of their home circumstances (Neill and Williams, 1992). The discharge of elderly people (in general) from hospital has long been the subject of research (eg Skeet, 1970, 1985; V. Williamson, 1985; Townsend et al.,1988). These studies showed that many elderly people experience difficulties in coping on discharge, and that these difficulties could be addressed through help at the point of discharge and for a period afterwards; but often these services were not provided. This pointed to a lack of coordination between hospital and community based services, and to wide geographical variations in policy and practice.

The Department of Health responded by publishing guidance (1989), which contained explicit criteria for good practice for all people discharged from hospital, and required patients and carers (with patients' permission) to be consulted before decisions are made. The requirement to consult is buttressed by the Patient's Charter which states that:

> "Your hospital will agree arrangements for meeting [your] needs with agencies such as community nursing services and local authority social services departments before you are discharged. You and, with your agreement, your carers will be consulted and informed at all stages." (Department of Health, 1992: Page 1)

The introduction of care management, as part of the new community care arrangements, has led to the formalisation of needs assessment within a cycle of planning, delivery, monitoring and review of services (SSI/SOSWSG, 1991a, 1991b). This is an important departure from previous practice, since social services personnel are involved in decisions about discharge; it is no longer the responsibility of hospital consultants alone. There are inconsistencies in policy statements, with some Department of Health guidance stressing the role of the hospital in discharge arrangements, while other guidance asserts the primacy of social services care managers. In practice this may not be important, so long as consultants and care managers agree - though what happens if they do not is less clear. This is one concrete example of the joint working promoted by the new community care legislation - and also the lack of clarity that attends some aspects of the new arrangements.

It should be stressed that social service involvement in hospital discharge is not new. Many hospitals have had social workers for a decade or more, and one study (Connor and Tibbitt, 1988) found that they improved coordination in the view of both hospital consultants and other social workers. However, their presence is no guarantee of good discharge practice.

This research is useful in illustrating the nature of hospital discharge arrangements, but leaves open many questions. Most important in this thesis is the absence of evidence on the experiences of people with dementia, which may well be different from those of elderly people in general. Also, any effects of the new needs assessments on discharge patterns, either for elderly people in general or for people with dementia, are not known.

4.9 Social Services

4.9.1 Introduction

Until April 1993 the key individual in the delivery of social services for people with dementia was the social worker. The social worker was in a direct hierarchical relationship with the local director of social services: in general it was the social worker's decision that a service should be provided, within budgetary constraints. Historically, social workers discriminated positively in favour of, and focused resources on, child care and family services where their main statutory obligations lay (Hunter and Judge, 1988): the main exception was entry to local authority homes, where a social worker was always involved. As a result, their importance to elderly people as advocates or providers of resources was relatively limited. This lack of attention, and the fact that social workers were not allocating resources on the basis of need, was sharply criticised in the Audit Commission's reports in the mid-1980s (Audit Commission, 1985, 1986).

The increasing numbers of elderly people referred to social services in the 1980s did, however, force social workers to devote more attention to elderly people, and the new community care policies have accelerated change since 1993. One development has been a move from a 'generic' model of social work to more specialised roles, and in practice it seems that social workers have become increasingly specialised over time, so that for example the role of psychiatric social worker is now common.

It is in the nature of social services that they may benefit both people with dementia and their carers. In their own homes, people with dementia may receive two main social services:

- Home helps and home carers, who are the most numerous providers of care. They help with a range of practical domestic tasks. Home help has often been described as the cornerstone of community care;
- Meals on wheels (these may also be provided by voluntary services);

Outside the home, the main services are:

- Day care, which may be provided in a day centre, a residential care home or by a voluntary organisation (eg. Age Concern);
- Respite care, where someone stays in a local authority residential care home or other institution, often for a fortnight at a time.

As noted earlier in the chapter, one or more of these services may now be charged for in many local authorities. There is research evidence that day care is valued, but there is controversy about the value of other forms of respite care, with some questioning its value (Rai et al., 1986; Melzer, 1990) and others supporting it (Pearson, 1988; Selley and Campbell, 1989).

4.9.2 Access To Social Services

A person with dementia may come into contact with social services in four ways. Firstly, family or friends may contact social services directly. This route is recognised in the academic literature, but no accounts of rates of referral or descriptions of who contacts social services were found. Secondly, as noted in the last section, people can come into contact with social services during an acute hospital stay.

Thirdly, as noted earlier GPs can be gatekeepers to social services. There is little concrete evidence about these patterns (Sinclair and Williams, 1990b: page 143), but for elderly people in general it appears that many GPs make no referrals while a handful make a sizeable number. Levin et al. (1989) noted wide variation in referrals by GPs, but their study did not investigate these variations.

Other research shows that relationships between GPs and social services in general have been problematic. GPs have criticised social services for being slow to respond and unreliable (Henderson, 1992), while social workers feel that GPs do not regard them as professionals (Sinclair and Williams, 1990). At the root of these problems, it seems, are the widely differing value systems of the two groups (Dalley, 1989). It is not clear whether the new community care policies, with their emphasis on co-ordination of services, have had any effect on these inter-professional problems.

The fourth route is via community-based nurses, typically either district nurses or community psychiatric nurses. Again, the existence of these referral patterns is recognised in the literature, but they do not appear to have been the subject of detailed research.

4.9.3 The Quantity Of Services

Relatively little is known about the use of these services by people with dementia. Levin et al. (1983) found that it was usually the case that confused people were in contact with at least one service, but that those who most need services do not receive them. Levin (personal communication) confirmed that a similar picture had emerged in a new study for the Department of Health, which had not yet been published. Dementia appears to be a condition to which the inverse care law applies (Tudor Hart, 1971). That is, the quantity and quality of care received is inversely proportional to need. Resources are often shifted towards people with relatively minor problems at the expense of those in greatest need.

An outstanding problem often left even by the best social services is practical support in the evenings, at night and at weekends. That is, even where people with dementia and their carers receive services, there is little support outside 'office' hours. The nature of the support required is straightforward, consisting for example of sitters who support carers by giving them 'time off', or intensive practical support when a problem arises. Such support does exist in some places, where people from any sector may have initiated service innovations, but this remains the exception rather than the rule (Woods, 1995).

Another major challenge for services, addressed in the new community care policies, was to improve co-ordination and increase the efficiency and effectiveness of resource allocation. As noted earlier, care management was

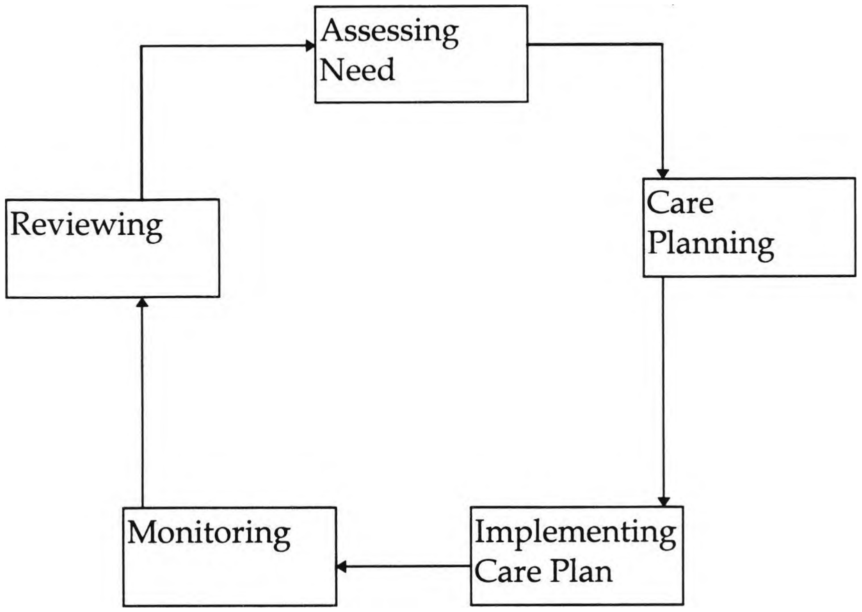


Figure 4.3

The Process of Care Management

Source: Social Services Inspectorate (1992)

advanced as the solution for social services, and for collaboration between health and social services.

4.10 Care Management

Caring for People (Secretaries of State, 1989) endorsed a particular approach to the organisation of services for elderly people, based on the model developed by the Personal Social Services Research Unit (PSSRU) at the University of Kent in the Kent Community Care Project (Challis and Davies, 1986). This is care management, where an individual is nominated as the principal support worker, holds a budget and allocates it on behalf of an individual. The basic process of care management is shown in Figure 4.3. The nominated person - the care manager - may in principle be anyone from health or social services. At present most are social workers, but increasing numbers of care managers are highly experienced, but not formally trained, people. Clearly, the possibility of employing 'lay' people to perform the co-ordination role poses a threat to social work as a profession.

Not everyone needs a care manager: it is intended for people whose needs are relatively complex and/or who may be on the margins of admission to institutional care. That is, care management is a process which complements rather than replaces the services described earlier. These other services will continue to be recommended on an *ad hoc* basis for many elderly people. However, the complexity of the needs of many people with dementia suggests that many will in practice require care management.

The devolution of budgetary discretion, its proponents argue, allows the care manager to act as a purchaser and coordinator of services tailored to an individual's needs, and to reconcile global and individual case budgets. (The next section gives a brief description of needs assessment.) A key objective is to maintain people in the community, and avoid institutionalisation. Evaluations have shown that care management is cost-effective for elderly people in this respect, in that it both improves the efficiency of service delivery - through improved co-ordination - and avoids the higher costs of institutional care (Challis and Davies, 1986; Challis et al., 1991).

The budget allows care managers to recruit home care assistants, people based in the local community who are paid to undertake any of a range of practical tasks or provide companionship. The care manager can also negotiate with a social services department for the resources listed above - home help, day care and so on - as well as with other statutory and voluntary organisations. (Details of the arrangements vary between authorities, depending in part on whether particular services are charged for. Where they are, care managers' budgets cannot be used to pay for them.) In the PSSRU schemes, there was a rule that the average weekly cost for a person must not exceed two thirds of the cost of a residential care home place.

The care manager is also in principle well placed to relate the allocation of resources to client outcomes, and so can monitor the whole cycle of assessment, allocation and outcomes. When they work well, care management schemes are undoubtedly an improvement on former poorly coordinated arrangements, and are more flexible and more acceptable to service users. The endorsement of the approach in Caring for People suggests that care management is the model of choice for the 1990's and that many people with dementia will therefore have nominated care managers.

Yet in spite of the evaluative evidence, the value of care management has been hotly contested in the literature (eg Jack, 1992; Wilson, 1993). The burden of the criticism is that the transition to national policy has led to the creation of a variety of models, all called care management but in practice having distinct characteristics and operating with varying success (Dant and Gearing, 1990). This has not been helped by central guidance, which offers 18 models of assessment and 13 models of care management (Social Services Inspectorate, 1992). On one level this is understandable: the Department of Health does not want to appear prescriptive. But it is also a potential source of confusion.

More important in the context of this thesis is that it is not clear that care management is appropriate for people with dementia. Von Abendorff and colleagues (1992) reported on a pilot scheme to extend care management to people with dementia and their carers in Lewisham. The general principles of care management followed the usual rules, but there was a pre-existing explicit commitment to multi-disciplinary working, with mental health teams for elderly people comprising both health and social services personnel. This meant that the organisational model used was different to the 'classic' care management model. The financial rules were the same but operated by a team, where social workers were appointed as care managers but worked as team members. Those people accepted for care management in the study were a sub-set of all those with dementia in the area, being those deemed most at risk of entry to institutional care.

The scheme was not a success. Institutionalisation was not avoided, nor the stress experienced by carers reduced. The care managers found administration and liaising with other professionals very time consuming, and there was no evidence that these increased adminstration costs were being offset by savings elsewhere. If anything, the project emphasised the high costs associated with dementia, with several people having three or more informal helpers allocated to them, as well as substantial more formal inputs. Care managers found it difficult to create these complex packages and balance individual needs against global budgets. Some people also proved difficult to provide for - for example, some were refused respite care in a residential home on the grounds of difficulties in caring for them, even though the team were agreed that this was needed.

The report does not go into great detail, making it difficult to know whether the problems were due to lack of resources or to flaws in care management when applied to people with dementia. Whatever is the case, the project points up a key issue, namely that there is no single accepted 'best' model of care for people with dementia. Care management, while now national policy, may not serve people with dementia well. A similar conclusion was reached by Ramsey and Coid (1994), following a study of dementia services in Fife. One alternative is pointed out by Levin et al. (1989), who point to evidence from their own work that small packages of care, directed at *carers*, can be very helpful and reduce stress and so enhance their ability to care.

However, the nature of the model of service delivery that might support these packages is not clear at present.

4.11 Needs Assessment and Care Planning

Here, a brief diversion is taken, to sketch out in more detail the process of care management, shown in Figure 4.3. As already noted, the delivery of services and assessment of needs was formerly variable and haphazard (Goldberg and Connelly, 1982). Needs assessment and care planning is designed to lead to more systematic delivery of care. Need is a notoriously difficult term to define, and central guidance states that it is:

> "a dynamic concept, the definition of which will vary over time in accordance with:
> · changes in national legislation
> · changes in local policy
> · the availability of resources
> · the patterns of local demand.
>
> Need is thus a relative concept." (SSI/SOSWSG, 1991a: page 12)

Rather than try to define need, then, it is perhaps best simply to note that those who assess need will in practice have to reconcile global financial and organisational issues with services provided to individuals. McWalter et al. (1994) note the difficulties associated with defining needs for people with dementia in practice. It is likely that an element of judgement will always be required, given the complexity of resource allocation decisions, and balances will often be difficult to strike.

There are different possible 'levels' of assessment (Table 4.2). For people with dementia, it seems likely that almost all will fall into one of the categories, and so few will fail to be assessed - and they will thus have a

Assessment	*Needs*	*Services*	*Agency*	*Staff*	*Examples of service outcomes*
1 Simple Assessment	Simple, defined	Existing universal	Single	Reception or administrative	Bus Pass Disabled Car Badge
2 Limited Assessment	Limited, defined, low-risk	Existing, subject to clearly defined criteria	Single	Vocationally qualified	Low level domiciliary support
3 Multiple Assessment	Range of limited, defined low risk	Existing in a number of agencies	Multiple	Vocationally qualified or equivalent	Assistance with meals, chiropody and basic nursing
4 Specialist Assessment (simple)	Defined, specialist, low risk	Existing, specialist	Single or multiple	Specialist ancillary	Simple disability equipment
5 Complex Assessment	Ill-defined, inter-related, complex, volatile, high-risk	Existing and/or new individual combinations of service	Single or multiple	Professionally qualified	Speech therapy
6 Comprehensive Assessment	Ill-defined, multiple, inter-related, high risk, severe	Existing and/or new individual combinations of service	Multiple	Professionally qualified and/or specialist professional	Family therapy. Substitute care or intensive domiciliary support

Table 4.2
Levels Of Assessment In Care Management
Source: Social Services Inspectorate (1992)

care manager. The Table can be interpreted as a major extension of the original PSSRU concept of care management, formalising the approach and extending it to all service users.

4.12 Team-Based Models

Care management promotes a model based on the concept of a single co-ordinator of services. A different type of model has been developed in a number of areas in the UK, based on the concept of teams. The starting point for these team-based models is the historical division between health and social services, and the need to overcome its deleterious effects. There have been many exhortations by governments down the years to both sides to collaborate, but it seems that little heed was taken in most localities before 1993 (Parker, 1990). The move of mental health services for adults and elderly people into the community in recent years has encouraged the formation of community teams, sometimes based in community mental health centres (see Jackson et al., 1993). Such teams take different forms in different places (Woods, 1995), but for the purposes of illustration the Community Team for Mental Health in the Elderly in Lewisham in south London comprises:

- Social worker;
- Occupational therapist;
- Community psychiatric nurse;
- Community-based psychiatrist of old age;
- Psychologist.

People with dementia may be referred to the service, often by GPs, or members may be contacted directly by relatives or friends. Each member of the team will undertake assessments and may co-ordinate services. There is open referral within the team if necessary. The potential attractions of such teams for people with dementia and carers is clear enough: as long as they are referred to any member of the team, the probabilities of coming into contact with services they need and of those services being properly co-ordinated are enhanced.

4.13 Models of Structure and Process

The material presented in this chapter has highlighted a number of important characteristics of the domain. The first part of the chapter led to identification of a high level model of the domain. This section seeks to distil out the main lessons for modelling detailed aspects of the domain in later chapters, and in particular the relationship between the 'care environment' and 'service providers' in Figure 4.1. It highlights:

1. The roles of individuals, particularly professionals;
2. The characteristics of formal service delivery systems.

First, the structure of decisions, and particularly the roles of professional decision-makers can be investigated. As the preceding sections have highlighted, the influence of professionals on the decision to enter an institution remains unclear. For health services in general it is known that there are significant variations in the way that doctors practice and in their outcomes for a range of acute medical conditions (Wennberg, 1987), and also in decisions about referrals and admission to hospitals (Coulter et al., 1990): one might therefore expect variations in decisions and treatment patterns for people with dementia. In fact, though, there is no little evidence about practice variations or the influence of professionals' judgements on outcomes for people with dementia.

Suppose, for a moment, that one is attempting to construct a feedback model to characterise the relationship between professional and person with dementia, along the lines of Cramp and Carson (1995). The simple model in Figure 4.4 highlights two questions.

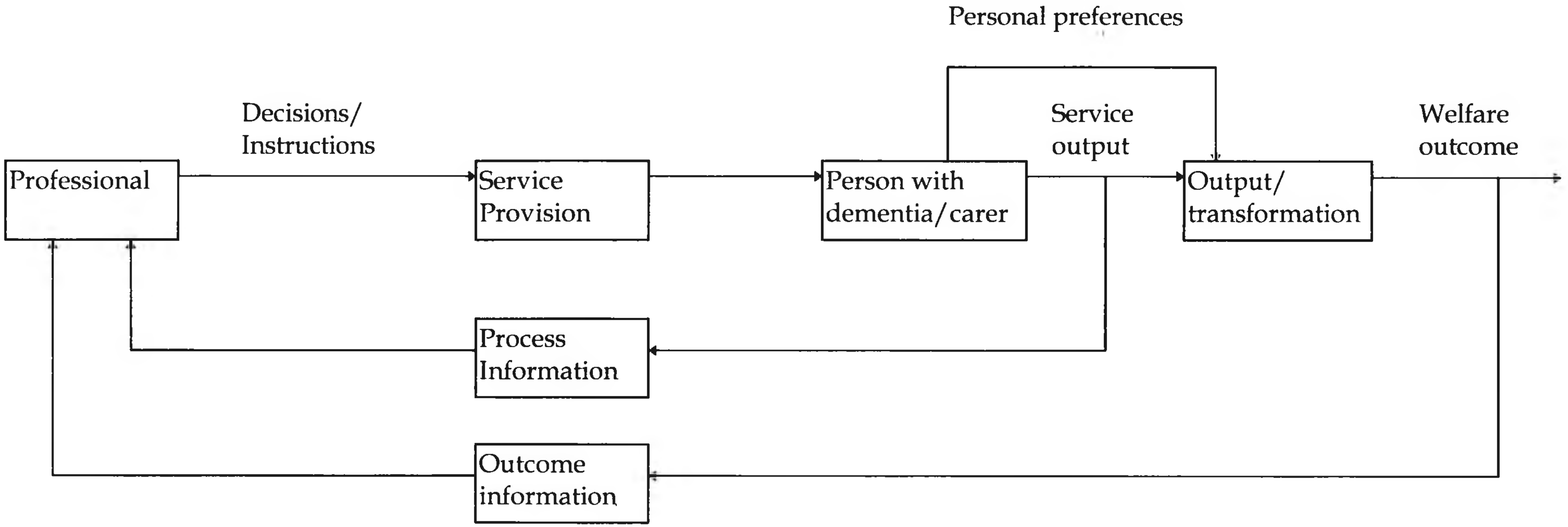


Figure 4.4

Feedback model

All arrows represent information flows

Influence of the wider environment and resource inputs are not represented

Based on Cramp and Carson (1995)

The questions are:

1. What are the desired outcomes for people with dementia and their carers? As discussed earlier in the Chapter, community care policies emphasise that one desired outcome is *avoidance* of entry to an institution. Put another way, it is living in the community with the highest possible quality of life.
2. Who is/are the decision-makers? There are two possible answers to the question. One is that professionals are in the best position to make judgments and are the appropriate decision-makers: this is what is represented in the feedback model. Others argue that decisions must lie with people with dementia and their carers. In recent years the policy debate has tended to favour the latter view, with individuals and families having to make major personal financial decisions about the costs (economic and otherwise) of different options, and the prevailing 'philosophy' is one of professionals helping - or enabling - people to make their own decisions.

Turning to service delivery, one can ask about both organisation structures and processes. With regard to organisation, earlier sections have suggested three distinct models:

1. Fragmented, poorly co-ordinated services - the absence of a consciously designed model;
2. Care management, based on a model of a single, local co-ordinator of services;
3. Team-based working.

The latter two models are explored briefly here. Even though care management may not be a desirable model of care for people with dementia, it may nevertheless be implemented in many localities. How does care management differ from 'traditional' models of service delivery? There appear to be two aspects to the answer. The first is that, in principle at least, it goes some way to resolving the problem of fragmented responsibility for decision-making. If one uses the negative feedback model first presented in Figure 4.4, one can identify clear roles. The care manager is the decision-maker/professional, able to draw upon a range of services. Moreover, care management a feedback loop: the care manager can assess needs, organise services and monitor outcomes. The care manager can also co-ordinate resource allocation decisions.

Care management also represents a move from hierarchical organisation to a more devolved way of working. The distinction is neatly captured in the contrast between traditional top-down control and more localised self-regulation (Beer, 1981, 1985; Dunsire, 1990, 1992).

Team-based working offers a radically different model. In this domain, the logic of teams appears to stems from a desire for better co-ordination, and effective referral of people to service providers, rather than a desire to optimise resource allocation. It cannot easily be represented in the feedback loop of Figure 4.4. Indeed, teams would appear to combine the 'professional' and 'service provider' boxes, blurring the identity of decision-makers. The differences between these models will be discussed at greater length in Chapter 5.

One can also model key processes within the domain. One might in principle model resource flows - including both money and the movements of people - and information flows. Since the objectives of the thesis are concerned with the movement of people from the community to institutional care, the focus here is on them. As noted earlier, it is difficult to study resource costs empirically, and some background information is provided in the Appendix. Information flows are undoubtedly important, and are discussed as part of a wider discussion of collaboration in service delivery in Chapter 10.

This Chapter has shown that relatively little is known about the movements of people with dementia between services. Levin et al.'s (1989) study provided insights into movements between the community and local authority homes. A study by Challis et al. (1995), tracked a cohort of elderly mentally ill people who had been discharged from an old long stay hospital over 18 monhs, and recorded when they entered a new institution. (That is, the nature of the group involved is different to that in this thesis, but there are useful lessons to be learned, and these are picked up in Chapter 7.) These studies aside, little is known about the flows of people depicted in Figure 4.2.

4.14 Conclusions

The organisation of services in the domain is complex, and cofirms the claim made in Chapter 1 that the domain provides as a valid but serious test of systems approaches. This chapter has shown that there are important aspects of the domain which merit investigation. These include:

1. The characteristics of health and social service professionals involved in decisions about treatment and support;
2. Organisation structures and processes, particularly the processes involved in entry to institutional care.

These are investigated in the course of the next four chapters. The next task, however, is to explore the relationship between services providers and recipients from a systems perspective.

CHAPTER 5

A SYSTEMIC VIEW OF THE DOMAIN

5.1 Introduction

Chapter 4 presented empirical evidence about the domain, focusing mainly on the organisation of formal health and social services and the movements of people with dementia into different institutional settings. A small number of good studies have been reported which are directly relevant to the issues raised in this thesis, but evidence about many aspects of service delivery is limited.

In the light of the discussion in Chapter 2, it is important to clarify the nature of the modelling appropriate to the domain. Two distinct approaches, Beer's Viable System Model (VSM) and Soft Systems Methodology (SSM), are used to frame the discussion. They are useful here because they embody a contrast, between positivist VSM and interpretive SSM.

At the end of Chapter 4 it was noted that three distinct service models can be identified, namely the 'traditional' fragmented service, the care manager who co-ordinates service provision, and team working. The nature of these models is explored in more depth in this Chapter, as a prelude to the empirical studies reported in Chapters 6-8: the purpose is to establish how far VSM and SSM can be used to provide useful insights. For both VSM and SSM, the basic theory is outlined, some brief comments are made about their application in areas similar to the domain in this thesis, and then the extent of the 'fit' between the models and the characteristics of the domain discussed.

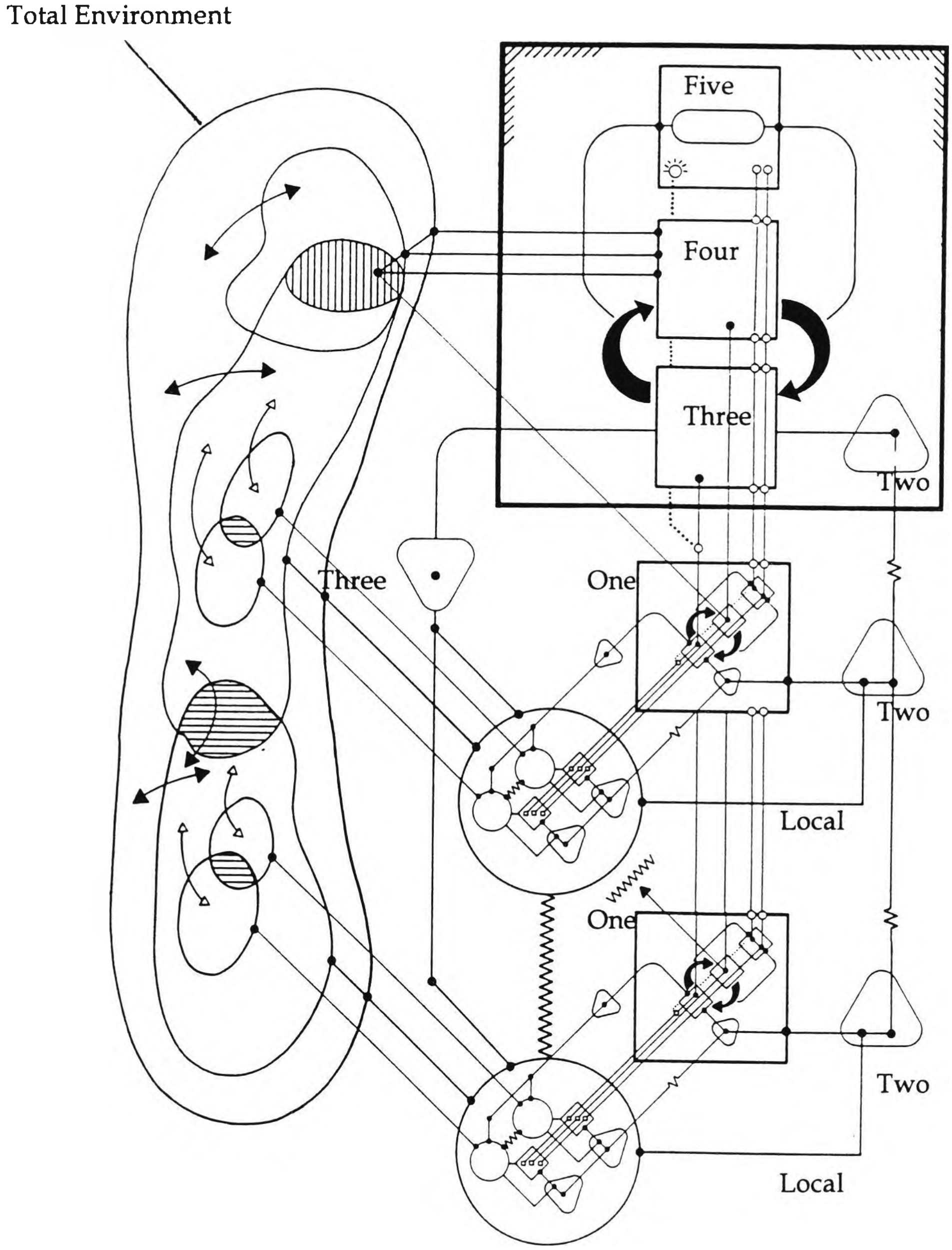
5.2 The Viable System Model

Beer (1979, 1981, 1985) advocated learning from the way that control is achieved in complex natural systems, and in particular the body and the brain of higher animals. Taking an engineering perspective on the process of control in organisations (and working from what he saw as basic principles, rather than taking the theoretically problematic route of relying on analogies), he identified underlying conditions for 'viability' (Ashby, 1965) in control systems, the fundamental components of systems of control, and alternative modes of control.

The main theoretical product of this line of thinking was the Viable System Model (VSM) which, he argued, was a generic model of all organisations. Figure 5.1 is a pictorial representation of the model, which shows that it has five principal components. The components are briefly described in Table 5.1. Control theory recognises that the standards or norms to be followed are always set outside a system, or more accurately at a higher level of the system: VSM codifies this concept in its hierarchical structure.

As presented, VSM is essentially positivist in nature, in that it assumes that a system can be understood objectively, independent of any observer. In Dando and Bennett's classification (1981: see Chapter 2) VSM represents the 'official' OR paradigm. It has been the subject of considerable debate, attracting both adherents and critics. The main criticisms, and some possible refutations, are outlined by Flood and Carson (1993). In their edited volume, Espejo and Harnden (1989) provide an extended critique, giving space to both supporters and critics of VSM.

If there is one key point to emerge from these critiques, it is that many of the problems of VSM have arisen from too-literal attempts to apply it to practical problems. VSM is almost totally silent about the political and cultural dimensions of problems, and some of the problems highlighted by



Local = local regulation
All lines joining filled dots are bilateral flows
Numbers refer to Beer's Systems One toFive (see Table 8.1)

Figure 5.1
Beer's VSM

Source: Beer (1985)

Beer argues that the major tasks of an organisation (he uses the term firm, implying an organisation operating in a market) are to ensure a stable internal environment and stable interactions with the external environment.

1. System One is the operational level, typically comprising several distinct units (eg. departments in a firm), which pass information vertically to other systems. It is assumed that performance can be measured, and so the information that is passed concerns the performance of the units.
2. System Two is the controller of System One, and may employ both negative feedback and feedforward control. Receives instructions from higher Systems which are passed down to System One.
3. System Three is principally concerned with top-down control, though also receives information from Systems One and Two, and monitors and sets overall direction for System Two.
4. System Four receives information from System Three, and monitors and acts on information flowing up and down the vertical axis. It also monitors the external environment. It 'arouses' System Five when significant deviation from plan are detected, and conveys System Five's commands downwards.
5. System Five is concerned with policy formulation, and assessment of the progress of existing policies. It receives 'arousal' information from System Four - and hence from a variety of sources.

Table 5.1

The Five Systems In Beer's VSM

Source: Beer (1985)

the contributors to Espejo and Harnden (1989) suggest that politics and culture are ever-present and undermine the best-laid (VSM) plans. But all is by no means lost, and the editors themselves provide a way forward:

> "the model is a *pointer for understanding and action*... from the methodological point of view, we have stressed its generative, rather than descriptive or prescriptive nature." (Espejo and Harnden, 1989: pages 458-459. Authors' italics.)

That is, VSM should not be used as a way of describing the world, but as a way of generating insights and deepening understanding. Taking this point to heart, the task here is not to apply VSM to the domain, but to start a 'dialogue' between VSM and the systemic characteristics of the domain identified in Chapter 4, with each informing the other.

It is important to stress what is happening here. Espejo and Harnden are arguing that VSM as a positivist theory is of limited value, but if used as an *interpretive* theory, to generate understanding of causal mechanisms in complex systems, it can be valuable. Recalling the discussion in Chapter 2, VSM was originally conceived as a positivist theory, but perhaps Beer himself was in error. VSM, as used here, does not belong in the positivist/official category, but in the interpretive/reformist.

Espejo and Harnden (1989) and Flood and Carson (1993) note that much management and organisation theory has an inherent cybernetic quality. Used as a normative theory of organisations, VSM suggests that the domain can be viewed as a whole, but also comprises a number of distinct sub-systems with different characteristics and objectives. The health and social services sectors might usefully be viewed as sub-systems within VSM, and the task is to characterise the relationships between these sub-systems and those comprising people with dementia and their carers. This line of thinking is now explored further through the work of Andrew Dunsire, before turning back to the domain itself.

5.3 Cybernetics In Public Administration

The cybernetic perspective has been applied most systematically to public sector organisations by Dunsire (1986, 1990, 1992). While Beer focused principally on firms in markets, Dunsire argued that cybernetic ideas could also be applied in public administration. He identified three basic types of control system (1990):

- Steering or regulation, where the analogy is with the helmsman on a ship. This involves setting norms and correcting deviations from them, and within organisations is most often associated with top-down bureaucratic control. It is based on a negative feedback control model.
- Homeostasis, analogous with homeostatic mechanisms in natural systems, which is based on negative feedback control. It involves self-regulation and is associated with the control exercised within relatively autonomous units in an organisation, as in monitoring expenditure against a budget. Self-regulation implies the existence of an original position to which the system returns by itself: the set point is set outside the system.
- Collibration, which involves the harnessing of coupled (often positive) feedback mechanisms. No norm or datum is set in advance, but there is rather a continuous tug of war between opposed forces or tendencies. There is a floating, rather than fixed, mean. Dunsire offers the examples of a predator species and its prey, where there is no 'correct' number of either population, and the coupled positive feedback actions linking the hormones renin and vasopressin in the control of body fluid volume.

The essence of collibration is intervention in relationships between rival maximisers. In organisations, collibrative mechanisms can be influenced by actions which 'tip the scales' in favour of one or other player. For example, using 'league tables' to encourage local authorities or hospitals to improve their performance is collibration. Similarly, subsidising community health councils is collibratory, in that the balance of power between health service providers and patients is tilted (albeit only a little) towards patients. In the domain here there are clear candidates for the role of external regulator of collibratory mechanisms, namely the government for national policies and purchasers at local level.

5.4 Cybernetics, VSM And The Domain

Dunsire notes that the three modes of control are not exclusive. This point is important, and not always recognised in the cybernetic literature, where one mode of control is presumed to dominate in any given context. (Thompson (1967) is an exception.) The question here, therefore, is which mode, or combination of modes, captures essential characteristics of the domain of interest? Evidence from Chapter 4 suggests that all three are present; and that there is a fourth that Dunsire did not identify. In the analysis that follows, ideas are drawn both from Dunsire and VSM.

5.4.1 Steering/top-down control (Systems 3,4 and 5 in VSM)

Top-down control is not a major theme of this thesis. What one can say, though, is that monies are allocated by the government and there is accountability for budgets within both to parliament (via select committees) and locally to health and social services purchasers: there is a measure of financial accountability within the system. This said, though, there are real difficulties of measurement of costs, quality and outcomes in both health and social care, so that control and monitoring are problematic. In practice, control is exercised over the more measurable inputs and processes rather than over outcomes.

The problems of measurement are symptomatic of wider problems of control in modern public services. The difficulties of achieving control have been the focus of considerable interest in the mainland European public administration literature (for example Kaufmann, 1991; Kooiman, 1992), where the concept of 'steering' has been explored by many researchers. This literature starts from the observation that organisations and their environments have become increasingly complex over recent decades. Traditional governance structures (which embody control mechanisms) have come under strain, and in some cases failed, because they cannot cope with the span or complexity of organisation processes. As a result, alternative control mechanisms have developed, often based on joint or shared control between organisations.

The development of community care policies can usefully be viewed as a response to the increasing complexity of service organisation. They are concerned with the development of new forms of control, since they seek to achieve a novel mix of bureaucratic and market-type processes. In the language of VSM, community care represents a new form of Systems 3, 4 and 5. These systems are, as VSM implies, intended to influence - though perhaps not control - Systems 1 and 2.

5.4.2 Self-regulation (Systems 1 and 2)

Dunsire points out that control in organisations is only possible if individual units successfully self-regulate, and are co-ordinated with one another. (This echoes one of the key features of VSM, in the design of Systems One and Two, and negative feedback loops in general.) There are two issues that can be addressed here, namely the nature of internal regulation, and the type of lateral co-ordination and monitoring between self-regulating systems.

The three models identified at the end of Chapter 4 - fragmented, care management and the team - can usefully be viewed here as alternative designs for sub-systems within Systems One and Two. Of the three, care management comes closest to the concept self-regulation in VSM. That is, care management embodies a specific concept of local control, with the care manager holding a budget and organising local services, though within the constraints imposed by higher systems (3,4 and 5). The 'fragmented' model is a version of System One where co-ordination/control in System Two is not working properly. The interesting model in this context is the team, since its characteristics are not well captured by VSM or Dunsire's thinking: the team is designed explicitly to dissolve boundaries between sub-systems. This point will be returned to below.

Another approach is to think of the different sectors in the domain - community, hospital, residential/nursing home - as sub-systems, and ask how they are controlled. There was some evidence in Chapter 4 that showed the movements of people between sub-systems: so here it is the movement of people that would have to be controlled. The discussion of community care policies showed that one of their main objectives was to end the fragmentation of service delivery, by a mixture of market-type and collaborative mechanisms. This would suggest that System Two, in VSM terminology, is complex, involving the creation of mixed - and as yet not well understood - control mechanisms. The empirical work in the next three chapters will help to provide further insights into the nature of the mechanisms actually in place on the ground.

A cybernetic perspective leads to the conclusion that the domain consists of a number of distinct, but interdependent self-regulating sub-systems, with mixed control of relationships between sub-systems.

5.4.3 Collibration

There are a number of collibratory mechanisms at work at different levels in community care. For example, the government can make clear what kind of decisions and behaviour it expects of providers, such as charging for services. Social services departments are not forced to charge, but charging is encouraged. Similarly, there is no statutory requirement to adopt care management structures, but there is a clear expectation that they will be adopted: it seems the government intended to create a bandwagon, without intervening directly to determine local structures. In the domain, organisations aiming to maintain people with dementia in their own homes may be 'rival maximisers' to those encouraging them to enter homes. Professionals, carers and others might therefore usefully be viewed as seeking to influence these collibratory relationships.

This thesis does not provide any direct evidence of collibratory mechanisms. Indeed, it is difficult to think of convincing tests of their existence, given that they are inherently indirect by nature. What can be said, though, is that community care can usefully be viewed as comprising professionals and other actors who seek to influence collibratory relationships.

5.4.4 Co-Production

There is a fourth situation which is common in public services and which requires a control mechanism, which is where two or more agents need co-ordinating, but the agents are not co-ordinated via a higher system and are not rival maximisers. For example, there are many situations referred to in earlier chapters where joint planning and service delivery mechanisms have been introduced. Top-down control may not be appropriate, since the problem surrounds lateral relationships. Self-regulation is, as noted above, insufficient by itself. Collibration is not appropriate, since something more active than 'tipping the scales' is required.

This fourth control mechanism is termed 'co-production' here, following Wilson (1994) who uses it to describe services where both (or all) actors contribute to the production of a service. She cites education as an example, where both teachers and students must commit resources if a desired 'product' (educated students) is to result. Her paper focuses on services for elderly people, where she observes that in practice elderly people do a great deal of caring, both for themselves and for others. Formal services complement these activities, so that the outcome of service delivery is a product of the effort of a number of actors. The concept of co-production may be particularly useful in the domain because it suggests a way of thinking about control that does not depend on identification of a single controller/decision-maker.

5.4.5 Implications

This section has investigated the domain from a cybernetic perspective, drawing particularly on VSM. It suggests that four distinct control mechanisms can be found: top-down, self-regulation, collibration and co-production. This means that the control mechanisms within the domain are very complex indeed - but theory is useful in creating some clarity amid the complexity.

Using VSM normatively, and comparing it with evidence about the domain, it would appear that there is a mismatch between the global financial control mechanisms, control mechanisms for individual sub-systems (in System One), and the flows of clients (and hence resources) between them. That is, most of the control mechanisms are not, in fact, designed to help regulate basic activity within the domain.

This section has focused on organisations, and not on individuals. The introduction of the concept of co-production suggests that the roles and behaviour of the many service providers with the domain will be important in determining outcomes for people with dementia. This provides an argument for investigating the role of key professionals, and the relationships between them, which is the focus of Chapter 6.

5.5 Soft Systems Methodology

One important strand of systems thinking proceeds from the belief that 'hard' approaches such as cybernetics are inadequate when applied to 'soft' situations, particularly those involving 'human activity systems'. One of the most completely developed bodies of thinking along these lines is Soft Systems Methodology (SSM: Checkland, 1981; Checkland and Scholes, 1991). Some of the basic thinking that underpins SSM is discussed in this section, and then a simple model of the domain is presented.

SSM is by its nature a formative methodology, and on the face of it does not fit well with the more summative approaches used in other parts of this thesis. (The use of a summative approach simply reflects decisions made by the author about the nature of the empirical work appropriate to the domain.) However, there seems to be no reason why it cannot be used to undertake an initial exploration of a domain of interest. SSM, its proponents argue, is valuable in identifying useful perspectives and ways of conceptualising a domain - very much what is required here. SSM also provides a contrast with VSM, since it is concerned with the process of doing systems studies, rather than with building generic models.

Checkland, commenting on the nature of systems thinking, argues that:

> "The core notion is that of a whole in an environment which is delivering shocks to it. It may contain smaller wholes, and may itself be part of a larger whole. This gives us the idea of a layered or hierarchical structure. And if that whole has processes of communication and processes of control, then it might, in principle,

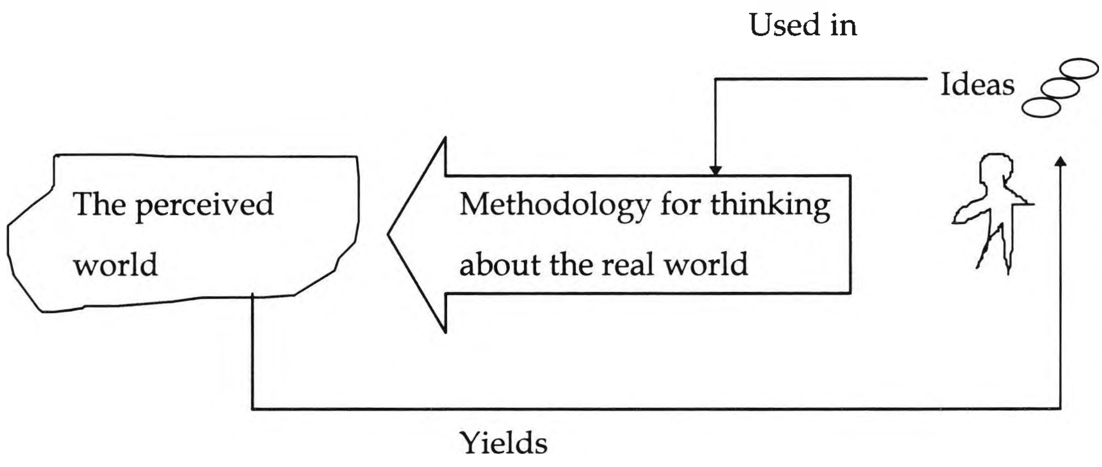


Figure 5.2
The World Interpreted Through Ideas
Adapted from Checkland and Scholes (1991)

> adapt and survive in a changing environment." (Checkland, 1992: pages 1025-6)

Figure 5.2 is adapted from Checkland and Scholes (1991), and shows the relationship between the domain and observers of its activities. It stresses the point that the domain is a construct, and not an objective reality peered down on by an outsider. Concepts that bind the domain together into a single system do not have an independent existence, but rather are useful conceptual devices for linking otherwise diffuse observations. This is important in this thesis, where for example the concept 'community care' is not a physical entity but a set of ideas, and a set moreover that is capable of widely differing interpretations by different people.

Checkland asserts that SSM should start with the identification of fundamental characteristics of the domain at the outset. He lists six: customer(s); actors; transformation; worldview; owners; environmental constraints. The first letters of each term combine to form the acronym CATWOE. Drawing on the material presented in Chapter 4, in the domain the following could be identified:

- Customers - people with dementia and their carers.
- Actors - people with dementia, their carers, health professionals, social services professionals.
- Transformation - in the welfare of the person with dementia (compared to the welfare without any intervention).
- Worldview - either (1) an individual professional's view, or (2) a view that focuses on the movement of people within the system.
- Owners - either (1) not clear, or (2) jointly by district purchaser and social services department.
- Environmental constraints - principally resources and government policies.

The Worldview and Owners both have two options. Later chapters will explore these options.

The next step in SSM is the formulation of a root definition. The root definition should seek to capture the objectives and key relationships within the domain. Checkland and Scholes provide a practical guideline, that the definition should be in the form, 'a system to do X by Y in order to achieve Z'. During the course of the literature reviews and fieldwork, several versions of the root definition were drafted. The final root definition was therefore the product of both evidence and reflection (see Chapter 6), and is:

"A system that delivers support and services to people with dementia, through the actions of informal carers and of public, private and voluntary bodies, in order to maximise the welfare of people with dementia. The system manages the delivery of both on-going services for, and ad hoc contacts with, people with dementia."

Checkland and Scholes also state that it is important to identify criteria for the assessment of the system. They suggest that the three 'E's', efficacy, efficiency and effectiveness, should guide the identification of criteria. The efficacy of the system can be assessed in terms of providing appropriate services to people with dementia. The efficiency of the system will not be investigated in detail in this thesis, but some general comments are made in the Appendix. The main indicator of the effectiveness of the system is the extent to which services are successful in maintaining a person in the community, and hence avoid entry to institutional care. This question is explored qualitatively in Chapter 6 and quantitatively in Chapters 7 and 8.

Next, Checkland and Scholes (1991) advocate processes that they call Analyses One, Two and Three. Analysis One is concerned with identification of key roles: client, problem solver and problem owner. In a formative research study these roles will usually be identified with relative ease, but here they are less clear. A practical solution is to imagine oneself as the problem owner, but with no direct role in the domain. The task is to identify which actors are the clients and problem owners. The roles can be identified as:

- Client - professionals, acting as agents of people with dementia.
- Problem solver - the author.
- Problem owner - professionals, acting as agents of people with dementia.

Analysis One highlights another important aspect of the domain, which is the central role of professionals. Although the use of SSM is artificial here - because there is no formal intervention in a service setting - it is still reasonable to imagine that in any 'real' application of SSM the results would be similar - the client might be a manager, but a manager working in collaboration with professionals rather than alone.

Analysis Two focuses on roles, norms and values. It picks up the strand of systems thinking pioneered by Sir Geoffrey Vickers (1968), which emphasised the point that human systems cannot be described solely in terms of quantifiable variables, and in practice are permeated with the different norms and values of the actors within it. The literature and fieldwork in this thesis will emphasise the point that roles, norms and values vary, sometimes quite starkly, across the system. The professionals all have different objectives and interests in relation to people with dementia.

Analysis Three is concerned with the political dimension of the system. The question here is, 'how is power distributed across the system?' In the domain of interest it will become apparent that it is fragmented between different professionals, notably GPs, hospital doctors and social workers.

The next step is to derive a conceptual model from the root definition. (In passing, it is worth noting that Checkland and Scholes are not as clear as they might be as to how the three Analyses feed into this conceptual model building exercise.) The conceptual model for the domain is shown in Figure 5.3. Like the root definition, it was refined during the course of the thesis. The Figure shows the main objective, to maximise the welfare of people with dementia. The main strategies for achieving the objective - in the context of this thesis - are the delivery of informal and formal services. This is important, because the one of the central objectives of the thesis is to investigate entry to institutional care: the conceptual model shows that entry is to some extent a by-product - even an indicator of failure - of the system.

The conceptual model also shows a monitoring and control system. The ways in which the monitoring and control are exercised are not specified -

these are discussed further in Chapters 9 and 10. The diagram highlights the need to define measures of performance for the system. As noted above, Checkland and Scholes recommend that the 'three E's' should be used to derive them. That is, in line with Checkland's (1981) early description of SSM, the domain requires both control and co-ordination.

SSM has been used here in an unconventional way, and its full potential has - unavoidably - not been exploited. SSM has, though, served to highlight some of the key issues that will be addressed in later chapters in the thesis.

5.6 Conclusions

This chapter has highlighted the potential of interpretive modelling. Espejo and Harnden's (1989) use of VSM to provide insights into the causal relationships (what they term generative mechanisms) in the domain has led to a comparison between a cybernetic/VSM model and characteristics of the domain. This is close to the stance taken by Pawson and Tilley (1997) in their work on realistic evaluation, in which they try to steer a 'middle path' between positivism and interpretivism. Here, VSM was used to help identify real-world relationships, without the researcher having to assume that the world works only according to the 'rules' embedded in VSM. Rather, VSM helps to direct the researcher to theories about causation which can be investigated empirically. For example, one of the key questions concerns the relationship between sub-systems: how do people move between them and how are those movements controlled?

Whereas VSM supports looking at the overall structure of a domain, SSM suggests that efforts can usefully be directed to partial modelling of domains, by adopting particular 'views' of them. The conceptual model in Figure 5.3 identifies particular aspects of the domain which might be the focus of attention in a field study, including the extent to which formal and

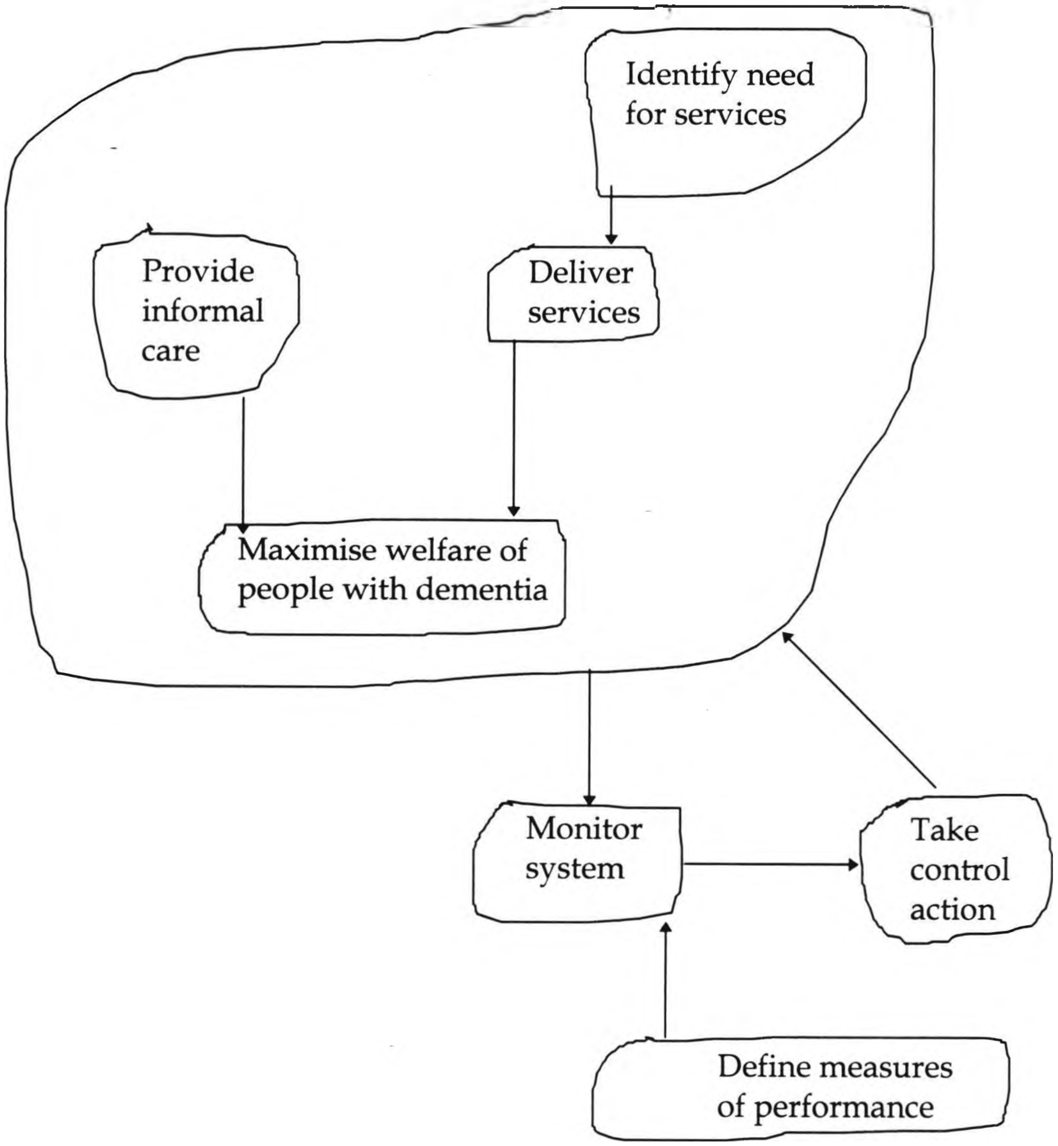


Figure 5.3

Conceptual Model Of The Domain

informal care actually maximise the welfare of people with dementia. As with VSM, the value of SSM lay in being able to construct a model of the domain within an explicit conceptual framework.

Taken together, use of VSM and SSM has confirmed the importance of some of the issues identified in earlier chapters:

- What is the role of professionals in the domain, and how do their actions influence outcomes for people with dementia?;
- What is the actual organisation of services on the ground, in the wake of the new community care policies?
- Is it possible to establish the nature of the relationships between the different sectors, and of the control mechanisms that are at work?

These questions are addressed in the next three chapters.

CHAPTER 6

QUALITATIVE MODELLING: THE ROLE OF PROFESSIONALS

6.1 Introduction

Previous chapters have shown that there is a modest amount of high quality research about the organisation of services in the domain. In particular, Levin and colleagues (1989) have described the experiences of people with dementia and their carers. They recognise the importance of health and social services personnel, but the main focus of their work is on the users rather than the providers of services. It has also been shown that there has been relatively little research into the ways in which GPs, social workers and others arrive at decisions about people with dementia, particularly those decisions relating to entry to hospital or a residential/nursing home. There is, therefore, a case for empirical study of the ways in which professionals make decisions about people with dementia in the community, and in particular at a point where they become candidates for entry to an institution.

The lack of previous work suggested that an initial, exploratory study was appropriate. A pragmatic decision was made to start with individual decision-makers, and then use the information gained to examine the design of service delivery systems. It was therefore necessary to identify a suitable method for studying decision-makers. This chapter has two main sections. The first describes cognitive mapping exercises undertaken in two localities - south east London and Kirklees in Yorkshire. Representatives of key professional groups involved in decisions about entry to institutions were interviewed. The second part of the chapter develops the diagram-based approach and derives influence diagrams for the domain.

6.2 Selection Of Cognitive Mapping

Following the line of thinking developed in Chapter 5, the task here was to understand professional decision-making relating to people with dementia, and an interpretive approach was deemed appropriate. In addition, interviews are often used in the early stages of both qualitative and quantitative research studies to help the researcher to establish key issues and questions (Silverman, 1993): they seemed appropriate here, in light of the relative lack of published information. There are many possible ways of conducting interviews and analysing them in social science research (Miles and Huberman, 1993; Silverman, 1993). Some of these lend themselves to systems science-like analysis, particularly those that use content analysis (Krippendorff, 1980) or allow the construction of influence diagrams (see Miles and Huberman, 1993). Other methods have been developed specifically with systems-style thinking and analysis in mind, a prominent example in the UK being cognitive mapping (Eden, 1989).

A choice therefore had to be made about the interview method. A method should ideally:

- Highlight causal and probabilistic relationships within the domain;
- Be able to cope with large number of relationships, i.e. deal with complexity; and,
- Show how decisions are affected by variables in the system environment.

The method selected was cognitive mapping: it is in effect a group of methods that are used to explore how people perceive relationships between elements of a situation.

One of the attractions of cognitive mapping is that it is explicitly based on an established theory, Kelly's personal construct theory (1955), and has been used by researchers in a wide variety of disciplines. Its strengths and weaknesses are therefore now well understood.

Since the 1960s cognitive mapping has developed in different directions, so that the term is now used to describe methods that use different conventions and are used to investigate different types of problem. Huff (1990) usefully distinguishes between five 'families', that can be thought of as being on a continuum demanding increasing interpretation from the researcher - or put another way, move from a positivist to an interpretive approach.

1. Maps that assess attention, association and the importance of concepts. These maps are concerned with 'taking inventories of mental furniture'. The map maker will typically look for frequent use of related concepts, and make (simple) associations between concepts. This family draws on, among other methods, quantitative content analysis.
2. Maps that show dimensions of categories and cognitive taxonomies. This family explore more complex relationships among concepts than the first category, such as hierarchies.
3. Maps that show influence, causality and system dynamics. This family is concerned with the search for causal relationships among cognitive elements. Huff states that:

   > "As such maps become more complex, systems theory is a natural source of guiding concepts and provides potentially powerful means of analysing the future growth or decline of nodes on the map." (Huff, 1990: page 16)

4. Maps that show the structure of argument and conclusion, i.e. the logic behind conclusions and decisions to act. Huff states that the map maker:

   > "includes causal beliefs... but looks more broadly at the text as a whole". (Huff, 1990: page 16)

5. Maps that specify schemas, frames and perpetual codes. This family is concerned with eliciting mental frameworks, that are believed to guide cognition but are not accessible to the individuals involved.

For the task in hand, the third family was chosen as the most appropriate. It was thought that the first two would not be able to capture the complexity of relationships in the domain. The fourth approach held attractions, but if anything was too sophisticated for an essentially exploratory study; and other modelling approaches used in the thesis would involve similar sophistication. The fifth approach was, it was felt, intended for use in rather different contexts than those encountered here.

The particular method selected was that developed by Eden and his colleagues (Eden, 1988, 1989, 1991) at the University of Strathclyde. For the remainder of this chapter the term cognitive mapping is used to refer to their method. A cognitive map, as used by Eden and colleagues, is:

> "...a model designed to represent the way in which a person defines an issue. It is not a general model of someone's thinking, neither is it intended to be a simulation model of decision making. It is a network of ideas linked by arrows: the network is coded from what a person says. The arrows indicate the way in which one idea may lead to, or have implications for, another. Thus a map is a network of nodes and links ('a directed graph')." (Eden, 1989: page 27)

The original work of Eden and colleagues started in the 1970's as a new approach to the study of decision making in organisations (see Eden et al., 1983), starting from the position that people could not make good decisions unless they reflected upon their own attitudes and values, which influenced those decisions. Building a cognitive map is an interactive, iterative process. A topic for investigation is agreed between participants, and the reasons for embarking on the exercise clarified. Discussion is initiated, typically by asking about objectives (called 'heads' when represented in cognitive maps) - what is the system of interest designed to achieve? The discussion then continues, essentially by persistently asking 'what' and 'how' questions. That is, 'what factors influence the achievement of the objectives?', and 'how do they do so?'. These factors are usually laid out on a board or on paper. As they are identified, links are drawn between the different factors, so that a diagram is developed.

During this process, the original objectives are also investigated - are they the real objectives of the system, or part of the process of obtaining some other, higher objective? Again, the essence of the process is persistent questioning, in order to build up the map. As the map develops, it becomes clear that there are one or more 'feet', which are the basic factors that, directly or indirectly, influence all of the others in the map. Eventually, the parties involved agree that there are no more factors and links to be drawn. A cognitive map may eventually contain dozens of items.

Depending on the circumstances, the map may then be used for a specific, intended purpose, or there may be a second stage, where the map is further refined. The purpose of the second stage is to allow reflection on the initial discussion, and may involve analysis of the map by the interviewer (or facilitator of a group) for consistency and identification of further questions, and/or further consideration by the individual or group involved.

Cognitive maps typically have many elements and links, and the iterative process of map drawing can be difficult to manage on paper and even on whiteboards. Computer software packages have been developed to aid the drawing process. A computer package, Software COPE, developed at the University of Strathclyde, was used for analysis here.

6.3 Literature Search And First Stage Of Fieldwork

6.3.1 Literature Search

Two literature searches were undertaken. The first focused on published cognitive mapping studies (as used by Eden and colleagues) in health and social services, and the second on studies of individual managers or professionals, whether in health and social services or elsewhere. The searches were undertaken using the databases Medline and ABI-Inform, and by contacting practitioners of cognitive mapping at the Universities of Strathclyde and Keele. The practitioners reported that most studies had focused on the strategic planning of services, rather than on their on-going management or on the cognitive processes of individual decision makers. These studies, on reading, appeared to be of limited relevance to this thesis. In short, the searches revealed no published studies of community-based services, and no studies of the structure of decisions by individual health and social service professionals, and thus no studies in the general area of the thesis.

The lack of published papers was surprising, given that Eden and others claim that their version of cognitive mapping can be used in both of the areas in which the searches were conducted. The explanation was that studies had been conducted but not published. A member of the Strathclyde group (Fran Ackermann) explained that they used cognitive mapping in many consultancy studies, and most of these had not been published. They were not able to provide any material from these studies, though they kindly provided general advice on the application of the method. This meant, then, that the fieldwork would to some extent be exploratory in nature: this was applying cognitive mapping in a new area.

Three professionals - a GP, a social worker and a consultant psychiatrist - based in a single locality in south east London were interviewed, to provide insights into their cognitive processes. They were identified pragmatically, with one recommending the other two. In addition to working in the same locality, they shared one important characteristic, which was their attitude towards institutional care. All three felt that entry to a Home should be avoided if at all possible. Equally, entry to hospital should be on the same basis as all other people - as needed, and not affected by the presence of dementia. The main focus of questioning was on entry to residential and nursing homes, rather than entry to hospital. The maps produced by the three are presented, and then the implications discussed.

6.3.2 The GP

The GP was recommended by the community-based psychiatrist (see below) as someone who, he felt, always made appropriate referrals. That is, he was perceived to refer only those people with dementia who would benefit from specialist advice and support - his 'error rate' for referrals was low. (His data are presented first here as GPs are important 'gatekeepers' to other services.) His practice covered an area that contained a large number of people who had been relocated from the areas around the southern docks of the Port of London during the 1920s, into estates of then-new housing. As a result, many people had grown old together, and had lived in the same houses for some 60 years. There were therefore many elderly people registered with the practice.

The GP was interviewed twice, once to develop an initial cognitive map and the second time to discuss and refine the map. In the first interview the approach adopted was deliberately open-ended, and the discussion ranged over any issues that the GP felt were relevant to entry to institutional care for people with dementia.

The GP's map proved to be relatively simple. He had one main objective for people with dementia, which was to maximise the quality of their lives, using any means at his disposal. There were several ways in which the objective could be achieved, which included advice to informal carers, arranging for regular visits by health professionals, and requesting social services support. Above all, he felt that it was important for people to continue to live in their own homes. The entry of one of his patients into a residential or nursing home (or Home) was, he felt, tantamount to an admission of failure on his part: entry to a residential/nursing home represented an irreversible loss of quality of life.

There were three factors which he felt were critical in deciding about entry to a residential/nursing home, namely:

- The wishes of the person with dementia;
- The capacity of the person for self-care if living alone, or the capacity of an informal carer to cope;
- The physical safety of the person with dementia, for example the likelihood of being a target for burglars, particularly if living alone.

These three factors were in effect judgment criteria that the GP used in assessing each person, and the outcome of the three judgments largely determined whether someone could remain in their own home.

The GP's map (Figure 6.1) was simple. There were three distinct components: the nature of the problem, which varied between individuals (the feet in the map); the three judgment criteria listed above; and, the single head, the outcome of the judgments. All other issues were considered to be of relatively marginal importance or not relevant to the decision: it was the GP’s decision that the map should be small, because he felt that when it came, the decision was simple. The decision about institutionalisation was based on a narrow set of criteria, concerned with the person's willingness and ability to cope. It did not include the severity of a person’s dementia - though this often lay at the base of assessments of willingness and ability to

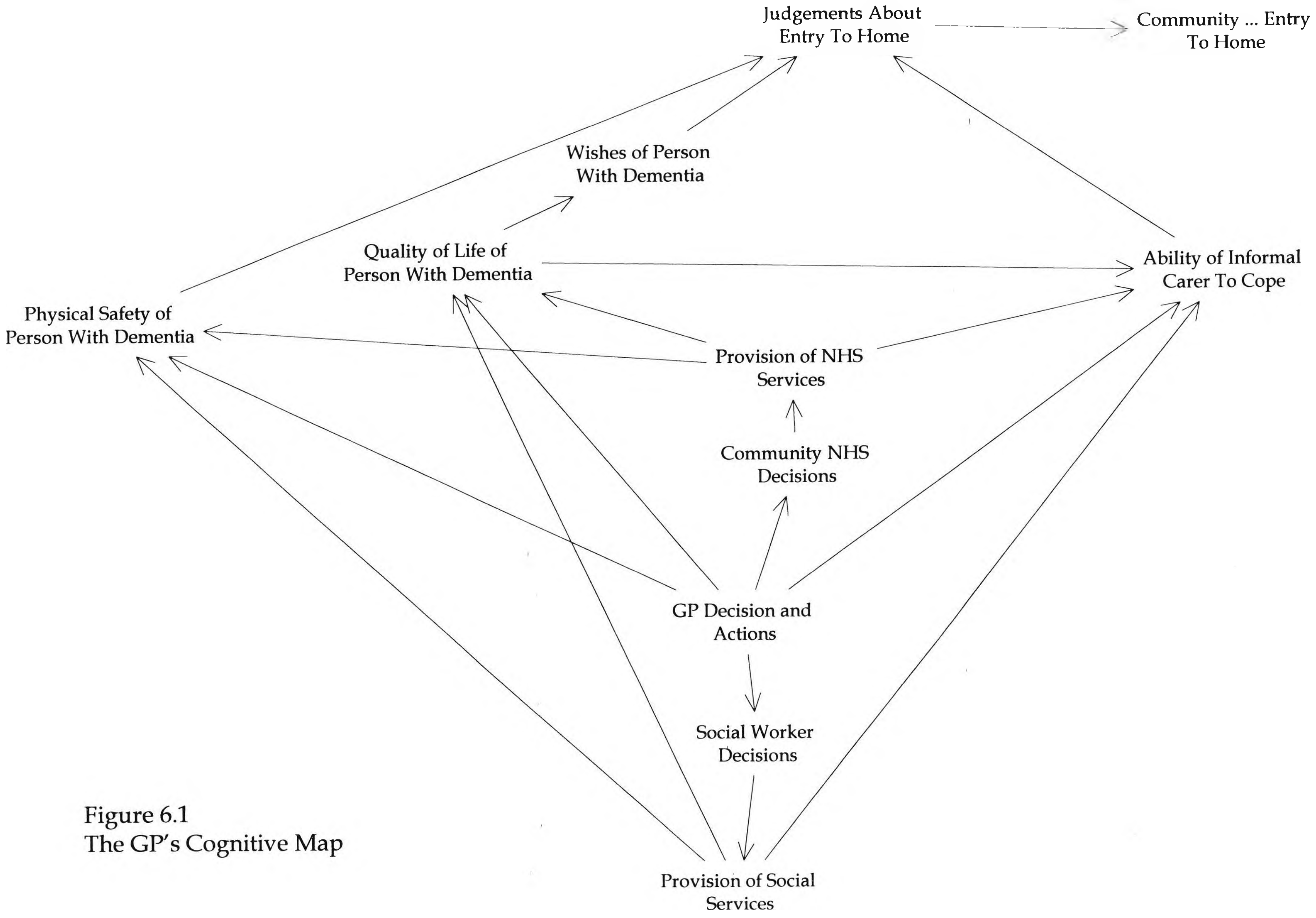


Figure 6.1
The GP's Cognitive Map

cope. When questioned about this, the GP insisted that he did everything in his power to provide appropriate services in the community, so at the time decisions about entry were made, people typically had the maximum level of service available. Whether this was in fact adequate was another matter: he felt it often was not, which reflected only on available resources, and not on the efforts of health and social services personnel.

The GP made the observation that other issues were important in arriving at decisions about the nature and level of support people needed in their own homes. Here, the person's health status was of central importance, and along with the carer's status determined the GP's assessment of the nature and level of support required. The factors involved in decisions about entry to institutional care were therefore distinct from those used in decisions about support in people's own homes.

6.3.3 The Social Worker

The social worker was responsible for an area close to, but not including, the GP's practice. She reported that it was mixed in terms of age and socio-economic status. The social worker was interviewed three times. The first two interviews were used to develop two cognitive maps, and the third to reflect on and refine them.

The social worker's responses (Figures 6.2 and 6.3) included more factors than did the GP. In contrast with the GP, the social worker felt that the nature and level of services provided to a particular person were relevant to the decision. She argued that there were often times when the provision of greater support might have prevented entry to a Home. Through discussion, it was decided that there should be two maps, though the two were linked. The first map (Figure 6.2) represented the delivery of services in the community, and the ways in which the provision of services

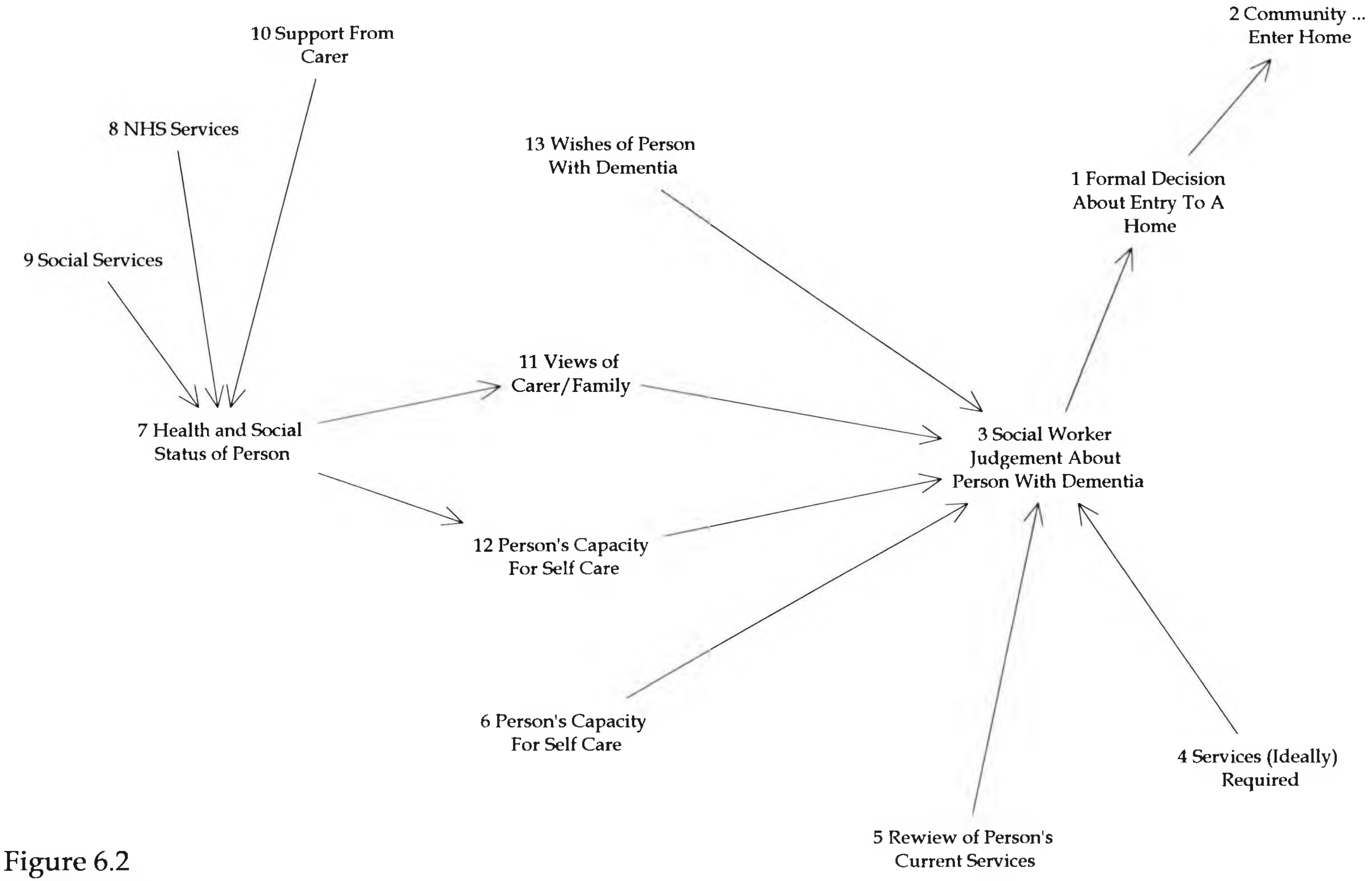


Figure 6.2
Social Worker: Arriving At A Judgement

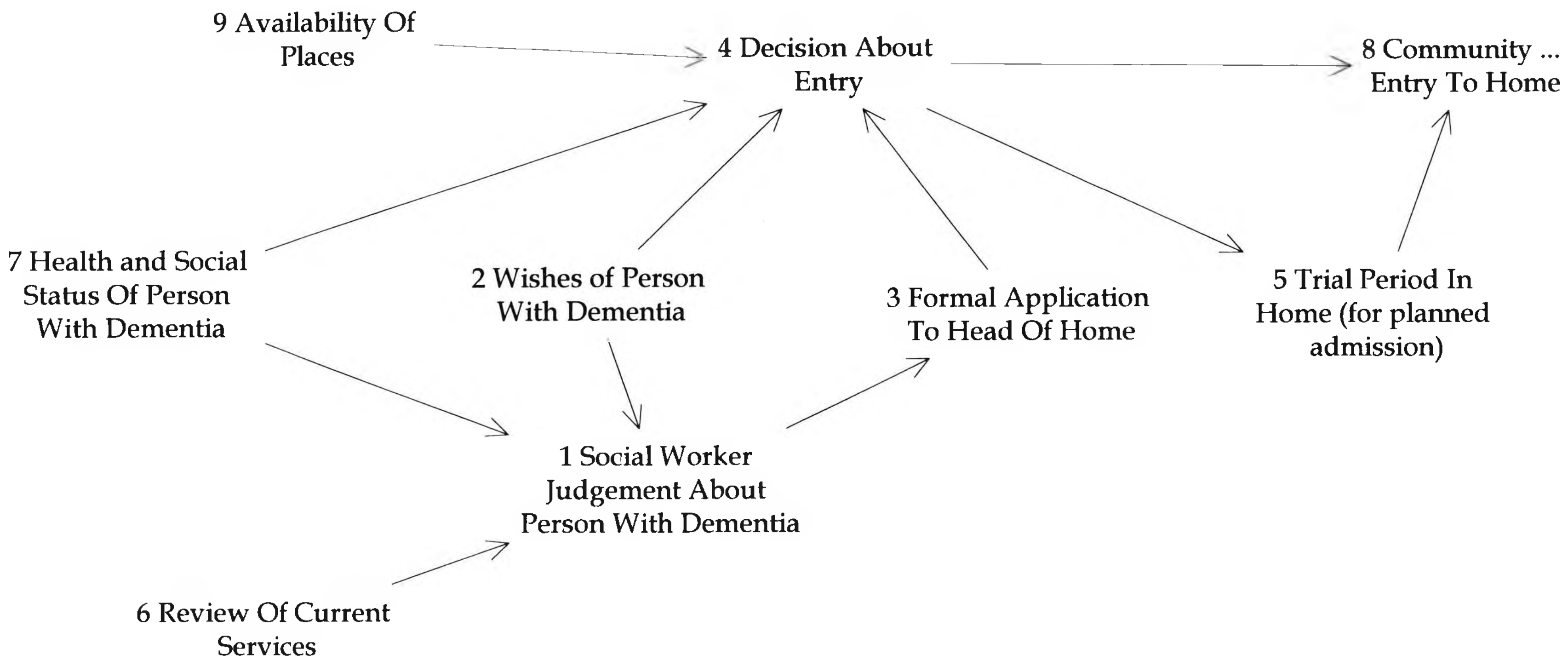


Figure 6.3
Social Worker: Entry To A Home

influenced her judgments. The second map (Figure 6.3) represented the decision about entry to a Home.

In common with the GP, therefore, the social worker felt that the decision about entry to an institution was distinct from decisions about strategies for maintaining someone in the community with a reasonable quality of life. The first map suggests an important relationship between informal carers, formal service providers and the person with dementia. These people are part of a nexus of considerations that influence decisions about services delivered in the community. The second map suggests that the decision about entry to a Home can usefully be viewed as a process, which can result in admission or staying in one's own home. The second map reflects a situation where the social worker has already decided that someone is a candidate for admission, and the process is the working out of the actions that follow from the decision.

6.3.4 The Consultant Psychiatrist

The role of the consultant psychiatrist in the lives of people with dementia was different to that of the GP and social worker. The GP and social worker were both 'front line' service providers and co-ordinators of services. This meant that they were likely to be involved with people over months and years. The consultant generally only became involved in the care of a person with dementia at a point where entry to hospital or a Home was becoming a real possibility. He would therefore tend to see only those people whose dementia was moderate or severe, or who had concomitant problems that required specialist assessment or advice.

This meant that the consultant tended to see a relatively small proportion of all people with dementia in his area at any one time, but he was involved in many decisions about admissions. He was based in the local community unit (though in management terms he was attached to a hospital Trust), and

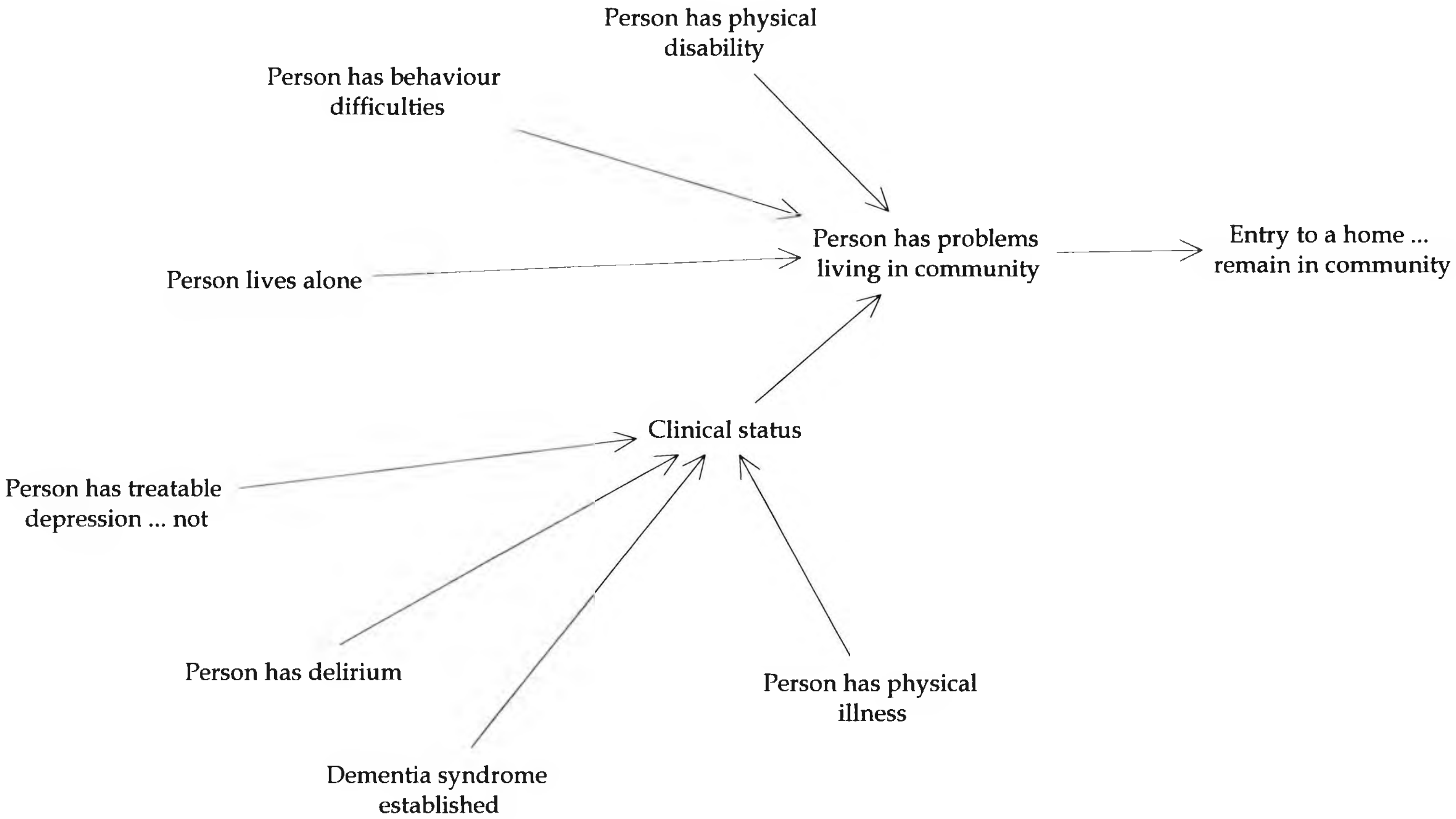


Figure 6.4
Consultant: Factors Influencing Admission

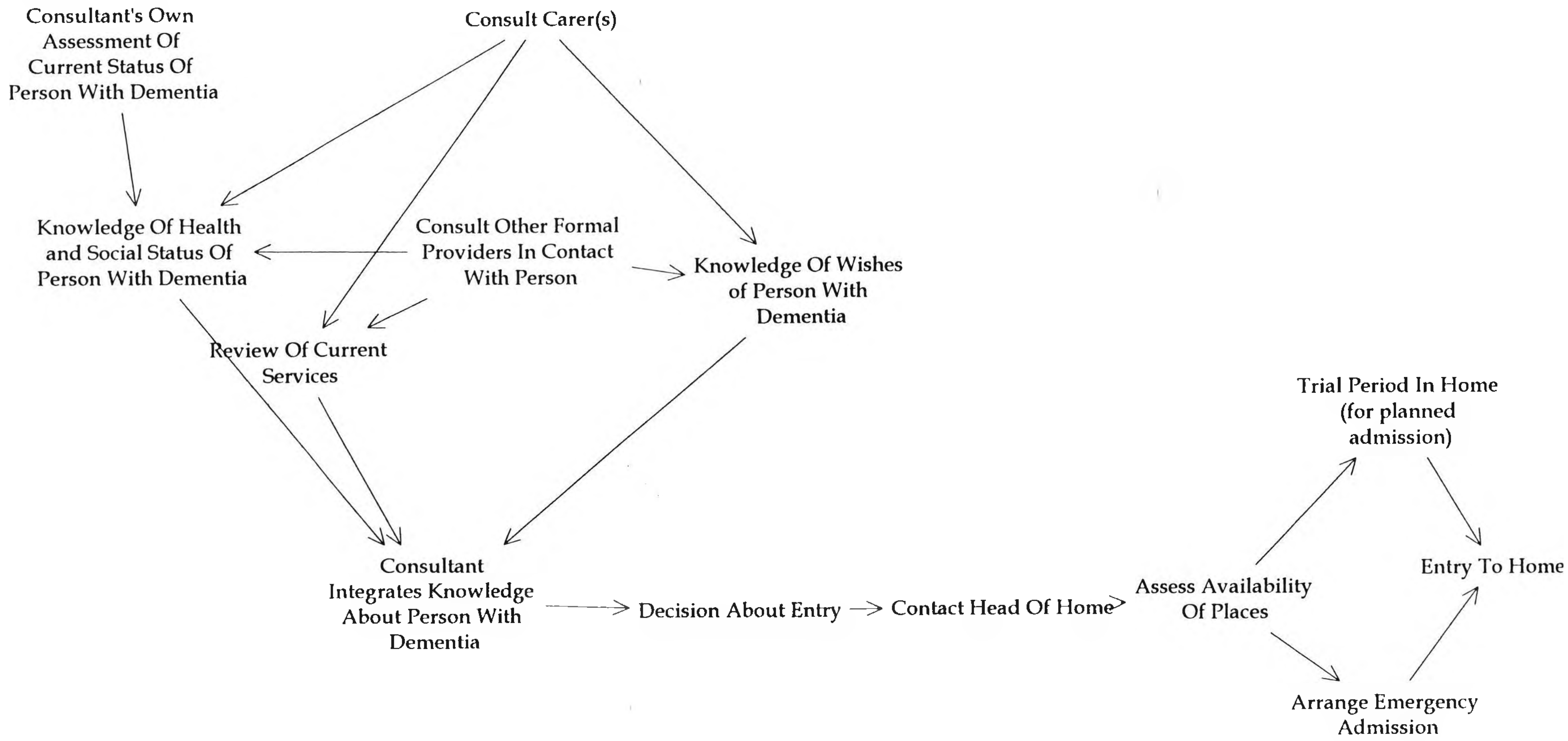


Figure 6.5
Consultant: Entry To A Home

was a member of a community team for elderly people with mental health problems.

The consultant was interviewed four times, and three different cognitive maps were produced. These were: a simple map of the main factors that he took into account when considering admission; a larger map that showed all of the factors he tried to take into account (Figure 6.4); and, the cognitive processes involved in deciding about entry to a Home (Figure 6.5). (Note that entry to hospital was discussed, but it was agreed that the interviews would be more useful if they focused on admission to Homes.) Between them, the maps provided a detailed representation of the processes involved in delivering services in the community and arriving at decisions about entry to a Home or hospital.

In common with the GP and social worker, the consultant believed that people should continue to live in their own homes for as long as possible, and his actions were designed to achieve this end. There was a small group of people for whom an institution was the only option, because the level of support they required could not (in practice) be provided in the community; but apart from this group, the objective was to maintain people in their own homes.

6.3.5 Overview of the cognitive maps

It is important to bear in mind the exploratory nature of these first interviews: they were not intended to provide a complete picture by themselves. The cognitive maps did , though, provide a useful foundation for further work. In particular, they:

- Revealed some of the structure of decisions about entry to a Home, at least for the three individuals interviewed;
- Suggested that decisions about services in the community are distinct from decisions about entry to a Home or hospital - they are different, though related, processes;

- Suggested that there comes a point in time when the professional decides - or perhaps realises - that a person with dementia is a candidate for entry to a Home, and begins to think differently about the options available.

The interviews suggested that the decision to seek admission might occur only after a long period of gradual deterioration in the ability of someone to cope, or might arrive suddenly as a result of a crisis - a carer falling ill, for example. Whichever is the case, the decision to seek admission initiates a formal process. Interestingly, the process may or may not result in admission. The maps provide some reasons, which include the availability of places, differences of opinion about the appropriateness of an admission, and the views of the person with dementia.

Given that this was a novel application of cognitive maps, it is worth reflecting briefly on their value in the domain. At the outset it was thought that he main strength of cognitive mapping would lie in its capacity to help capture the relationships between different types of entity - resources, information, and so on. This strength seems to rest on the persistent style of questioning used to elicit information, where interviewees are encouraged to think about all kinds of relationships. In addition, the relative lack of formality of cognitive mapping, in relation to other methods, means that it offers a flexible way of capturing the important features of a domain. In practice, cognitive mapping proved difficult to use in this study. In spite of spending a number of hours in interviews, with helpful interviewees, it was not easy to draw the maps. The principal problem was the difficulty of knowing how to relate different types of concept, such as personal attitudes towards admission to institutional care and the personal circumstances of the person with dementia.

Further, Richardson (1991) has argued that the kind of coding scheme used by Eden and colleagues lacks rigour, which leaves interpretation of maps open to question. His comments were part of a more general concern about inappropriate uses of 'soft' systems methods - he was not talking specifically about cognitive mapping. The experience of using cognitive mapping here suggests, though, that Richardson's view has some merit. The very flexibility that allows the method to capture a wide range of relationships also makes it difficult to be sure what the resulting map is telling you. The simplest way of thinking about this is to ask, 'what do the arrows in the maps actually represent?' An intelligent user can make inferences from the maps, but this is not the same as saying that a map captures some valid and reliable features of a domain. The validity and reliability of cognitive mapping was not investigated here - this would have been a separate study in its own right - but it was not obvious how they could be assured in practice. Overall, then, the conclusion was that the maps were difficult to use, and it was not clear that they produced valid and reliable findings.

Two further problems should be mentioned. The first is the difficulty of combining maps. Discussion with members of the Strathclyde team revealed that it was not possible to combine cognitive maps, so as to integrate the results of a series of interviews or meetings. That is, there was no obvious mechanism for moving from individuals' maps to a generic or 'core' map that captured some essential feature of a domain. This meant that cognitive maps lacked a key property, namely the ability to lead a user inductively to valid generalisations. To take a specific example from the maps presented earlier, it was not possible to combine the maps to find out whether or not there was a core of ideas or values common to the three professionals.

The second problem is the difficulty of representing values and value judgments. One of the striking features of the interviews was the extent to which the views expressed were based on a particular set of values held by the three professionals - for example, the belief that institutional care should be avoided if at all possible. In principle it should be possible to include a set of values in a cognitive map, but this proved remarkably difficult in practice. Rather, the maps represented the practical expression of the interviewees' values. This may be a slightly harsh judgment - the five element classification presented earlier suggest that Huff's (1990) fifth category is designed precisely for this problem, to study mental processes that the interviewee may not be fully aware of herself. These criticisms do not mean that cognitive mapping should be written off. Rather, like any method it is important to be clear about its strengths and weaknesses.

6.3.6 Lessons Learned

The individual cognitive maps had some value, but did not reveal how the actions of the three professionals, and the circumstances of people with dementia and their carers, interacted to produce particular outcomes. The evidence presented in Chapter 4 suggested that there were many variables likely to affect admission, and it was necessary to disentangle the effects of professional decisions and actions from other factors. In addition, use of the method prompted doubts about the validity of the results obtained. What was required, therefore, was a study which linked the decisions and actions of professionals with the consequences for people with dementia, and separated these from other factors.

During the early stages of the fieldwork, it became apparent that it would be useful to produce an accurate chronological account of events from the perspective of the person with dementia. Adopting the perspective of the recipient of services would make it possible to develop an integrated picture of different actors over time. Cognitive mapping would not be appropriate. An appropriate method would capture both decisions and actions, and the time course of those actions.

A decision was made to use two methods, namely to record accounts of the chronological sequences of events leading to entry to a Home, and inference diagrams.

6.4 The Organisation Of Services: Case Studies

The exercise was undertaken in two locations, south east London and Kirklees in West Yorkshire. The approach was discussed with a number of managers and service providers in both areas. Discussions held during the cognitive mapping exercise discussed above, and discussion with other professionals and managers, suggested that there were important variations in the individual circumstances of people with dementia, and these could affect decisions about entry to institutional care. It was therefore appropriate to undertake case studies of individual people with dementia, and then look for any patterns that were repeated across cases.

Potential candidates were identified through two GP practices, one in each locality. The process was pragmatic - the task was to identify people who, in the GP's view, were likely to enter a Home within a few months. This approach introduced one type of bias, which was that the GP had to be aware of a person in order to recommend them - so the study could not identify people who were candidates for entry, where the GP was not familiar with their circumstances. Discussions with staff on the ground suggested that in practice one or more service providers almost always knew about someone before entry to a residential/nursing home, so this was not felt to be a serious problem.

Individuals were tracked over a period of one year, or until they entered a Home, if this occurred before the year was completed. In each case up to six key people were interviewed: the carer (if there was one); GP; CPN; social worker; domiciliary help organiser; and Head of Home. Those who were in contact with a person might be interviewed on two occasions, first at a point where they were living at home, and second within a week of entry to a Home, if that occurred. The GP was contacted regularly over the period of the study, to keep abreast of developments, and supplementary telephone interviews were conducted as necessary. The face-to-face and supplementary telephone interviews had two purposes:

- To piece together a chronological sequence of key events in the lives of the people with dementia and their carers, and any decisions and actions taken;
- To record the reasons why particular decisions were taken.

All community-based staff were contacted at the start of the exercise, to check whether they were in contact with the case study individuals at that point. In principle this might have influenced the behaviour of those contacted - but in practice this does not seem to have happened.

The person with dementia was asked about his or her experiences - in the event it was not possible to use the responses in this study. In some cases there were others involved in delivering care or material support, including meals on wheels. None of these people was interviewed.

Before any fieldwork could start, it was necessary to consider the ethical questions that might arise. The adoption of a case study approach meant that personal details of people with dementia and their carers would be revealed to the researcher. In both locations, letters were written to the chairs of both the health and the social services ethics committees. In both cases 'chair's action' was taken. That is, the chairs indicated that they were happy for the research to go ahead, without a full proposal being put to the ethics committees. There was a condition, however, which was that any visits to people in their own homes should be in the presence of a professional. This requirement was adhered to, with all visits organised in conjunction with a GP or social worker, and permissions for interviews from the people with dementia and/or their carers always obtained in advance of a visit.

The case studies, and their time lines, are presented first, in the next two sections. Then the inference diagrams are presented in Section 6.7.

6.5 South East London Case Studies

6.5.1 Background

The first case studies were undertaken in south east London. Initially, seven people were identified who were on the list of the GP interviewed for the cognitive map, or his three practice partners. All seven were believed to be candidates for entry to a Home. In the event three of the seven people entered a Home, one was still at home after one year, one went to live with relatives in another part of England, and two died at home. The accounts of the three who entered a Home and the one who remained in her own home are reported below. Time lines are shown in Figure 6.6.

6.5.2 Case Study A

Mr A was a 78 year old man, living in his own home, with the support of a live-in housekeeper. Mr A had had a successful professional career, and could afford the housekeeper from his own savings. He had only one close relative, a son who lived abroad; his wife had died some years earlier. He was able to maintain a conversation for a few minutes at a time, and his permission and the permission of the housekeeper for the study were both gained.

At the initial contact, Mr A was being visited only by the GP and a CPN, the latter approximately monthly. The housekeeper provided for his social care

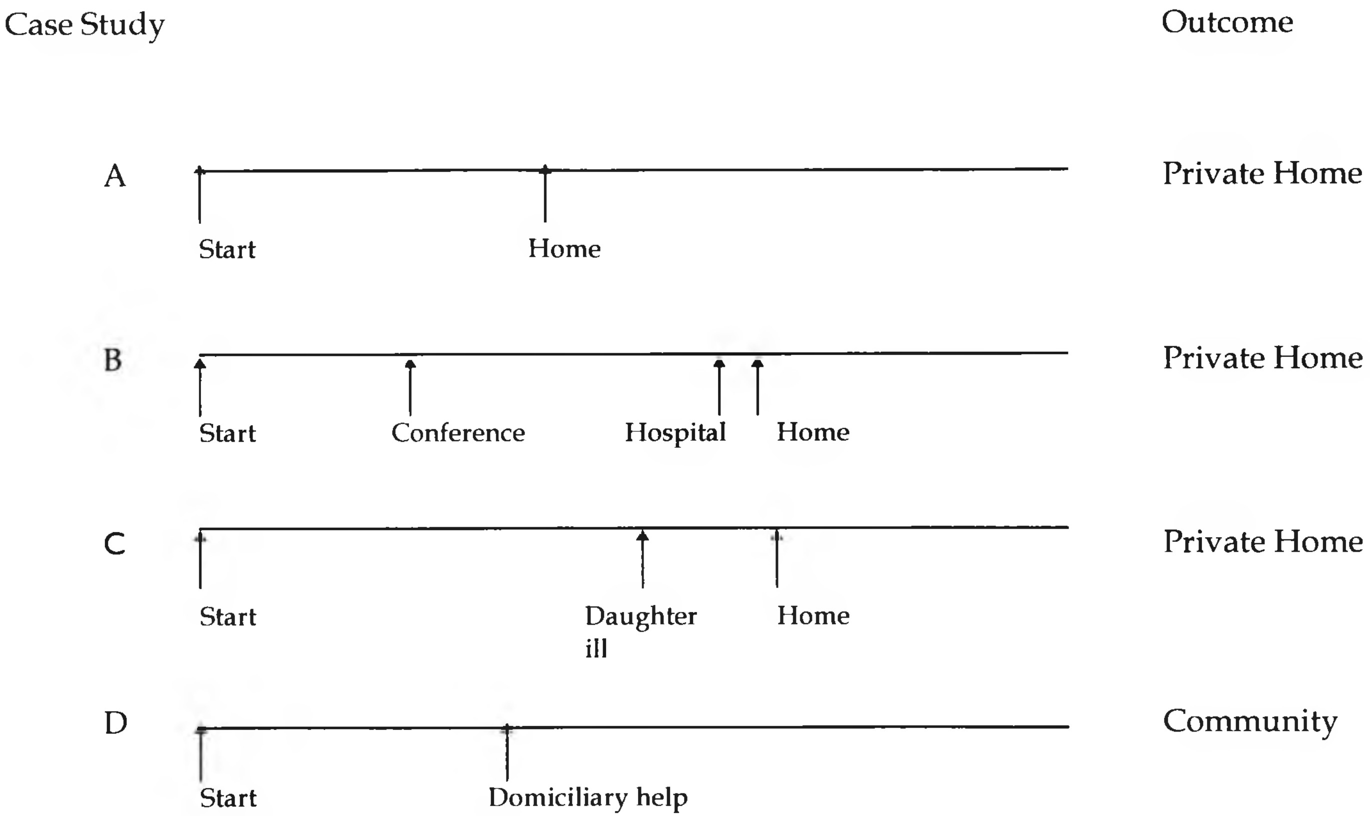


Figure 6.6
South East London Case Studies: Time Lines
Length of line = 1 year

needs, including cooking and laundry. Mr A was able to walk short distances and could toilet himself. He was, however, becoming progressively more demented.

Over the following months Mr A did indeed deteriorate further, becoming incontinent and experiencing severe disorientation and further memory loss. The housekeeper became increasingly concerned, and both the GP and CPN visited more frequently. Mr A himself expressed a strong desire to remain at home, though. Eventually, the housekeeper reported that she was no longer able to cope. The GP referred Mr A to a social worker, who felt that the presence of the housekeeper meant that Mr A was not a priority for any social service, except a day centre place - which he declined.

Mr A's son was contacted, and he arranged, with the housekeeper, for Mr A to enter a private nursing home, some five months after the initial contact.

6.5.3 Case Study B

Mr B was an 80 year old man who lived on his own. He had a daughter who lived some 50 miles away. The daughter's permission was gained for the case study. In the event it proved impossible to interview the man, but interviews were conducted with the GP, CPN, social worker and domiciliary help organiser.

At the time of the initial meeting, Mr B was already in contact with both community health and social services. A CPN visited periodically. Mr B received meals on wheels three times a week - the GP had requested five days each week, but social services could only manage three. All found it difficult to contact Mr B on a regular basis, since he did not always answer the door when they called, but one neighbour kept an eye out for him, and both CPN and social worker kept in regular contact with the neighbour.

There were differences of opinion about Mr B's ability to cope in his own home. The GP and CPN both thought that he was managing. The social worker and home help organiser were concerned, and reported that other neighbours had complained to the local council about smells coming from his house. Eventually the council had sent in a team to fumigate his house - when they found that he was living 'in squalor', though Mr B was basically in good health.

Following this incident a case conference was held about Mr B between health and social services (this was three months after the initial contact). The decision made was that Mr B could continue to stay in his own home, but would be closely monitored. The key points to emerge at the meeting were that the people present held quite different views about the risks that Mr B faced at home. In particular, the GP thought that there were indeed risks that Mr B could hurt himself, but thought the risk was worth taking in order for Mr B to continue his independent existence. In contrast, the social worker thought that the risks were too great to bear - Mr B needed to be in a Home, in part to help prevent accidents.

Mr B continued to live on his own for another four months. Then he fell ill with bronchitis and was admitted to a local acute hospital. He stayed there for just over two weeks. The hospital consultant decided that Mr B could not be discharged home without someone else living there, and his daughter was unwilling to care for him. Mr B was discharged to the 'dementia wing' of a local authority residential home.

6.5.4 Case Study C

Mrs C was a 74 year old woman who lived with her daughter and son-in-law. Her husband had died a few months before, and she had moved in with them after his death. The daughter had not worked for many years, but the son-in-law had a full-time job.

At the time of the initial contact, Mrs C was only in contact with the GP. The GP suggested that the daughter had become depressed herself, and to some extent dependent upon the mother. That is, the daughter felt a moral burden to care for her mother, and that only she could provide for her properly. The daughter had therefore declined previous offers of support from the GP.

Shortly after the initial contact the GP contacted social services because he was concerned about both daughter and mother. A social worker visited and offered a day centre place for the mother. The daughter again declined. Nothing further happened for six months, until the daughter fell ill. During this time the mother's condition appeared to have deteriorated further. At this point the son-in-law discussed the situation with the GP, and they agreed that social services support should again be considered.

A social worker and home care organiser visited together. After lengthy consideration, it was finally agreed that the mother should apply for a private residential home. No places were available immediately, however. Social services agreed to provide limited home care until a place became available. The son-in-law took substantial time off work to look after the mother and his wife, until a place became available in a private nursing home about eight weeks later and the mother moved in.

6.5.5 Case Study D

Mrs D was an 80 year old woman who lived with her daughter. The possibility that she had dementia had come to light when she had been admitted to hospital (from her own home) after a fall and nursing staff noted that she seemed confused. She was discharged to the care of her daughter, and a CPN had made a follow-up visit, and the GP had visited her at home.

At the time of the initial contact, Mrs D had been living with her daughter for some four years. The daughter seemed to be under considerable stress, but was determined to continue to care for her mother. The mother had become progressively more demented and was now incontinent. About four months later, the CPN put in a request for an assessment by social services, believing that the daughter needed support. A home care organiser visited, and after discussion with the daughter agreed to provide limited home support with basic domestic tasks. At the end of the year, the situation was little changed: the mother and daughter were being visited periodically by the CPN and were in receipt of home care.

6.6 Kirklees Case Studies

6.6.1 Background

The same exercise was undertaken in Kirklees in West Yorkshire, as part of the case study described in Chapters 7 and 8. It had initially been hoped that extensive work could be undertaken in south east London, but some local staff had been involved in a nationally-supported experiment (since published as von Abendorff et al. (1994) - see Chapter 5 for a description of this study), and it was not possible to continue the work reported here alongside the other study. An approach was therefore made to Kirklees.

The initial approach to Kirklees is described at the beginning of Chapter 7. The key point to note here is that all necessary permissions were obtained before starting any fieldwork. Eight people who were deemed likely to enter a Home were identified, and again monitored for one year. Three died during the year, two remained in their own homes and three entered private nursing homes. All eight people were drawn from the list of a single practice, which was felt to be 'typical' of those in the locality - that is, they were 'average' referrers of people to health and social services. The accounts of three people who entered private nursing homes are presented below. Time lines are shown in Figure 6.7.

6.6.2 Case Study E

Miss E was a 78 year old woman who lived on her own. She had never married, and her brother and sister had died. A neighbour had become concerned about her, and contacted her GP, requesting that he intervene. The GP visited Miss E in her own home, and referred her to the CPN. The CPN visited the next day and decided that Miss E would be able to manage in her own home with domiciliary support. The CPN therefore contacted the domiciliary help organiser, who visited later the same day and arranged for a daily visit from a Home Care Assistant to help with simple tasks, and requested a day care place. The day care place was subsequently arranged, and Miss E attended for three days each week. The organiser also contacted the social worker and told her what had been arranged. The social worker visited two days later and decided that the arrangements were appropriate.

The arrangement continued for some four months, at which point Miss E appeared to deteriorate further, experiencing more difficulty with simple household tasks. The home care co-ordinator called and decided that Miss B should have a formal assessment. She was therefore admitted to the local Social Services residential assessment unit. She continued to deteriorate over the next four weeks, to the point where it was considered that she would be unable to maintain herself in her own home. A social worker at the assessment unit recommended her for a permanent residential place. Miss E herself was reported as feeling that she could not cope if she went home.

Initially a place was sought in a local authority home, but none was available. A place was found for her in a private residential home and she was admitted after some six weeks in the assessment unit.

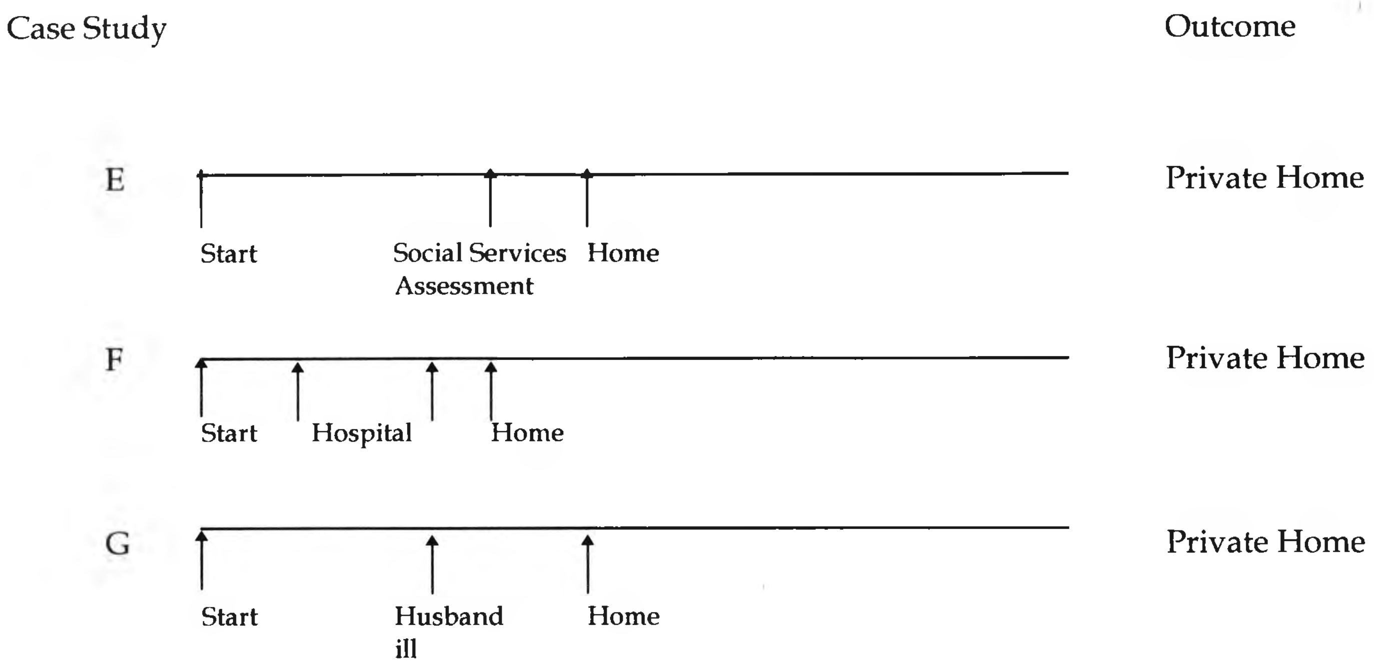


Figure 6.7
Kirklees Case Studies: Time Lines
Length of line = 1 year

6.6.3 Case Study F

Mrs F was an 80 year old widow who had two children living nearby and who visited every day. At the time of initial contact she was believed to be coping well by her GP. She was not in contact with social services.

About a month after the initial contact Mrs F had a fall and was admitted to hospital. She had not broken any bones but was severely bruised. She was discharged after one week to her own home, and a CPN made a follow-up visit. The hospital episode brought her to the attention of social services, who discussed her care with the CPN; it was agreed that the CPN would monitor her progress.

Some two months after the hospital episode Mrs F had another fall. She was admitted again to the hospital. The hospital consultant and hospital-based social worker discussed Mrs F's case with the children, and it was agreed that she could no longer cope at home. She was discharged from hospital, after two weeks, into a private nursing home.

6.6.4 Case Study G

Mrs G was a 76 year old woman who was looked after by her 77 year old husband at home. They had a son who lived ten miles away, who visited regularly. At the time of initial contact Mrs G and her husband were in receipt of home care support - organised following a request from the husband - but were not in contact with community-based health services.

Three weeks after the initial contact Mrs G was visited by her GP for a minor illness. The GP decided that she should be assessed by a hospital consultant and requested a domiciliary visit. A hospital consultant visited four days later, and referred Mrs G to a CPN. The CPN visited the next day, and made his own assessment, but no further action was taken.

There were no further developments for two months, at which point Mrs G's husband fell ill and was admitted to an acute hospital bed. The son alerted the home care organiser and CPN. After discussion with the son the CPN arranged for Mrs G to go and live with him temporarily. The husband proved to be seriously ill, and eventually the son arranged a private nursing home place for Mrs G, with support from the GP, which she entered five months after the initial contact.

6.7 The Case Studies: Inference Diagrams

A key objective for this phase of the fieldwork was to build up a valid and reliable representation of the domain. One way of doing this was to derive inference diagrams - the diagrams would be composites of the individual case studies.

Inference diagrams - also known as signed digraphs or oval diagrams - are a formal way of representing cause and effect relationships between variables within a system and between system variables and the system environment (Cramp and Carson, 1993). A key difference from cognitive mapping is that it is possible to build up inference diagrams to form an overall, composite picture of a system. In order to construct inference diagrams, it is necessary to abstract key features of a situation. The first step here, therefore, was to identify key aspects of the domain that were highlighted in the case studies. These could be grouped under five headings; triggers, decisions, referrals, the care regime, and values.

6.7.1 Triggers

The case studies suggest that there are events that trigger entry to an institution, the main ones being a deterioration in the person with dementia or a problem arising with the main informal carer. It was noticeable that people tended to come into contact with new services only when something happened at home - so in those cases where a carer fell ill, it was the carer's contact with health services that prompted a review of the person with dementia. So, the shape of services could change as a result of events that were not directly connected with the presence of dementia.

6.7.2 Decisions

The case studies emphasised the point that key professionals such as GPs and social workers were not, in any meaningful sense, in control of events. The domain did not approximate to control system-based models of services. Rather, control was distributed among a number of actors, whose identity varied from case to case. If anything, where there was an informal carer then that person came closest to being a co-ordinator of services. In other cases the professionals took their cues from the preferences of the people with dementia. The most appropriate way of thinking about the domain, therefore, might be as one where the person with dementia or the carer exercises control, and the role of formal services is to support them.

6.7.3 Referrals

It was not obvious why people were referred to health or to social services for assessment. When people were asked about this two comments were made. Firstly, it was a matter of chance which services were actually received at home, but the presence of a trusted and liked home care worker tended to lead to referrals to social workers. Secondly, where members of the family were involved they tended to contact their GP, who then made decisions about referrals. Clearly, it is difficult to draw strong conclusions on the basis of these case studies, but the referral patterns do appear to reflect a combination of chance (who was providing services already) and choice (for example families electing to contact GPs).

6.7.4 Regime

The picture painted by the case studies is rather more mixed than the accounts in earlier chapters implies. On the one hand, those accounts point to serious weaknesses in the allocation of resources and the co-ordination of services, and these were found in the case studies. In some of the cases it was not obvious why particular services were being offered - the interviews suggested that social services tended to offer what was available at the time, and health professionals could only play a monitoring role - waiting for events to occur. There was little feedback between formal service providers, so that the researcher was often the person who reported back what had happened to someone after referral or entry to a Home.

In spite of the introduction of formal social services assessments for more severely ill people, it was not obvious that rounded needs assessments were in fact being made. The exception here was Mr B, but here there was conflict between health and social services about the most appropriate course of action. In general, it appeared that the services being offered were very modest in relation to the needs perceived by some of the carers - though some carers rejected all services, reminding us that needs are to some extent in the eye of the beholder.

On the other hand, there were examples of professionals communicating well, with the south east London GPs having good relationships with their local social worker, the Kirklees consultants working with social workers, and in both localities CPNs and social workers reporting that they co-ordinated with one another. These good working relationships tended to be evident once problems had already occurred, rather than in advance of problems - so any co-ordination of effort was reactive rather than proactive.

6.7.5 *Values*

One of the issues that did not arise directly from the questions asked during the study, but was evident at many points, was that the values of the actors varied considerably. There were differences between informal carers (within the same family), between health and social services personnel, and between professionals within each sector. They also became apparent when people with dementia expressed preferences that (to a detached observer) conflicted with the interests of a carer, or with the assessment of a professional when offering services that were refused.

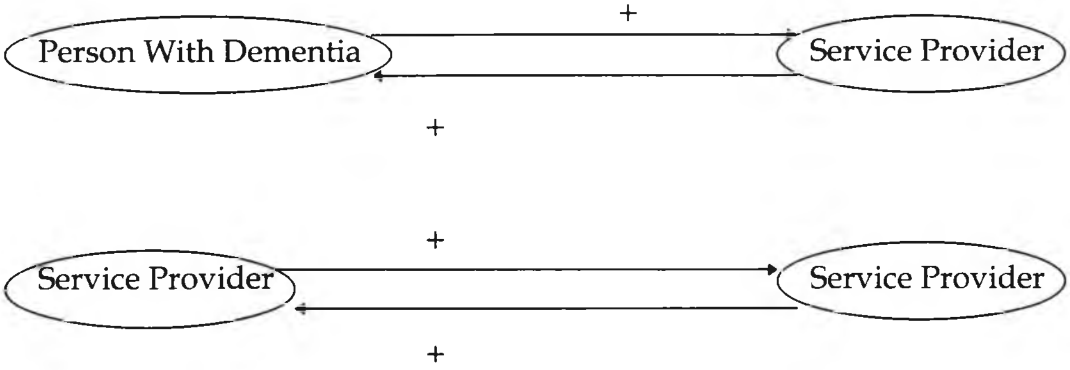
This raises questions about the objectives of the different actors - what were they seeking to achieve? In the cognitive mapping study, the three interviewees agreed that the main objective was to help people to continue to live in their own homes. The case studies suggest that is a useful way of conceptualising entry to a Home - as a failure of existing support. But it is important to add that community-based services are not well organised to achieve this objective, and different professionals have different views about the circumstances that merit thinking about institutional care as an option.

6.7.6 *Inference Diagrams*

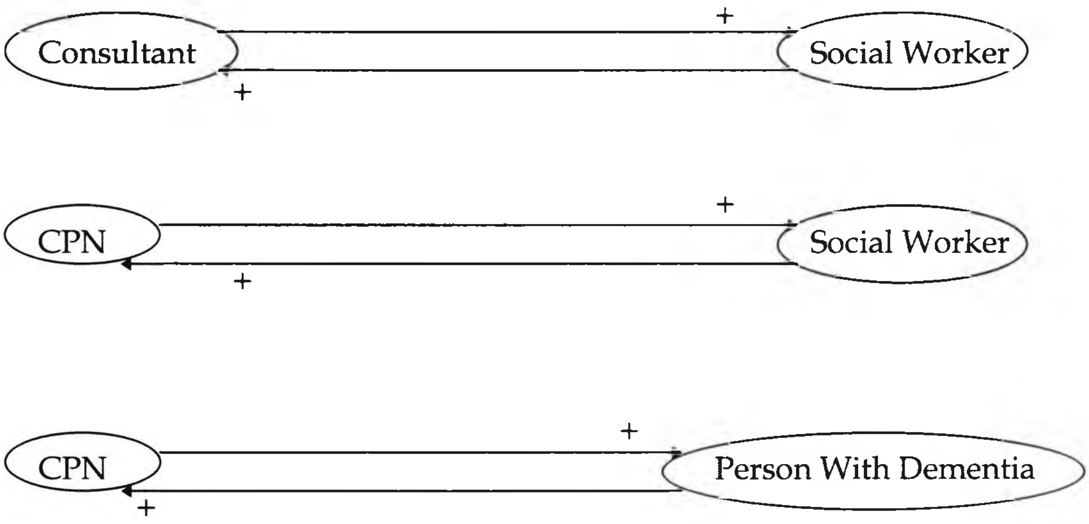
The essential features of the domain are captured in two inference diagrams, Figures 6.8 and 6.9. (Note that *influence* diagrams are presented in Chapter 8, as part of the development of a System Dynamics model of the domain.) These combine evidence from the case studies and insights from the cognitive maps.

Figure 6.8 is a simple diagram showing services as a set of bilateral relationships. This might seem a rather obvious representation, but it is important not to lose sight of the unco-ordinated aspects of the formal care

(a) General Form Of Relationships

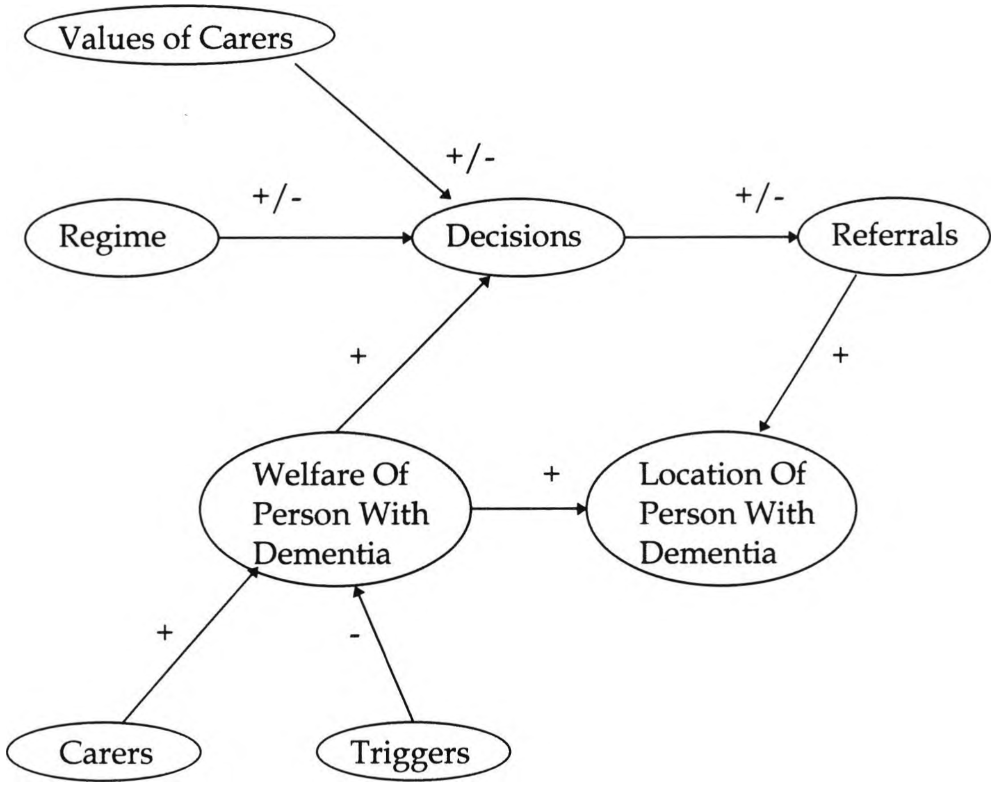


(b) Specific Examples Of Relationships



Arrows represent flows of information, or of information and resources together

Figure 6.8
Inference Diagrams: Bilateral Relationships



Signs show nature of relationship. +/- where relationship may be either positive or negative, in different circumstances, and from different perspectives.

Figure 6.9
Inference Diagram: Synthesis Of Evidence

system. There are periods when community care amounts to no more than support from a single formal carer (and there are occasions when the informal carer provides the only input, and presumably other occasions where there is no informal or formal input).

Figure 6.9 shows a more complex set of relationships. The evidence suggests that there are a number of variables that affect the overall status of person with dementia, and in particular the ability to continue living at home. These include the progress of the dementia itself, the carer's willingness and ability to cope, the level of formal services provided, and preferences about where someone should live.

6.7.7 Commentary

It is recognised that inference diagrams require the person drawing them to exercise judgment, in abstracting key aspects of a situation, and that it is therefore preferable for that person to have a detailed understanding of a domain. That is, inference diagrams are *interpretations* of a situation. They therefore have some of the advantages of both formal (positivist) modelling and of interpretative research. As used here, Figure 6.9 is necessarily provisional, based as it is on just seven diverse case studies. It is, though, consistent with the evidence presented in Chapters 4 and 5, concerning the multivariate and fragmented nature of services in this area.

The weakness of inference diagrams is that they do not capture the nature of the relationships between variables. All that they show is that there is a relationship - but the strength of the relationship is not clear. (Indeed, the diagrams represent causation but the mechanics of causation are not spelled out.) The nature of links often cannot be established beyond doubt - it is possible to show that certain relationships do *not* exist, but typically difficult to provide proof of the existence of a relationship. To set against these problems, the strength of inference diagrams lies in their utility in clarifying relationships between important variables in a domain. Arguably, it is not necessary to be certain about the strength of relationships between variables - this can be established through further work if necessary. The diagrams are a device for capturing the essence of a problem, and they can be validated either through checking with actors or through further empirical research. In the context of the thesis, the inference diagrams provide a useful basis for further modelling, which will be presented in Chapters 7 and 8.

6.8 Conclusions

This chapter has presented a detailed account of the domain using two main methods, cognitive mapping and inference diagrams. The chapter has led to a view of entry to a residential/nursing home as a systems failure, rather than as the inevitable consequence of a sequence of processes. The design of any system for the care of people with dementia should ideally, therefore, have maintenance in one's own home or avoidance of institutionalisation as an objective. This confirms the view developed in the course of Chapters 4 and 5.

The cognitive mapping study was to some extent breaking new ground, given the lack of published work in the area. The experience was a little disappointing, in that it was difficult to be confident about the value of the maps produced. The disappointment may be misplaced, as there was no opportunity to test the validity and reliability of the method; but there seems to be no good reason to rely on cognitive maps, alone, in the type of domain of interest in this thesis.

These concerns notwithstanding, the cognitive maps provided some useful insights into the structure of decision-making of three professionals involved in organising and providing services for people with dementia. They highlighted some of the factors that they take into account, and suggested that the needs of the person with dementia really are taken into account when decisions are made.

The case studies and their associated time lines stress the point that having dementia makes people vulnerable to events. A carer falling ill, which might be coped with by many older people, seems to precipitate consideration by profesionals of entry to a residential/nursing home. This raises the possibility that while professionals strive to focus on the needs of people with dementia and their carers, they can easily be overtaken by events.

Overall, the studies in this Chapter have provided insights into issues that other authors have not examined in any detail. The use of a case study approach, while appropriate to the circumstances, leaves open questions about the systemic qualities of the domain. How many people with dementia in a locality actually enter an institution, and what routes do they take in getting there? How far does the design of the system influence what happens to them? These questions are explored further in the next two chapters.

CHAPTER 7

REFERRAL PATTERNS: THE ROUTES TO INSTITUTIONAL CARE

7.1 Introduction

Chapter 6 provided insights into the ways in which professionals assess people with dementia and decide whether they should consider entry to institutional care. This chapter moves away from the focus on individual professionals and investigates the overall pattern of organisation of services.

In Chapter 4 it was shown that studies of health and social services provided to people with dementia have reported the number of contacts in a time period or have focused on the characteristics of individuals with dementia that are predictive of later admission to institutional care (for example, Levin et al., 1989). A Personal Social Services Research Unit (PSSRU) study (Challis et al., 1995) of the fate of elderly mentally ill people discharged form an old long stay hospital provided evidence that the organisation of services can have clear, measurable effects on elderly people and their carers. These are all excellent studies, but inevitably they leave important questions not having been addressed. In particular, the groups of people studied have generally been selected on the basis of contact with a single service: Levin et al.'s group were applicants to local authority homes, and Challis et al.'s group were discharged from long-stay hospital care. This chapter addresses two questions:

- How far does the behaviour of individual decision-makers affect the outcome? Put another way, what is the extent of variation between professionals?; and,
- What are the characteristics of the system that people with dementia use and the professionals operate?

Before starting, decisions had to be made about the overall design of the fieldwork. Broadly, there were two options. One was an observational case study approach (Yin, 1994), along the lines of the Levin et al. (1989) study, which recruited a cohort of 60 people with dementia assessed for entry to Local Authority Homes, and followed them for a year. One strength of this design was that it recorded actual practices in a locality. An important potential weakness was that there were no comparison groups - only a relatively weak comparison of those people who gained a place at application and those that were turned down. There was no sense of the extent to which practices might differ from place to place. In the event, though, and given the lack of other good studies, it is probably fair to say that the quality of the descriptive data and the decisiveness of the results outweighed the lack of control in the design.

The alternative was to use a quasi-experimental (interventional) design (Campbell and Stanley, 1966), as employed by Challis et al. (1995). There is a very large literature relating to the choices available in experimental research and the strengths and weaknesses of different designs. Arguments revolve around issues such as the importance of internal and external validity, and the extent to which different types of result can be used by policy makers. The main point here is that Challis and colleagues followed the argument that external validity was likely to produce the best balance between valid and reliable research results and policy relevance. The main argument in favour of an interventional, controlled design is that it provides evidence about the effects of an intervention. The argument against, in the context of this thesis, was that this type of study is expensive to mount, and requires substantial funding; neither the time nor the resources were available.

The decision was made to use an observational case study approach, though with a different design to that used by Levin and colleagues. The main reasons for this were practical: it was possible to arrange for data to be collected without frequent visits to fieldwork sites, which was difficult in a part-time study. It was also felt that, in spite of a lack of experimental control, a case study approach would yield rich data about the movements of people in a locality. Data collection would focus on people who were referred for specialist assessment or treatment, on the basis that they were most likely to enter an institution at some later date.

7.2 Methods And Data Sources

7.2.1 Background

The first task was to identify a case study site. The criteria for selection included:

- Health and social service boundaries had to be co-terminous, so that the same population was catered for by each service;
- Willingness of NHS and social services managers and service providers to co-operate in the study.

These criteria ruled out a number of areas. Approaches were made to three areas, and Kirklees was selected on the basis that the responses received from senior managers were the most positive. It was reported to have a mix of urban and rural services and a balance of NHS and social services - rather than a single dominant service.

Once Kirklees had been selected, initial contact was made with St Luke's Hospital, which is located on the outskirts of Huddersfield. St Luke's had a Department for the Care of the Elderly and a Psychogeriatric service. Both offered acute services, and there is also one long-stay psychogeriatric ward. (Almost all other acute services were provided at Huddersfield Royal Infirmary.) Access was granted to manual data held in log books, covering in-patient, out-patient and domiciliary services. One of the consultants spoke to relevant social services managers, who in turn granted access to the files they held on people with dementia.

It was realised that in order to match up data from different sources accurately, it would be necessary to record patient names. The legality of recording patient names and basic details on computer was discussed with Brunel University's Data Protection Officer, who advised that recording a person's name was legal, as long as no additional information was recorded that could be used to work out where someone lived. This guidance was adhered to in the fieldwork.

Data were obtained from the following sources for the period April 1993-November 1994:

- The local hospital (St Luke's), which provided both acute and long term beds for people with dementia;
- The social services assessment centre (Stoneleigh);
- Social workers based in the community.

Details are given below. Each site was able to provide data about the patient (age and sex), the patient's GP, source of referral, the contact (eg. social services assessment), and any action taken. Between them the sources were able to provide a fairly complete picture of these services provided to people with dementia during the period.

7.2.2 Ways of Viewing the Data

It is important to distinguish between three types of relationship between people with dementia and statutory services. First, there is the on-going relationship of people who are 'on the list' of a service provider. (For example, everyone in this group was on a GP's list.) Second, there is the 'one off' contact with a professional, such as a social worker visiting someone at home: there may be no further action following a contact. Third, people may be referred from one professional to another. This chapter focuses mainly on the third of these types, referral patterns.

The pattern of referrals between different service providers is complex, at least in the sense that there are many possible routes available. Discussion with local staff indicated that the sources of referral for a consultation or assessment could be:

- Social worker;
- Other community-based social services, including home help organiser;
- GP;
- Community health services, including CPNs;
- Acute hospital;
- Head of a Home.

The outcome of a consultation or assessment might be:

- No further action, and the person returns home;
- Increased support from health or social services at home;
- Admission to hospital;
- Entry to a residential or nursing home.

It was also necessary to distinguish between the different places that people can live - and hence receive services:

- In their own home - referred to here as the community;
- In hospital;
- In a residential or nursing home - or Home.

There were therefore many different possible combinations of referral and location of service delivery. It was necessary to decide how to proceed with an analysis, given the many possible pathway involved. There were a number of different possible ways of modelling the data, reflecting different 'views' of the domain:

- Use the data to provide a rich description of the nature of contacts with health and social services, and the paths people take over a period of time;
- Investigate the variation in patterns of contacts, eg. by analysing the variations in referrals from different GPs;
- Analyse a cohort, eg. all people known to a service on a given date, and where they were a year later;
- Model transitions between different 'states', eg. the movement from 'living in the community' to 'living in an institution'.

Each of these options is pursued, in this Chapter and in Chapter 8.

7.3 Research Design

In order to investigate the two questions posed at the start of the chapter, two designs were used, a cohort and a cross-sectional design.

7.3.1 Cohort Study

Data were collected on all referrals to St. Luke's Hospital, to Stoneleigh assessment centre and to community-based social workers during the six month period June 1st to November 30th 1993. The data were collected prospectively, by arrangement with relevant staff. All of the data were collected as part of local routine recording, with staff agreeing to make a special effort to record data accurately and completely.

While data were collected on all referrals, the nature of the services meant that those referred would include both people presumed to have dementia and also others, for example elderly people with schizophrenia or depression. It was necessary to distinguish people with dementia from others: the way this was done is described in the next section.

The data collected at the point of referral included the person's GP, the referrer, and the service the person was referred to. The key assumption in this strategy was that all people who were felt to be candidates for a change (typically an increase) in community-based support, or for admission to institutional care, would be referred to one or other of the two services. (It was known that this was not strictly correct, since a small number of people were admitted to Homes as emergency cases without being referred for assessment, but this was taken into account in the data collection strategy.)

Data were also collected on all referred peoples' movements during the next year. Since people were recruited over a period of six months, each person's year started on the date of their referral and ended on the same date one year later; this avoided bias that might be introduced through tracking people for unequal periods of time. There were two data collection strategies:

1. Data were collected on any change of location (entry to hospital or Home) during the year after initial referral;
2. Their location at one year after initial referral was recorded - they could be living at home, be in hospital, in a Home, or have died. This was in effect a census of where people were located one year after referral - it was their 'one year outcome'.

The second data collection strategy also took account of the emergency route, since data were collected on all admissions to Homes during the period, and this included all people with dementia who had not been referred during the six months. These emergency admissions were not crucial to the analysis of the cohort, but were potentially important in understanding the behaviour of GPs in relation to this group of people.

7.3.2 Cross-sectional Study

One question that cannot be investigated in a cohort study is: what are the effects of the capacity of different resources on the behaviour of the system? Data were collected in order to build a System Dynamics model of rates and flows in the domain. The details of the data collected and the results are presented in Chapter 8.

7.4 Data Collected For The Cohort Study

7.4.1 Background

A total of 246 people were recruited during the six month period 1st June 1993 to 30th November 1993. These 246 people were a subset of all people who were living in the community and referred to each service. They were all new to these services - they had not been referred at any point in the past, so far as service providers were aware.

They were a subset because people with other problems were referred to the same services - people with severe depressions, or with other organic brain disorders, for example. It was therefore necessary first to establish whether each person was a candidate for recruitment. In the light of the discussion in Chapter 3, it was clear that there was no definitive test available for dementia, and it was not possible to employ an expert panel to review cases without formal research funding, so it was necessary to be pragmatic. (Even where an expert panel was used, by Levin et al. (1989), it was still not possible to be certain that all people in the study had dementia.) The criterion for inclusion were:

	Referred to hospital - seen at hospital	*Referred to hospital - seen in own home*	*Referred to SSD - assessed at Stone-leigh*	*Referred to SSD - assessed at home*	*Totals*
Men	**24**	**15**	**11**	**23**	**73**
Women	58	35	26	54	173
Total	**82**	**50**	**37**	**77**	**246**
Average Age (years)	80.60	82.14	78.41	78.10	79.43

Table 7.1

Age And Sex Characteristics Of People Recruited To The Cohort Study

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- The person's GP reported signs and symptoms consistent with dementia; and,
- The assessor, whether a hospital consultant or social worker, felt that the person had dementia;
- Where possible, the initial assessment made on referral was reviewed at the end of the year. This was not possible in all cases, for example where someone died soon after referral.

This approach allowed the study to go ahead, but inevitably introduced the possibility of bias in the results. This and other possible sources of error are discussed in the next section.

7.4.2 Characteristics of the people recruited

Table 7.1 shows the age and sex of the people recruited, broken down by the service they were referred to. In total 53.7% were referred to hospital services and the balance to social services. The proportions of men and women referred was almost the same for the two services - 53.4% of men

Carer	*Numbers*
Same generation (husband or wife)	**22**
Other relative	2
Friend	**7**
No carer	6
Total	**37**

Table 7.2

Carers Of People Referred To Stoneleigh

and 53.8% of women were referred to hospital and the balance to social services. The average age of those referred to hospital was slightly higher than those referred to social services, with those referred to hospital and seen at home in a domiciliary visit by a consultant being the oldest group on average.

Table 7.2 shows, for those people referred to Stoneleigh only, how many people had informal carers and who those carers were. Since the relationship between informal caring and admission to a Home had been investigated in detail by Levin et al. (1989), Livingston et al. (1990) and by Challis et al. (1995), there seemed little merit in a further detailed investigation here. In addition, establishing home care arrangements would have been very resource-intensive. Hence the decision to study the arrangements for one group here: this work was not taken any further.

7.4.3 The referring GPs

Table 7.3 shows the numbers of people referred and who their GPs were. A total of 81 GPs were associated with the referral of the 246 people, giving a crude mean of 3.04 referrals per GP. The distribution is skewed towards smaller numbers of referrals, with 56 of the GPs (69%) referring one, two or

Number of referrals	*No of GPs referring*	**Total referrals**	*Cumulative total of referrals*
1	27	**27**	27
2	16	**32**	59
3	13	**39**	98
4	6	**24**	122
5	9	**45**	167
6	2	**12**	179
7	3	**21**	200
8	1	**8**	208
9	2	**18**	226
10	2	**20**	246
Total	81	**246**	246

Table 7.3

Frequency Of Referrals (Per GP)

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three people. As will be shown below, however, the GPs did not always initiate referrals.

There were 119 GPs in the area covered by the two services. That is, 81/119 or 68.1% of GPs made at least one referral in the recruitment period.

7.4.4 The referral routes

Tables 7.4 and 7.5 provide an overview of the use of each referral route by GPs. They show that the numbers of referrals to hospital-based and social services are approximately equal, for those GPs who were associated with 0,1,2 or 3 referrals. However, those GPs associated with referral of four or more people referred only to the hospital-based service.

It was shown in Chapter 4 that there are local variations in the provision of local services for elderly people, with some areas dominated by hospital

No. of refs.	*No. of GPs who referred to hospital - seen at hospital*	***No. of GPs who referred to hospital - seen in own home***	*No. of GPs who referred to SSD - assessed at Stoneleigh*	***No. of GPs who referred to SSD - assessed at home***	*Totals - frequency*
0	35	**52**	54	**31**	172
1	23	**21**	18	**29**	91
2	14	**2**	8	**15**	39
3	5	**3**	1	**6**	15
4	4	**1**	0	**0**	5
5	0	**1**	0	**0**	5
6	0	**0**	0	**0**	0
7	0	**1**	0	**0**	7
Totals	81	**81**	81	**81**	324

Table 7.4

Referrals By GP And Service

	Referrals to hospital	***Referrals to social services***	*Totals - frequency*	***Total number of referrals***
0	87	**85**	172	**0**
1	44	**47**	91	**91**
2	16	**23**	39	**78**
3	8	7	15	**45**
4	5	0	5	**20**
5	1	0	5	**5**
6	0	0	0	**0**
7	1	0	7	**7**
Totals	162	**162**	324	**246**

Table 7.5

Referrals To Each Service: Summary Of Table 7.4 And Total Referrals services and others by social services. In Kirklees, at the time of the data collection, the two services were used to approximately the same extents.

It cannot be assumed that the GP was always the person who made the referral. In the case of health services, it appears that the formal referral to hospital almost always did come from GPs, though it may well have been prompted by an informal carer or another professional. The hospital's records suggested that only three of the 132 hospital referrals were not initiated by a GP: all three came via social workers.

For social service referrals the situation was different. Again, a more detailed study was made of those people assessed at Stoneleigh. Table 7.6 shows the sources of referral and the action taken after assessment for the 37 people referred. The results are striking: there was only one referral by a GP to Stoneleigh. All but two of the referrals were by social services staff (which here included meals on wheels) or CPNs.

Table 7.7 shows the source of referral and action taken after assessment of people by social workers in their own homes. The pattern is similar, with only 5 GP referrals in a total of 77, and the bulk of assessments coming from the social services or from CPNs.

This means that there is no merit in trying to establish a statistical association between a person's GP and referral patterns. At the start of the fieldwork it was assumed that a larger number of GPs would refer people to social services themselves, even given the historical scepticism of GPs about social workers. (The reasoning was that since people with dementia often received both health and social services in their own homes, there must be a degree of co-operation and hence a proportion of GP-initiated referrals to social services. In addition, the evidence from the community team in south London suggested that GPs would refer to a team that

Source/ Action	*No Action*	*Increased community support*	*Admission to Home*	*Totals*
Social Services	10	13	1	**24**
CPN	6	**4**	1	**11**
GP	0	**1**	0	**1**
Acute Hospital	0	**1***	0	**1**
Totals	16	**19**	2	**37**

* Referred via accident and emergency department

Table 7.6

Sources Of Referral And Action Taken For People Attending Stoneleigh

Source/ Action	*No Action*	*Increased community support*	*Admission to Home*	*Totals*
Social Services	20	**18**	2	**40**
CPN	17	**14**	1	**32**
GP	1	**2**	2	**5**
Acute Hospital	0	**0**	0	**0**
Totals	38	**34**	5	**77**

Table 7.7

Sources Of Referral And Action Taken For People

Assessed At Home By A Social Worker

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included a social worker.) This assumption was found to be wrong, at least in this case study site. The important inference to be made is, rather, that the route that a person takes appears to depend heavily on who makes the initial referral. If the referral is by a GP it is likely to be to a hospital-based service. If it comes from a member of the social services then it is likely to be to a social worker.

7.5 Possible Sources Of Error

Before considering the implications of these results, and moving on to the analysis of the outcomes for the cohort, it is necessary to consider the possible sources of error in the cohort sample. These may have occurred due to: people not in fact being new to the services; inaccuracies in data collection by NHS and social services staff; inappropriate application of recruitment criteria; variations in the severity of dementia; inaccurate recording of deaths; and, people leaving the Huddersfield area and being lost to the study.

7.5.1 People referred were not new to the services

If some people recruited to the cohort had been referred before, it might bias the results: people who had previously been referred might have different probabilities for their one year outcomes than new referrals. One way of designing the study to avoid this source of bias was to include only new referrals. The problem lay in ensuring that they were indeed new to the services. Two checks were made. In the case of hospital services, there were manual records going back several years, and these were checked back two years (to April 1991), for the whole cohort, for previous contacts.

The situation in social services was different, because there were not good records available before April 1993. This said, the new arrangements for formal assessment of people with dementia only came in April 1993, so the system in this part of the service was new and could not be properly checked using older records. (Locally, social services had run a 'shadow' service including formal care assessments for the six months before April 1993, so the system was not entirely new, but equally it was not well established either.) Social workers were asked whether people in the cohort had been referred during the 'shadow' six months - there was no reliable way of going back any further - and eliminated two people who had previously been referred.

In summary, then, it was possible to be fairly confident that people in the cohort had not been referred to any service in the previous six months, or to the hospital-based services in the previous two years. Before September 1992, the social services arrangements for assessment of people with dementia were different, and there was no comparable process to use as a check.

7.5.2 Data collection

The quality of the data collected was in the hands of staff who voluntarily collaborated in the study. In both the NHS and social services, the basic method of recording for recruitment was manual, in books managed by consultants or social workers. There was no obvious reason to doubt the accuracy of the records, particularly since the staff involved had agreed to pay special attention to data recording. Even so, some simple checks were possible and were carried out. Firstly, it was possible to check the details of people who used both services during the year of the study, to ensure that names, dates of birth and identity of GP were correct. Where the records differed, checks were made by a consultant's secretary, who rang GP practices. Secondly, data were obtained from CPNs, who had a number of people in the cohort on their lists. The CPNs' data were used to check basic patient details, and any discrepancies again checked with GP practices. The main remaining error was that people with dementia were assessed but not recorded. There was no obvious way of avoiding this error, given the circumstances of the study; but there is no good reason to suppose that large numbers of people were missed.

7.5.3 Recruitment Criteria

Errors made in deciding that people had dementia are probably the largest single potential source of error in the study. Evidence presented in earlier chapters suggests that identifying dementia is genuinely difficult. In the absence of formal funding, there was no possibility of convening an expert panel to review cases. Dementia is very rarely recorded as a cause or contributory cause of death on death certificates. As noted above, the one step that was taken was to review the cases of all of those people who were still alive one year after their referral. In the event three people were removed from the sample at this point. However, it is recognised that other people in the cohort may have been misclassified, and the extent of the resulting error is not known.

There are two arguments in favour of living with this type of error. Firstly, the other strong studies in this area avoided the problem to some extent by using narrowly defined samples - only people applying to local authority homes (Levin et al., 1989) or being discharged from long-stay hospital care (Challis et al., 1995) - and even here the authors noted that this error was still likely to be present. This study attempted to identify all people referred to *both* health and social services, who were deemed to have problems serious enough to merit referral. This was the broadest group so far studied - so the advantages of breadth were deemed to outweigh the inevitable errors. Secondly, the results of the study would be useful even with the errors, since they still represented a carefully defined population of people - it is just that the population is not necessarily defined as people with dementia, but as a more broadly defined group, of people with particular health or social care problems.

7.5.4 Severity of dementia

One of the weaknesses of the study design is that it did not take account of the severity of dementia of the people referred. The argument for doing this is that it is not important - what matters here (and in Chapter 8) is the behaviour of the system, and not the detailed characteristics of those referred into it. This said, it is likely that there were differences in the characteristics of those referred to health and to social services, and that these differences affected the one year outcomes. Indeed, the anecdotal evidence is that people who go into long-stay hospital care have more severe dementia than those who move into a Home.

There was no obvious way of dealing with this problem. Since this was a case study design, it had to be accepted that there might be differences in the characteristics of those referred to NHS and to social services. The data on age and sex of those referred to the services in Table 7.2 suggest that the proportions of the sexes recruited were similar, but that the social services referrals were on average younger than those referred to hospital consultants. This may well also reflect a difference in severity of dementia at the time of referral.

7.5.5 Recording deaths

The recording of deaths was monitored by arranging for the local Registrar (of births, deaths and marriages) to send all death certificates (on computer disk) to one of the consultants. There was no means of ensuring that the consultant received all relevant death certificates, but two checks were possible. Firstly, checks were made at the end of one year, for all people, with the original referral service. Where there was uncertainty about whether someone had died, the patient's GP was contacted. Secondly, it was possible to check with Homes for all people who had moved into one, whether they were still living there or had died. There may be a residual error after these checks, but it is likely to be small.

7.5.6 People who leave the area

At the start of the study one of the concerns was that significant numbers of people might move away from the Huddersfield area during the following year. In fact nobody left during the year.

Overall, therefore, the argument advanced here is that the advantages to be gained by knowing the results of the study outweigh the biases inherent in the design. In most cases the biases are likely to be small, though strictly speaking the extent of any biases cannot be known.

7.6 Implications For Organisational Analysis

While the data collection exercise described above was quantitative, the main lessons to be learned appear to be qualitative in nature. For the case study site, the referral patterns suggested that :

- GPs generally referred people to hospital services, and made very few referrals to social workers;
- People who were in contact with community-based social services personnel were likely to be referred to a social worker;
- CPNs may refer to either hospital or social services.

Overall, then, the picture is more mixed than suggested by the three models ('fragmented', care management and team working) discussed in Chapter 5. Most GPs behave as if there are no teams, and only NHS services are useful, at least where assessment is required. On the other hand, CPNs behave in a more team-like fashion. The results also hint that there are limits to the extent to which social workers can act as care managers - they can only assess those people who are referred to them. These points will be returned to in later chapters.

7.7 Cohort Outcome At One Year

7.7.1 Location At One Year

The sample recruited in this study, 246 people, is larger than those used in the major studies reported earlier. Levin et al. (1989) had a sample of 60 people and Challis et al. (1995) had 101 people in their intervention group and 113 in their control group. The earlier studies were concerned mainly with the experiences and opinions of service users, and data collection was designed to obtain a detailed picture of a relatively small sample of people with dementia and their carers. This study is concerned with the behaviour of key professionals and with the overall properties of the system, rather than with the users of the services.

How could this be done? Two approaches suggested themselves, both based on modelling of the available data. The first was to compare different groups within the cohort: that is, examine the individual pathways taken by people after initial referral, and establish whether there were any differences between the two groups at one year. The second approach was to establish the likelihood of each available outcome at one year; that is, model the behaviour of the whole system. Both required knowledge of the outcomes associated with each pathway.

Tables 7.8 and 7.9 show the outcomes at one year for the cohort, by the nature of the referral and the initial contact respectively. Overall, at the end of the year just over a third of the cohort (90 out of 246) were still living at home, 39% (96 out of 246) were in long-stay hospital or a Home, and the remainder (60 out of 246) had died.

7.7.2 Face validity

In the light of the discussion of errors in section 7.5, it is important to assess the validity of these results. The nearest comparable sample was that used in the Challis et al. (1995) study. The relevant data are reproduced in Table

Referral path/ Outcome	*Community*	*Long-stay hospital*	*Res/Nursing Home*	*Dead*	*Totals*
Hospital	46	30	21	35	132
Social Services	44	11	34	25	114
Totals	90 (36.6%)	41 (16.7%)	55 (22.3%)	60 (24.4%)	246 (100%)

Table 7.8

One Year Outcome For The Cohort, By Referral Route

Referral path/ Outcome	*Community*	*Long-stay hospital*	*Res/Nursing Home*	*Dead*	*Totals*
Hospital referral - seen at hospital	31	21	8	22	82
Hospital referral - seen at home	15	9	13	13	50
SSD - At Stoneleigh	14	3	11	9	37
SSD - At home	30	8	23	16	77
Totals	90	41	55	60	246

Table 7.9

One Year Outcomes For The Cohort, By Initial Contact

Location	*Project Group*	***Comparison Group***
At home	56%	**9%**
Institutional Care	4%	**60%**
Dead	40%	**31%**
Number of cases	101	**113**

Table 7.10

Face Validity Of The One Year Outcome Data

Comparator data from Challis et al. (1995, page 181)

7.10. These show that the mortality rates are lower in the cohort than the Challis et al. sample (24.4% compared with 31% and 40%), but this may be explained by the lower age of the cohort in this study and the likelihood that the cohort had less severe problems than the Challis et al. sample, since the latter had all been into hospital already. The proportions of people in the cohort living at home or in institutions lie between the figures for the project and comparison groups in Table 7.10. One might expect this, given that the Kirklees services are neither as integrated as the project group's, or - so far as one can tell - as disaggregated as the comparison group's. Overall, then, the figures seem broadly consistent with Challis et al.'s sample, and it is reasonably to say that the results have face validity.

7.7.3 Predictive Probabilities for One Year Outcomes

Table 7.9 can usefully be viewed as a contingency table. Contingency tables have been used over many years in clinical decision analysis (see Weinstein and Fineberg, 1980: Chapter 4). The most common use is to calculate the probability of a particular outcome, given certain information. In this case, Table 7.9 can be used to calculate the probability of each one year outcome given the nature of the initial referral (Table 7.11). This gives a 'user-

Referral path/ Outcome	*Community*	***Long-stay hospital***	*Res/ Nursing Home*	***Dead***	*Totals*
Hospital referral - seen at hospital	12.6	8.5	3.3	8.9	33.3
Hospital referral - seen at home	6.1	3.6	5.3	5.3	20.3
SSD - At Stoneleigh	5.7	1.2	4.5	3.7	15.1
SSD - At home	12.2	3.3	9.3	6.5	31.3
Totals	36.6	16.6	22.4	24.4	100.0

Table 7.11

Table 7.9 Recalculated As A Probability Matrix

All values are percentages

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centred' perspective on the domain - it is as if someone with dementia can ask, 'given that I have just had a domiciliary visit from a hospital consultant, what is the probability that I will be in hospital in a year's time?'

Overall, the probability that someone is still living in the community after one year, given an initial hospital consultation is 31/90 (34.4%). Similarly, the probability that someone is in a Home a year after a hospital consultation is 15/90 (16.7%). The probabilities of a particular outcome *given a particular initial contact* are shown in decision tree form in Figure 7.1. The decision tree was constructed in the following way:

- The left hand side of the tree represents the fact that the whole cohort started the year living in the community, and were then referred to either hospital or social services;

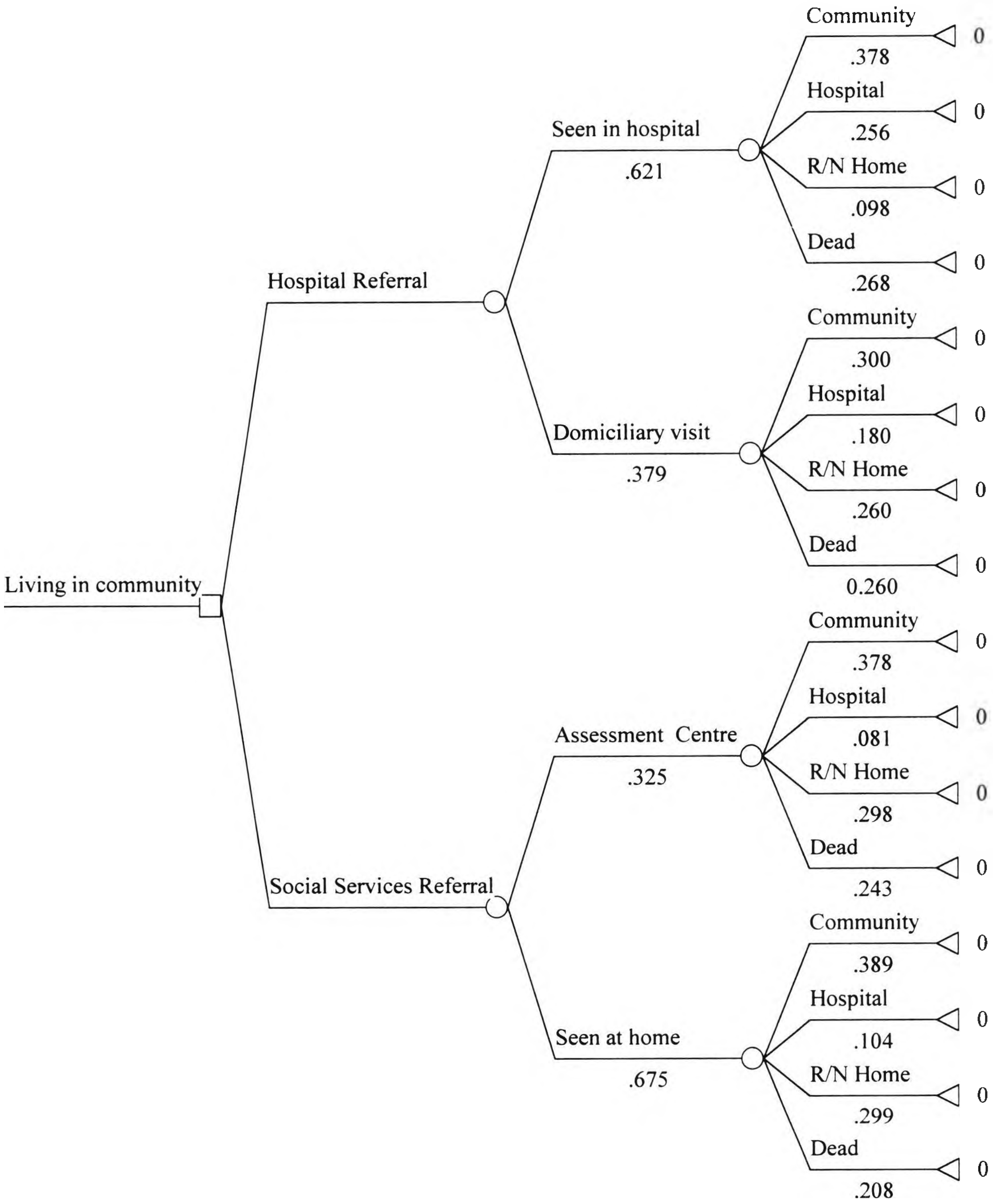

Figure 7.1: One Year Outcomes By Pathway

- Branches representing the links between initial referrals and one year outcomes were constructed. For example, taking the uppermost branch, an initial referral to a hospital service may lead to a hospital-based consultation and to someone still living in the community at one year;
- It was a moot point whether some of the nodes in the tree really represented choice or chance events - many decisions appear to be a blend of the two - but here they are represented as chance nodes, reflecting the conclusions of Chapter 6;
- Probabilities were assigned to each branch, such that the probabilities of the outcomes from any one node summed to one;
- Probabilities could then be multiplied along each branch, to obtain a probability of each outcome - these values are shown at the tips of each branch on the right hand side of Figure 7.2. The P values are simply the product of the two probabilities that lead to each outcome.

7.7.4 Commentary

Figures 7.1 and 7.2 help to make useful points. Firstly, whatever the initial contact, the most likely outcome at one year is that someone will still be living at home. Secondly, the probability that someone will be in a Home at one year does vary by initial contact. It is more likely that someone referred to a community-based social worker will be in a Home ($p=0.202$) than if they were referred anywhere else (p always less than 0.1). Similarly, the probability that someone who has a hospital-based consultation is in hospital a year later ($p=0.159$) is greater than if seen anywhere else (p always less than 0.1).

Figure 7.1, together with the information about who actually initiates referrals made earlier, provides additional insights into the nature of the domain, and in particular the relationship between referral patterns and likelihood of entering an institution. At one level it is clear that the initial

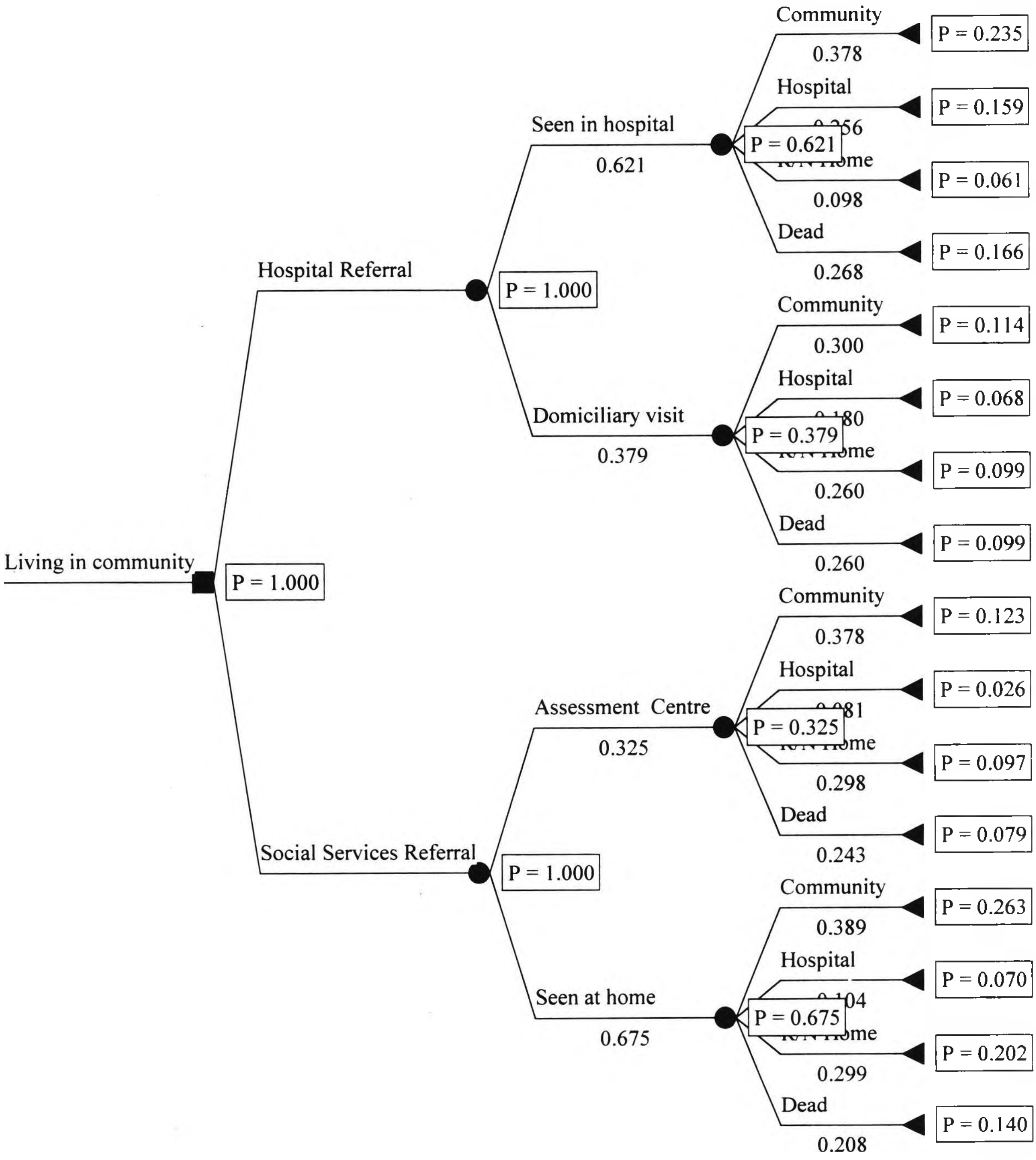

Figure 7.2: Probabilities Of One Year Outcomes

referral does not determine the one year outcome - it is possible to be in any of the end states whatever the referral route. But at a more detailed level, there are differences between pathways, particularly in the likelihood of being in hospital or a Home at one year.

It has to be remembered that there may well be differences in the characteristics of people referred to each service, so these results have to be treated with caution. (These differences may help to account for variation in the probability of being dead at one year.) The initial referral is important, but not the only variable that may affect the one year outcome.

7.8 Markov Analysis

7.8.1 Background

As stated at the start of the chapter, the strategy was to focus on referral patterns, and in particular on movements from the community to hospital or a Home. The last section showed relationships between initial referral and one year outcome, but did not explore any within-year movements. Data were also recorded on within-year movements, so they could be modelled.

One possible way of modelling was to expand the decision tree in Figure 7.1 to reflect the within-year movements. It was felt, however, that this would not provide any additional insights. The main points to emerge from an analysis of the data were that there was a small number of movements directly from acute hospital to Homes (14 over the year), and there were nine discharges from hospital back into the community. A different approach was adopted, which was to model the data as a Markov cohort. That is, a decision analytic approach would be used, but one that would help to reveal the dynamic behaviour of the system of interest. Markov models are in effect specialised forms of decision trees.

Markov models have particular strengths and weaknesses. Their main strength is that they can be used to model change over time, whilst representing uncertainty, using information about the states that people can be in and the transition rates between those states. The movements between states can be tracked over time. In this context, as Figure 7.1 shows, the states are:

- Living in the community - in one's own home;
- Being in hospital;
- Being in a residential or nursing home;
- Dead.

The main potential weakness of Markov models is that they depend on a strong assumption, that a transition from one state to another does not depend on previous transitions. (That is, Markov models have no memory.) It was not clear how much this assumption mattered in this domain. Markov models are often used to model chronic health states such as end-stage renal failure (see Dowie, 1996), and Astin et al. (1997) argue that Markov processes can be used to model the economics of treatment of chronic conditions, so there was some reason to believe that it was a reasonable approach here. To set against this, there was no evidence (positive or negative) that the assumption of independence of cycles was correct.

7.8.2 Using the Cohort Data Uncorrected

The decision was made to go ahead, and to review the results to help decide on the merit of the approach. Figure 7.3 shows a representation of the Markov process, for the cohort described earlier. Markov states have to be collectively exhaustive and mutually exclusive. Figure 7.3 was built up in a number of stages to ensure this:

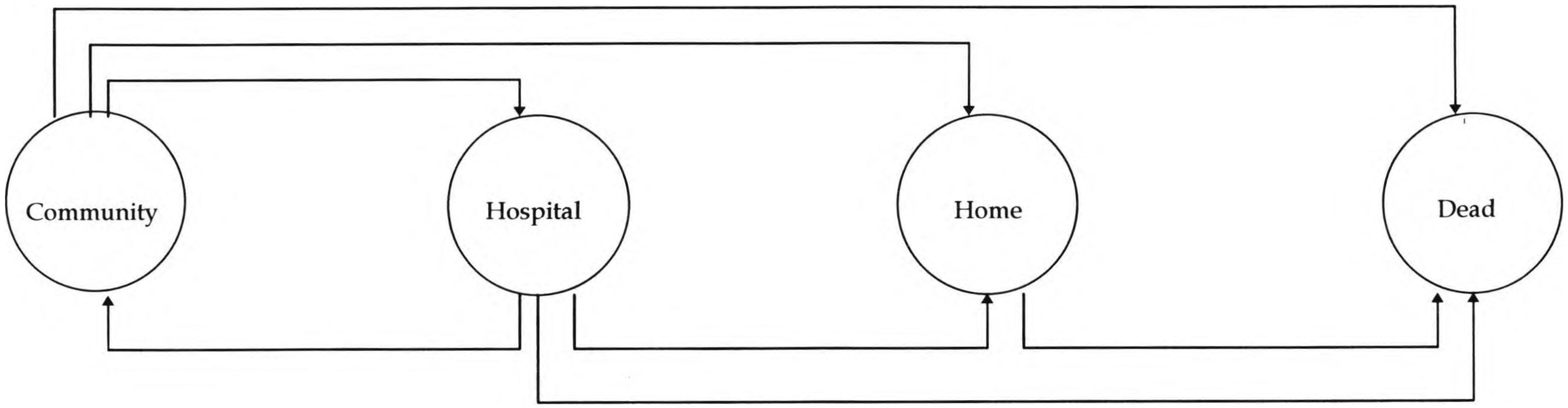

Figure 7.3
Representation Of Markov Process Model For The Cohort

- Identify the states, as noted above;
- Show all people at the outset as living in the community, by setting the probability of the 'community' state to 1 and the others to 0;
- For the community arm, identify way of leaving the state during the year, and the probability of moving from the community to any other state (including community itself) during the year. The probabilities must sum to one, in the same way as they do in each set of arms in Figure 7.1;
- Then for all states, identify the ways of leaving them and the actual probability associated with each route;
- Identify 'dead' as the absorbing state.

The model was re-created in the software package DATA 3.0. This is shown in Figure 7.4, which is an unusual representation of a Markov process. Conceptually it is identical to Figure 7.3, but it is worth working through it:

- On the left hand side, the four states - community, hospital, home and dead - are shown;
- Community is set to 1, representing the fact that all people are there at the outset;
- The triangles on the ends of the arms (except dead) represent state transitions;
- Dead is the absorbing state.

Figure 7.5 shows the result of running the model. It shows the behaviour of the model over 15 stages - in effect the years from the start of the cohort, where the average age is just under 80, up to an age of just under 95 years. The model runs using the probabilities alone, as if there is an infinitely large number of people in the cohort.

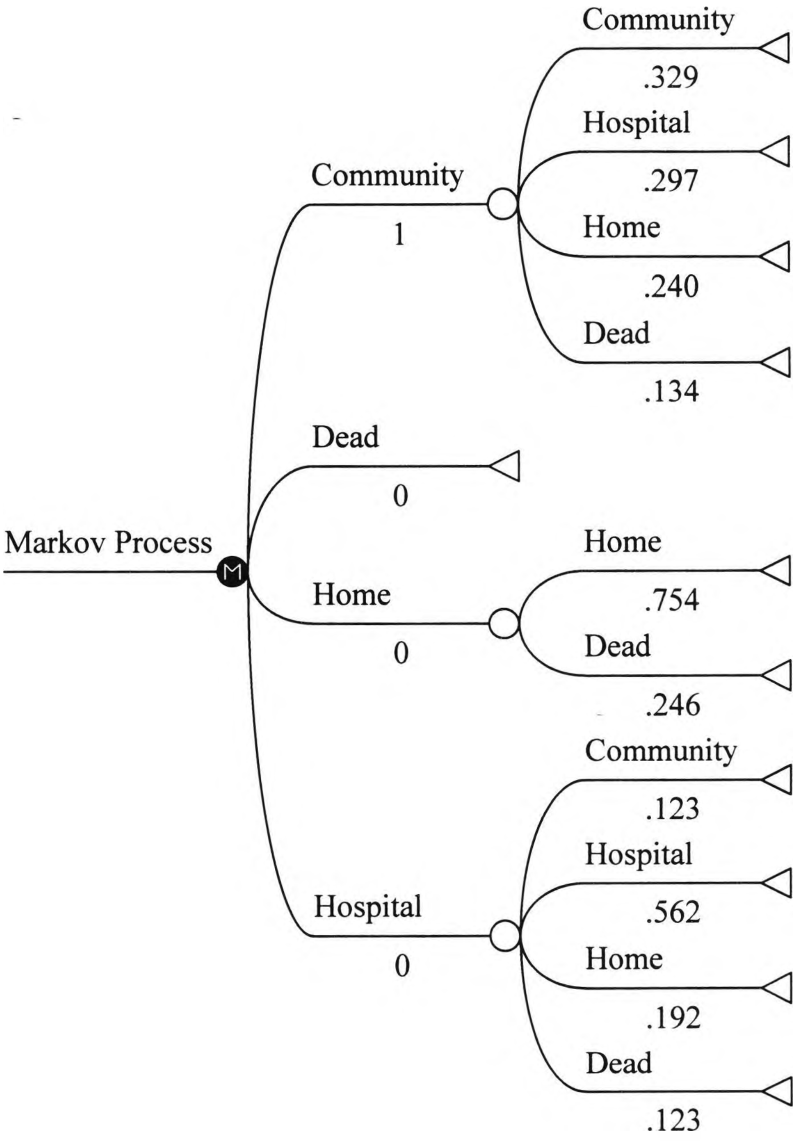

Figure 7.4: Markov Model Of One Year Outcome Data

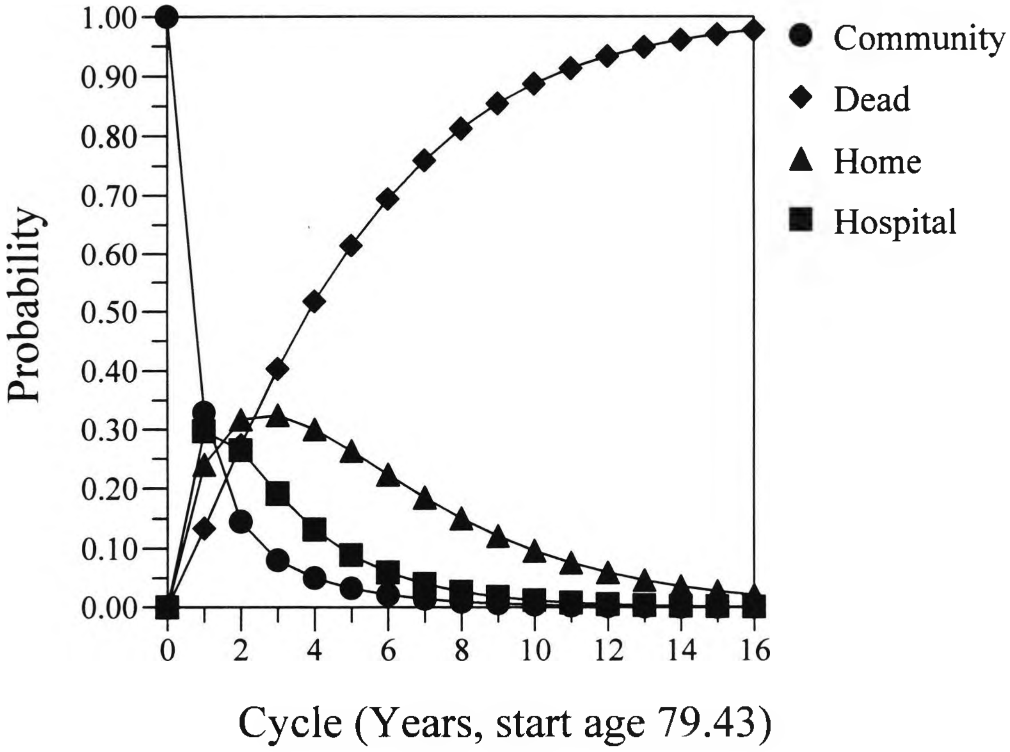

Figure 7.5: Markov Probability Analysis

The interpretation is straightforward:

- The numbers of people living in the community decrease rapidly in the early years;
- The numbers of people in hospitals and Homes increase and then decline;
- The number of people who dead accumulates until most people have died by the end of the last cycle.

In order to give these results some meaning, it is possible to convert the percentages back into numbers relevant to the cohort. At the end of the last cycle, when people are around 95 years old, 98% (241 people) have died and the remaining five are living in Homes.

7.8.3 Correcting For Changing Mortality Rates

While Figure 7.5 is interesting, it assumes that the probabilities generated using the cohort data are the same over all cycles. In practice, this is unlikely to be true: as the cohort ages, the probability of entering a hospital or Home, and of dying, will change. The probabilities of entering a hospital with increasing age seem likely to increase - though there are no data on this specific to people with dementia. The age-related probability of entering a Home are not known, either. The probability of dying will certainly increase: the change in probability with increasing age was discussed in Chapter 3.

There seemed no useful way of exploring possible variations in these three probabilities together, but it was important to establish whether increasing mortality rates affected the behaviour of the model. Figure 7.6 shows the DATA version of the Markov cohort, with an additional set of arms on the tree that capture the increasing mortality rate over time. Data on mortality rates were estimated from published data (see Chapter 3). The resulting

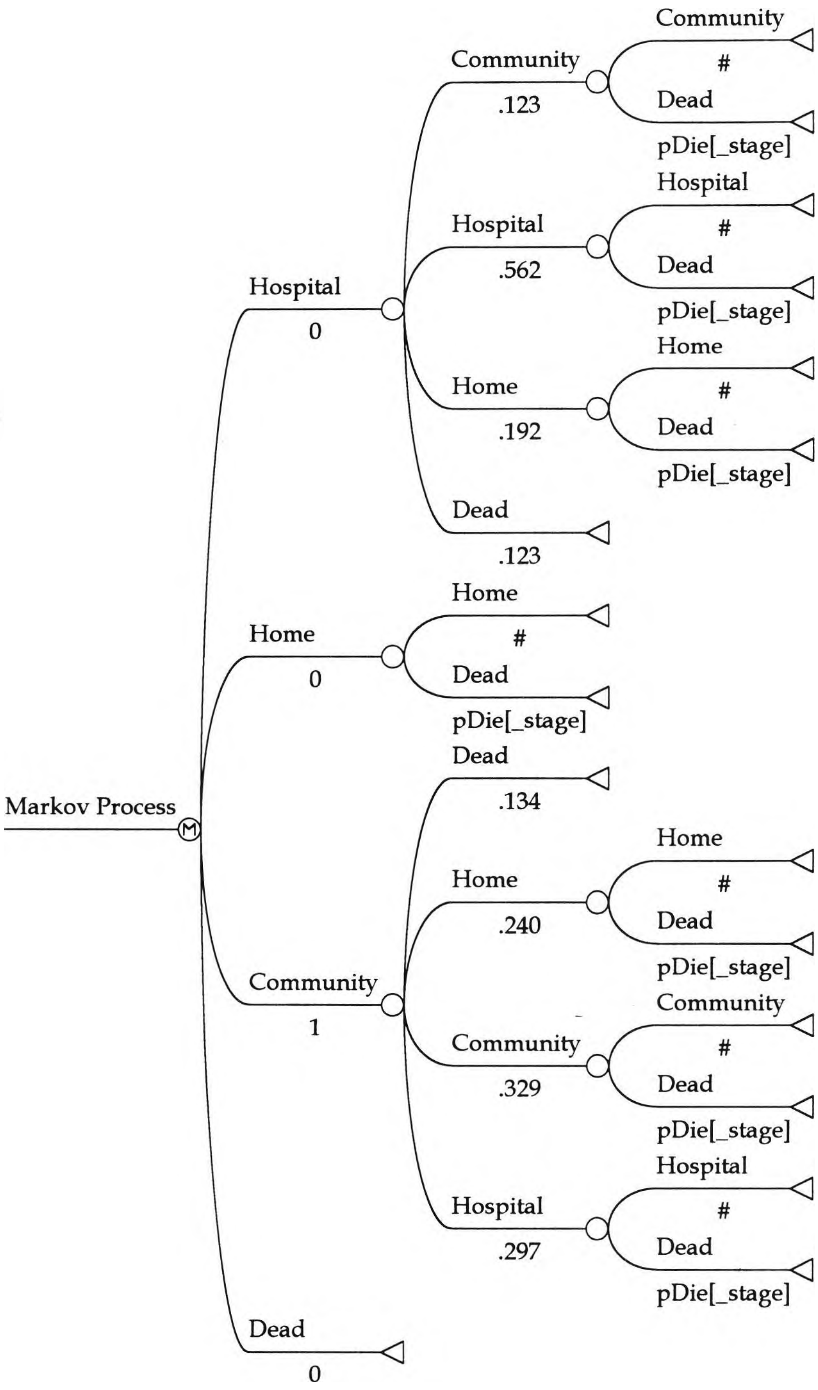

Figure 7.6: Mortality-Adjusted Markov Cohort

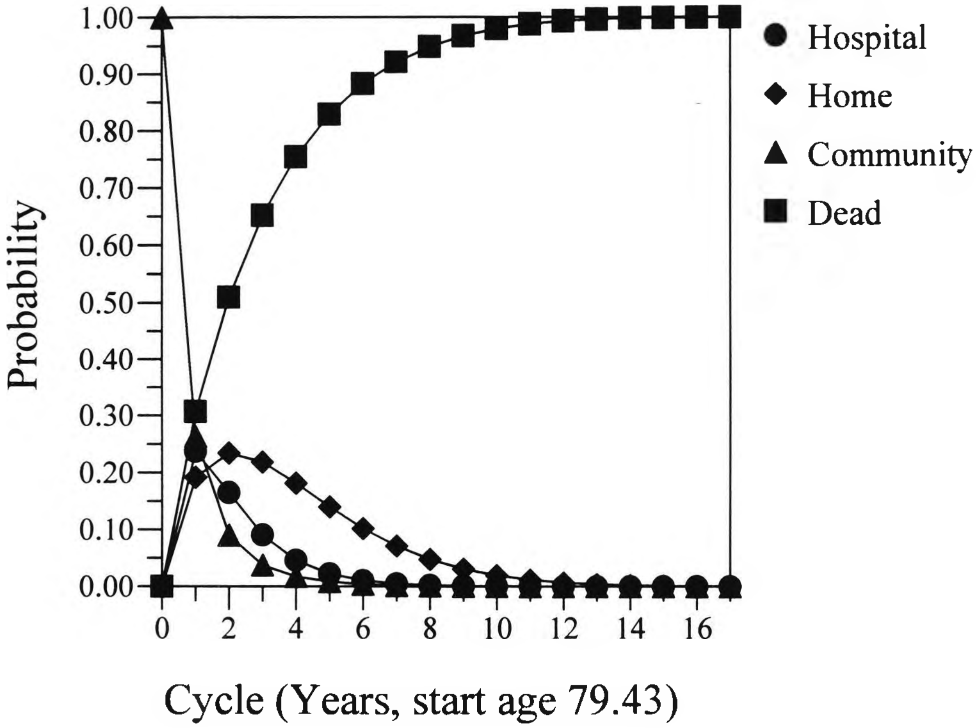

Figure 7.7: Mortality-Adjusted Markov Probability Analysis

graph, in Figure 7.7, shows that correcting for mortality rates has little effect: there is still an early peak of institutional admission, and most people have died by the age of around 95 years.

7.9 Discussion

The data presented in this chapter have added considerably to understanding the relationship between the actions of service providers while people with dementia are living in the community, the referral paths taken by those people with dementia, and the subsequent likelihood of admission to institutional care. Thus it appears that likelihood of admission to hospital is associated with an initial referral to hospital, while admission to a Home is most likely if initial referral was to a community-based social worker. It is also true, however, that an initial referral can lead to any outcome at one year.

The results have to be treated with caution, because no attempt has been made to control for the differences between the groups of people within each referral group. The reason for this was to allow examination of what actually happened on the ground, but one consequence is that some of the variation in the results may be due to group differences.

The cohort study has been useful in itself, but does not reveal anything about the capacity of the system - in particular, the capacity of hospitals and Homes to cope. This is explored in Chapter 8.

CHAPTER 8

SYSTEM DYNAMICS MODELS OF THE DOMAIN

8.1 Introduction

The last two chapters have presented empirical evidence about the domain, revealing some of the 'fine structure' of the events that lead up to entry to an institution, including the cognitive processes of key professionals, and the pathways that a cohort of people took over the course of a year. Taken together, the studies suggest that:

- The main objective of the formal service systems in the domain is to maintain people in their own homes;
- There are weaknesses in the flexibility and co-ordination of services, which tend to undermine the achievement of the objective, though at least for some professionals these weaknesses are not perhaps as serious as some commentators have claimed;
- The pathways that people take are a mixture of choice and chance - they are neither random nor well controlled.

Most of the studies were descriptive in nature, the exception being the Markov cohort model presented at the end of Chapter 7. This model suggested that the time course of demand for hospital and nursing home places peaked at one and three years after recruitment respectively. It also suggested that demand would tail off fairly rapidly after the peaks, and that most people would have died ten years after recruitment - around 90 years of age.

This chapter continues the exploration of the dynamic behaviour of the formal service delivery system in Kirklees. System Dynamics (Forrester, 1994; Wolstenholme, 1990, 1993) models are used to investigate the possible consequences of changing characteristics of the domain - which are based on changes which are actually taking place in Kirklees and elsewhere.

8.2 Systems Studies And Community Care

Current UK community care policies pose a challenge to systems practitioners. They are complex, and their long term effects are difficult to predict, as earlier chapters have shown. What is more, they have been little studied. There have been many systems science and operational research (OR) studies of health and social services reported in the literature, but the great majority focus on hospital-based services (see Butler et al., 1992; Cropper and Forte, 1997), rather than on primary or community care. (An important exception here is the Balance of Care model, designed to help health authorities to allocate community-based resources (see Forte and Bowen, 1997): this thesis does not address questions relating to the allocation of numbers of staff, focusing instead on the organisation of services, as discussed in Chapter 5). By and large these studies have been undertaken within a 'hard' tradition, and have used quantitative modelling techniques to analyse the workings of operating theatres, out-patients and other services.

There have, though, been a few accounts of approaches used in community health services and local authorities in recent years. For example, Checkland and Scholes (1991) report a study (using SSM) of NHS district community medicine departments, and Galliers et al. (1981) carried out a study of services for mentally handicapped people for Camden Social Services Department. Midgley (1996) reviewed different approaches to the evaluation of services for people with disabilities, and used a variety of methods in a case study he reported. There are further examples, but they are few in number: the key point is that there is relatively little in the published literature that can be used as a basis for decisions about approaches and methods.

Of the studies available, one by Wolstenholme (1993) of the possible consequences of community care legislation, and in particular of the changes in funding mechanisms for services for elderly people, is most relevant to this thesis. It is discussed in some detail here, since it serves as a useful starting point for the analysis that follows.

The paper uses qualitative System Dynamics, which Wolstenholme describes as an interpretative modelling technique. System Dynamics provides a 'language' for modelling a system, where all components are states, rates or auxiliaries. Auxiliaries are steps linking states and rates, and are used to help specify the relationships between the two. A model is therefore a set of relationships between rates, states and auxiliaries. System Dynamics typically involves the following steps:

1. Creation of an influence diagram that captures the key variables (or states) and relationships between them;
2. Conversion of the influence diagram into a formal model, termed a qualitative System Dynamics model. This is in effect an influence diagram constructed according to a particular set of rules, where everything is either a state, a rate or an auxiliary;
3. Conversion of the qualitative into a quantitative System Dynamics model, through inclusion of equations that describe the relationships within the model.

In principle, System Dynamics offered a means of moving from qualitative to quantitative analysis in a structured way, and of exploring changes in the organisation of services. Wolstenholme has stated:

> "System Dynamics means exactly what its name implies. It is concerned with creating models or representations of real-world systems of all kinds and studying their dynamics (or behaviour). In

> particular it is concerned with improving (controlling) problematic system behaviour... The purpose in applying System Dynamics is to facilitate understanding of the relationship between the behaviour of a system over time and the underlying structure and strategies/policies/decision rules." (Wolstenholme, 1990: page 2)

In his 1993 paper Wolstenholme studied the movements of elderly people between the community, hospital and residential care. The paper describes an iterative process of discussion with senior NHS managers, which resulted in the creation of influence diagrams (Figures 8.1 and 8.2). The model has a number of positive and negative features. The main positive feature is that it seeks to make relationships between health and social services explicit, and points up possible effects of changing particular elements. For example, it highlights the potentially deleterious effects of delays in discharges from hospital on hospital services and waiting lists. It also makes the interesting suggestion that GPs may seek access to hospital services by sending patients to accident and emergency (A and E) departments, thus avoiding long waiting lists. The same point has been made by other commentators, in the context of the NHS reforms (Glennerster, Matsaganis and Owens, 1994).

There are, though, important problems with Wolstenholme's paper, revealed in comparison with the material presented in earlier chapters. Firstly, there are some factual errors. The most important are the omission of hospital consultants, and the failure to represent NHS community services properly. Consultants influence hospital admission and discharge rates, and the role of CPNs and other community-based staff has been demonstrated. The author also omits the private sector (which he acknowledges) and the voluntary sector (which he does not). Informal carers are represented only in their role in delaying hospital discharge. But the literature shows that most carers *want* to care for relatives and friends, and their attitudes are a predictor of admissions to local authority residential homes (see Chapter 5) - that is, they can exert a positive or

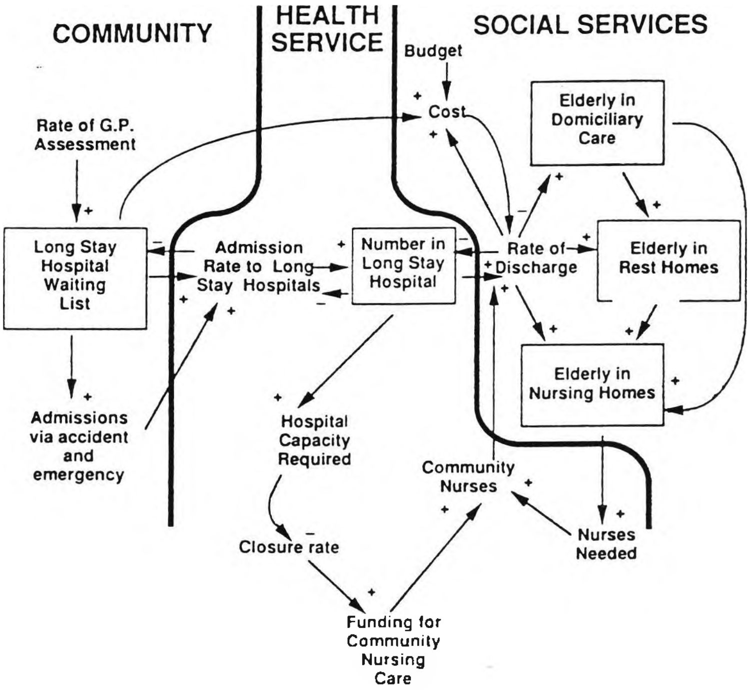

Figure 8.1
Influence Diagram
Source: Wolstenholme (1993)

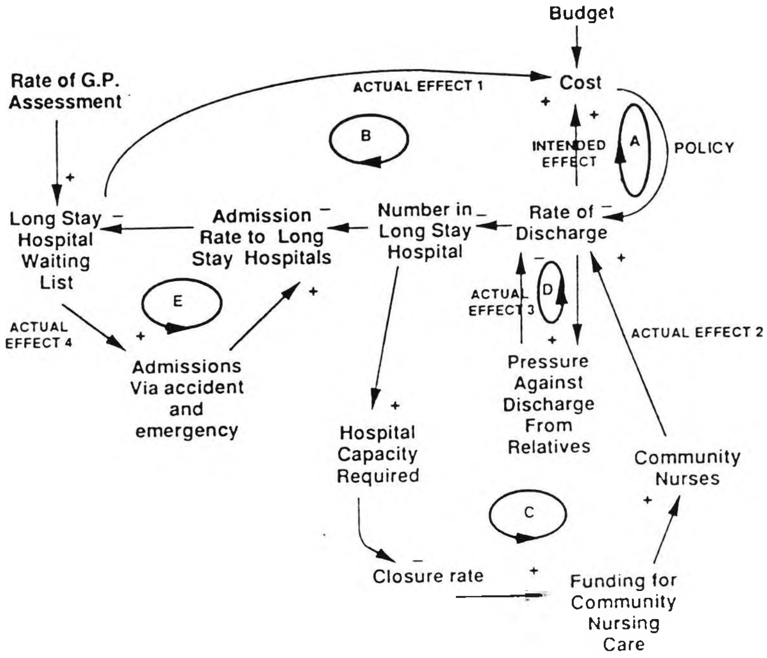

Figure 8.2
Simplified Influence Diagram
Source: Wolstenholme (1993)

negative effect on admission rates, depending on how well they are coping.

In addition, the only financial input to Wolstenholme's model is from social services, which is simply not correct: as Chapter 4 showed, a major thrust of government policy is to require individuals to contribute to the costs of services themselves. The omission of NHS inputs would appear simply to be a mistake: NHS resources are real, significant and must come from somewhere. These problems with the model are not trivial, as they will lead to mistaken conclusions about the possible effects of the behaviour of the system on the budgets of different services, particularly the shift that is taking place from state to individual responsibility for financial provision in old age. If the model cannot represent this shift then it will produce a misleading picture of current developments.

Secondly, the model focuses on resources. This is the author's intention, but the consequence is that the volume and quality of care, the capacity of different services, and wider equity issues are not addressed. This paints a partial picture of current community care policies, and particularly the process of assessment on hospital discharge at the heart of the model, which is at least in part concerned with ensuring that services will be provided after discharge. The model does not allow assessment of whether the changes in resource flows might result in achievement of quality objectives.

Thirdly, the signs on the arrows in the model are overly deterministic. For example, the rate of discharge from hospital is assumed to have a positive effect on the numbers of people in residential care. Yet again, this interpretation ignores the stated intention of NHS and community care policies, in this case to increase the numbers of people living in their own homes and decrease the numbers in long term institutional care. In principle, then, the arrow might be positive or negative; and the direction and magnitude of the flow will be an important indicator of the success of government policies. Indeed, it is quite reasonable to suppose that decision-makers might respond to changing patient flow rates by adjusting the *thresholds* for access to a service up or down, as necessary. The model does not appear to allow for intelligent behaviour by professionals in the face of resource constraints.

Fourthly and finally, the model has at best weak predictive value. This is a crucial objection, since one of the model's purposes is to understand policies which have only recently been implemented, and whose effects may take some time to work through. For example, Wolstenholme predicts that the rate of discharge will increase costs in all social services (since all arrows have positive signs in his model). One might wonder whether this is correct: one interpretation of hospital stays is that they solve problems (for example, they can improve a person's mobility through hip replacement) and so *reduce* costs to social services (and individuals themselves), at least in the short term.

The key policy question in Wolstenholme's paper is, so far as one can tell, 'how will changes in rates of hospital discharge *actually* affect social services?'. If the model does not discriminate between options, then it will lead neither to understanding nor to useful prediction. The outcome will be very different if (say) GPs continue to refer at their current rates, or change their own criteria and decrease referral rates. The complex interaction of different elements is not well described by this type of diagram.

It is important to distinguish between System Dynamics as a modelling technique and its application to community care in this paper. The view taken here is that is a potentially useful technique, that needs more careful application. The arrows in Wolstenholme's influence diagrams show some useful aspect of relationships between services, but are not adequate to explain and predict their behaviour under current or possible future circumstances.

8.3 A System Dynamics Model: First Steps

It was therefore decided that a System Dynamics model of the domain would be developed, and the model would be used both to understand the domain and to explore the consequences of particular changes in its behaviour. Given the focus of the thesis on entry to residential/nursing homes and hospitals, the model would be designed to explore how changes in the organisation of community-based services might affect entry patterns.

The first step in System Dynamics, as described by Wolstenholme (1990: Chapters 2 and 3), is to create influence diagrams. An influence diagram was developed following Wolstenholme's (1990) guidelines, building particularly on the material presented at the end of Chapter 6. The first step was to identify states and rates. Wolstenholme's paper, for all of its problems, provided some useful clues here. For example, he chose to focus on a particular level of analysis - above the behaviour of individuals but below the aggregated level of whole organisations. Under the new arrangements in the NHS and community care, this is the level at which 'service level argreements' are made. Wolstenholme also focused on the movement of elderly people (rather than, say, the activities of service providers) and a focus on the movements of people with dementia seemed appropriate given the objectives of the thesis. Accordingly, the resources were identified as people with dementia, the states chosen were their places of residence, and the rates were their rates of movement between states (Figure 8.3).

The next step was to identify delays in processes. Evidence collected during the fieldwork suggested that services were generally delivered in a timely fashion - the problem was whether they were delivered at all, to the level

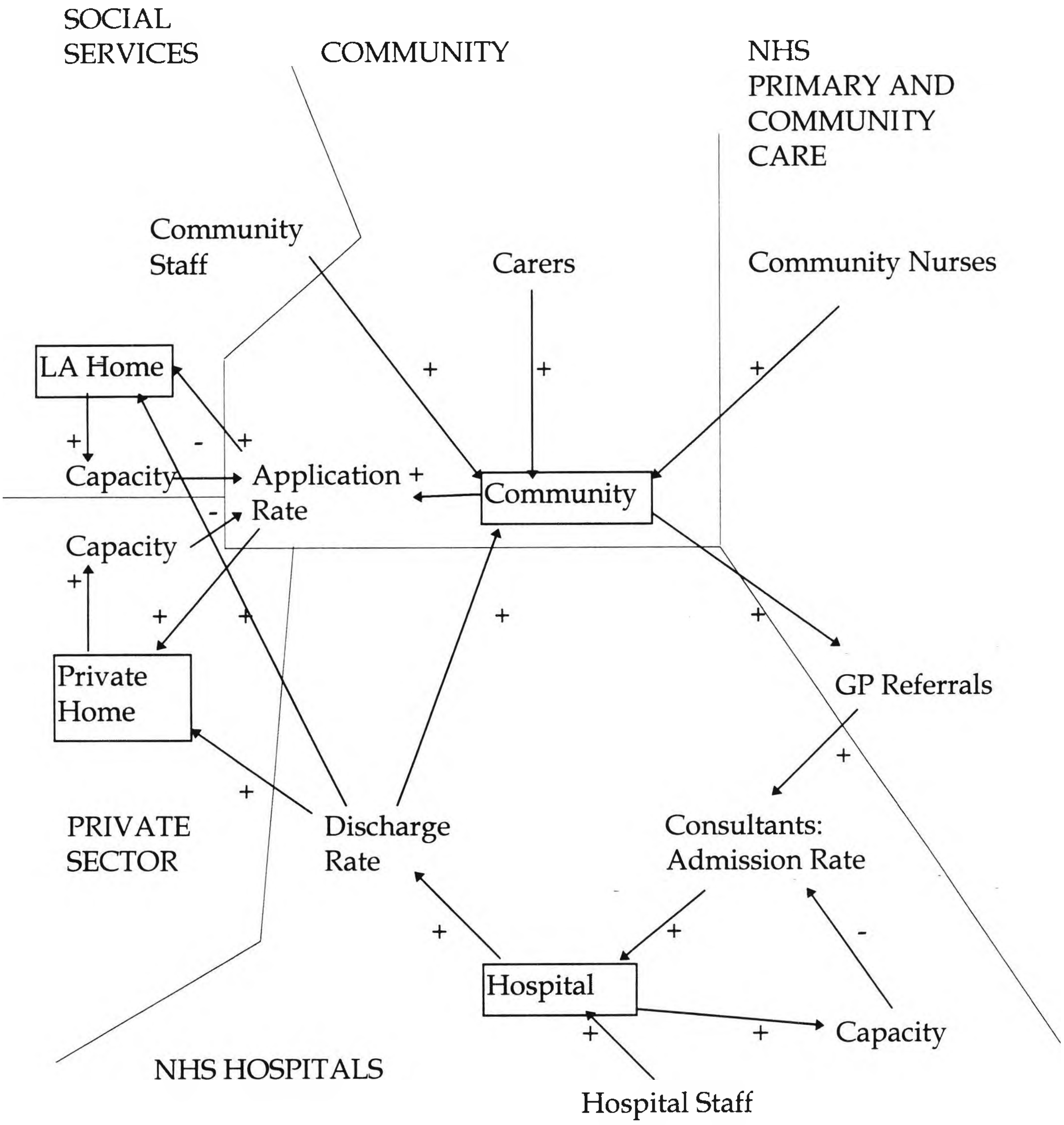

Figure 8.3
High Level Influence Diagram Of The Domain

Drawing conventions as used by Wolstenholme (1990) required, and in a sufficiently co-ordinated way. It was decided that delays were not an important characteristic of the system.

Wolstenholme recommends that the next step should be to identify relevant organisational boundaries. Wolstenholme is not as clear as he might be about the process of identification, and here Checkland's (1981) approach to boundary identification was followed, even though it is concerned with a rather different approach to modelling. Checkland stresses the point that boundaries are important, but the boundaries of organisations - which are typically legal or budgetary boundaries - may not be the most important for the systems practitioner. Boundaries may be created by physical distance, by differences in beliefs and other factors that are just as important as the legal boundaries of organisations.

In the event, the boundaries were consistent with formal organisational boundaries. This is perhaps not surprising, given the sharp divisions in the funding arrangements and in the objectives of people working in different sectors. There was a key difference with Wolstenholme's diagram, however, which was the identification of the 'informal sector' as an area in its own right. This area represents the home life of the person with dementia and any carers, that continues whether health and social services are being provided or not. There were thus five areas in the influence diagram: the informal sector; social services; NHS primary and community services; NHS hospital services; and, residential and nursing home care.

The final step in the creation of an inference diagram is the identification of information strategy and structure. This step was omitted at this stage, but included when quantitative information from Kirklees was used to refine the model: this is described in Section 8.5.

States For People With Dementia	*Capacity**
Living in own home	**No limit**
Respite Care places	37 places
Hospital	**40 beds**
Residential Care	40 places

Table 8.1

The Four States In The System Dynamics Model Of The Domain

* The capacity figures are estimates or averages for the financial year 1993-94.

Wolstenholme suggests additional steps that may be undertaken, the most important of which is the identification of any information feedback loops. This proved to be relevant in the domain, as evidenced by the diagrams presented in Chapter 6: failures to feed back information were an important issue. Again, this is discussed in Section 8.5.

8.4 Baseline System Dynamics Model

The next task was to build a System Dynamics model that captured the situation found in Kirklees. This involved fundamental decisions about the design of the model - what were the states and rates? It was decided that there were four main states, listed in Table 8.1. Compared to the influence diagram in Figure 8.3 there was one change, which was that the informal sector and primary/community care were made into one state, since all of the care was delivered in the same place, the community.

8.4.1 The Sample

The cohort design used in Chapter 7 was useful in understanding the movements of people down particular pathways, but did not include any information about the constraints imposed due to lack of resources or poor co-ordination. In order to explore these issues a cross-sectional design was used. Data were collected on all movements over a 12 month period from 1st September 1993 to 31st August 1994. No attempt was made to track individuals. A movement is defined here as either a formal move arranged by a professional from one state to another, or a person dying (in effect moving from a place of residence to death). The approach to data collection was as described in Chapter 7.

Data were collected from both NHS and social services sources and validated using a variety of practical checks. The validation was not as thorough as that described in Chapter 7, since it was not practically possible to track all of the people who made movements during the year. However, just as in Chapter 7, checks were made with consultants and social workers as to the likelihood that the person recorded as moving actually had dementia.

The four states identified for the model corresponded to the places where people actually lived - albeit for only two weeks at a time in the case of respite care. The main rates were the movements of people between the states, and are shown in Table 8.2. These rates are distinct from those reported in Chapter 7. In Chapter 7 the one year outcome figures reflect the numbers of people in a particular state on a 'census' day, whereas the figures here are total movements over the year. As Table 8.2 shows, the movements were more complicated than implied by the analysis in Chapter 7: for example, there were movements out of hospital back into the community. These occurred in instances where a person was recruited to the study, then entered hospital, but was treated in a short-stay rather than

Type Of Rate	*Movements/ Year*
Community/Hospital	222
Community/Home	22
Community/Respite Care	192
Respite care/Home	120
Respite care/Hospital	72
Hospital/Community	120
Hospital/Home	6
Home/Hospital	0

Table 8.2

Rates: Movements Per Year Between States.

Location	*Deaths Per Annum*
Community	106
Hospital	164
Home	32
Respite Care	0

Table 8.3

Mortality Data By Location

a long-stay bed, and then discharged. The other key rates were mortality rates: Table 8.3 shows the mortality rates for the different states.

Data for the states reflect the numbers of places or beds available. Each of the figures is, strictly, an estimate since the numbers of places and beds fluctuate - so average usage data were used to build the model. Care was taken in arriving at these estimates, with data provided by NHS and social services being checked with Heads of Home, to establish both that the movement had taken place and that the person was believed to have dementia.

The collection of detailed data on movements meant that it was possible to calculate the annual rates of movement between states precisely. Similarly, access to mortality rates and the ability to tie these data to place of death meant that it was possible to calculate separate figures for each location.

Figure 8.4 shows the actual movements between states in Kirklees. The Figure is not a conventional System Dynamics model, in that all of the parameters are determined: it is based on the figures in Tables 8.2 and 8.3.. Its value lies in the fact that it represents actual movements in the case study site - and therefore moves beyond Wolstenholme's conceptual treatment. It shows that:

- There are movements in both directions between the community and hospital and between the community and respite care;
- There are flows from the community and hospital into homes;
- There were no deaths while in respite care;
- People move out of the system when they die, which can occur in the community, hospital or a home.

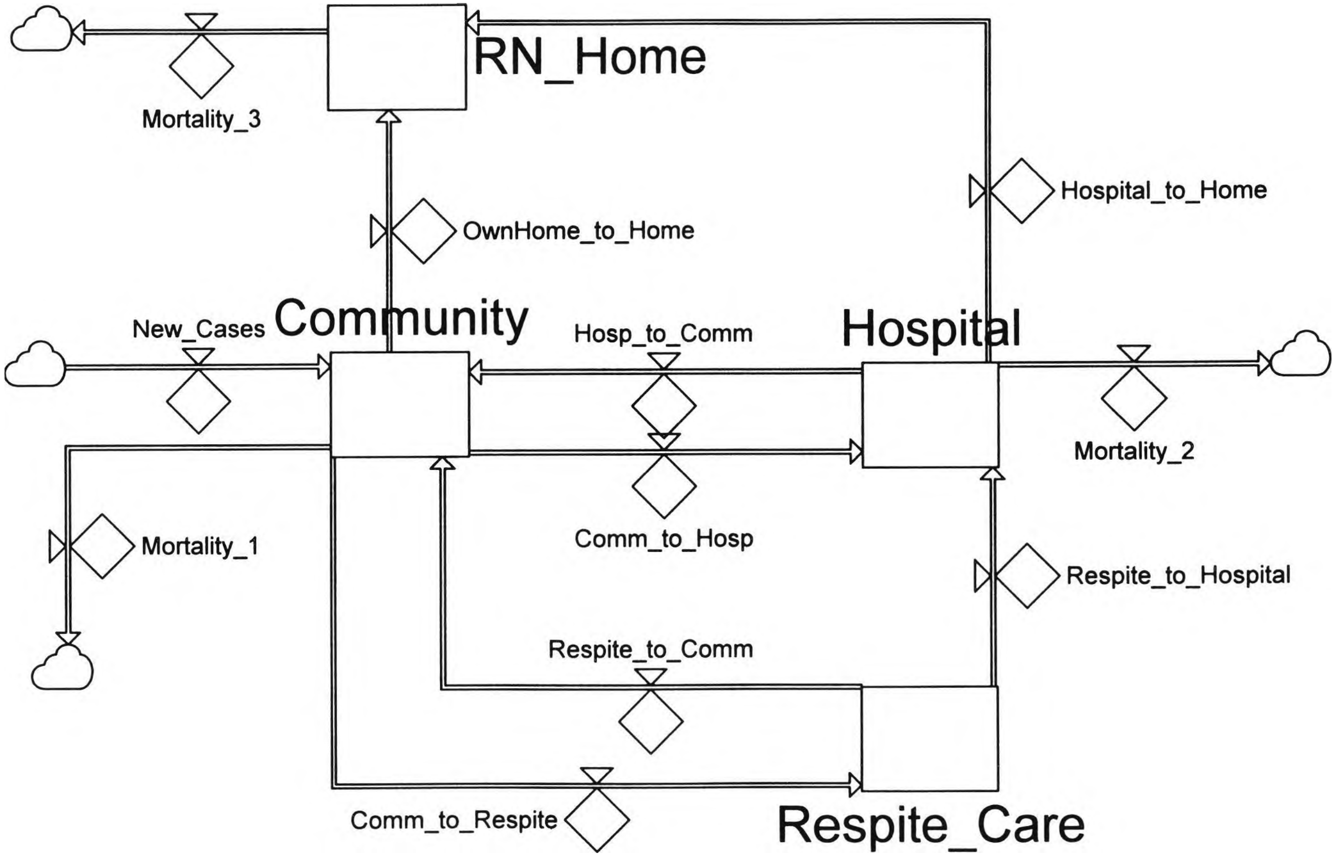

Figure 8.4: First System Dynamics Model

Building the model required making assumptions which are not immediately apparent in Figure 8.4. The model was designed so that the numbers of people in each of the states remained largely constant over the year. The only change is in the numbers of people living in their own homes, which rises slightly from 200 to 205 (or 2.5% over the year): this is a notional figure used to drive the model. The figure for entry to the system was difficult to estimate accurately in practice: as noted in Chapter 3, even careful epidemiological studies have produced a range of estimates. The estimate was therefore based on the subjective judgements of the hospital consultants.

It is also important to recognise that Figure 8.4 represents a particular interpretation of what happened - that the system is almost in equilibrium, with the only departure from equilibrium being a slight rise in the numbers of people assumed to have dementia living in their own homes. This conscious building in of assumptions about the behaviour of the system emphasises the point - made in Chapter 5 - that the model can be used to provide partial insights into the dynamics of the domain, but does not in any sense represent external reality.

These comments notwithstanding, the model confirms some of the observations made in earlier chapters, including:

- People enter residential and nursing homes and do not leave them to return to the community;
- Both hospital and residential/nursing homes are important in the institutional care 'equation', so that focusing on homes alone reveals only part of the picture.

8.5 Development Of The Model

8.5.1 A Partial Model

The next step was to refine Figure 8.4 to explore the domain. In order to do this it was necessary to change one or more rates and observe the change in the states. This meant that the completely specified model had to be changed so that the rates and states were linked by equations rather than absolute numbers: in other words, it was necessary to develop a conventional System Dynamics model.

Figure 8.5 shows the first stage in the development of the model. This includes the information system noted in Section 8.3. The Figure shows one part of the model, representing movements into and out of an institution, where the rates are admission and mortality rates. The information system specifies the relationships between rates and states. Its key feature is a feedback loop linking the numbers of places occupied to the admission rate.

Features of the model include:

- The admission rate is influenced both the number of places occupied and the numbers of people applying for them;
- If the number of applications (assumed to be eligible for admission) is smaller than the numbers of places then the level will fall;
- There is a maximum number of places - the capacity of the system;
- If applications exceed places then the level rises to a maximum, beyond which the application rate must fall.

This partial model was used to test the underlying logic of the system. For example, if the admission rate and mortality rate were set to be the same, the level of the state (number of places taken) should stay the same throughout a simulation run. If, instead, the application rate was set high, so that there were more applicants than places, the level of the state should

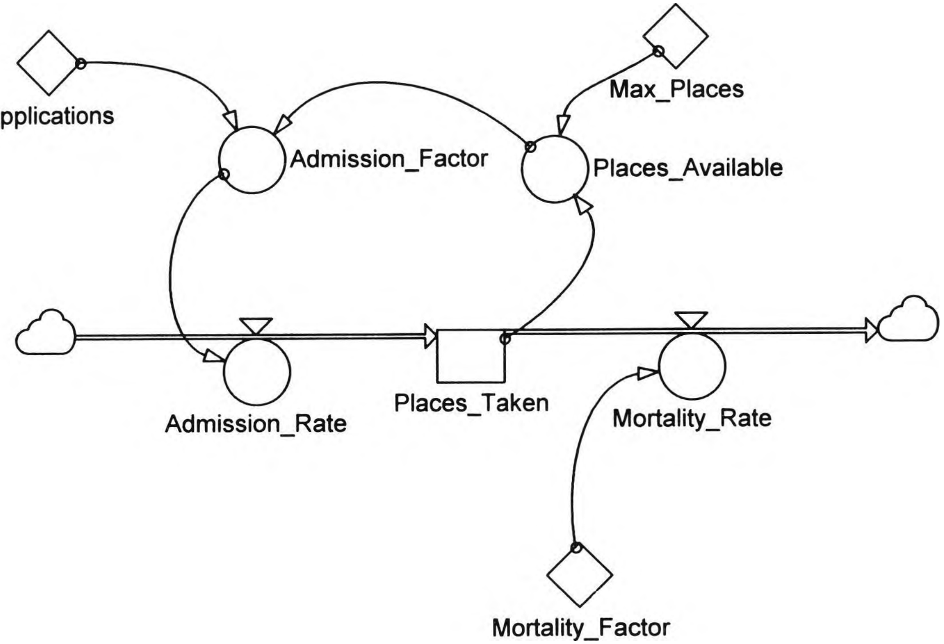

Figure 8.5: First Stage Of The Full Model

rise to the maximum and then stop increasing. These tests were run and the model validated.

8.5.2 The Whole Model

Figure 8.6 shows the complete System Dynamics model for Kirklees, including both the resource flows and the information system. It includes two information feedback loops which control the rate of movement between community and institutional environments. The RH (residential home) admission factor influences both routes into a home, from community and hospital, so that the two routes are co-ordinated with one another. The two-way flows of Figure 8.4 have been replaced with a single, net flow.

The model is simple in nature. The number of rates and states is small compared to models published elsewhere, including Wolstenholme's own models of community care (Wolstenholme, 1993; Wolstenholme and Crook, 1997). The 'respite care' state from Figure 8.4 is omitted as marginal to the modelling: this is not strictly true in practice, since Figure 8.4 shows that people do in fact enter hospital from respite care, but it seems reasonable to aggregate this route with the community-to-hospital route. Thus the state has been omitted, but the rate of movement into hospital reflects all routes into it.

Figure 8.7 is similar to Figure 8.6, but shows the dynamic behaviour of the model. There are 80 places available in both homes and in the hospital. The current occupancy of the homes is set - arbitrarily - at 60 places to show change over time. The numbers of people in the community starts at 400 and is set so as to rise at 2.5% per cycle - reflecting the figure given for annual changes in the numbers of people with dementia earlier in the chapter. The numbers of applications for places in both home and hospital is - also arbitrarily - set at a low rate (2 per cycle).

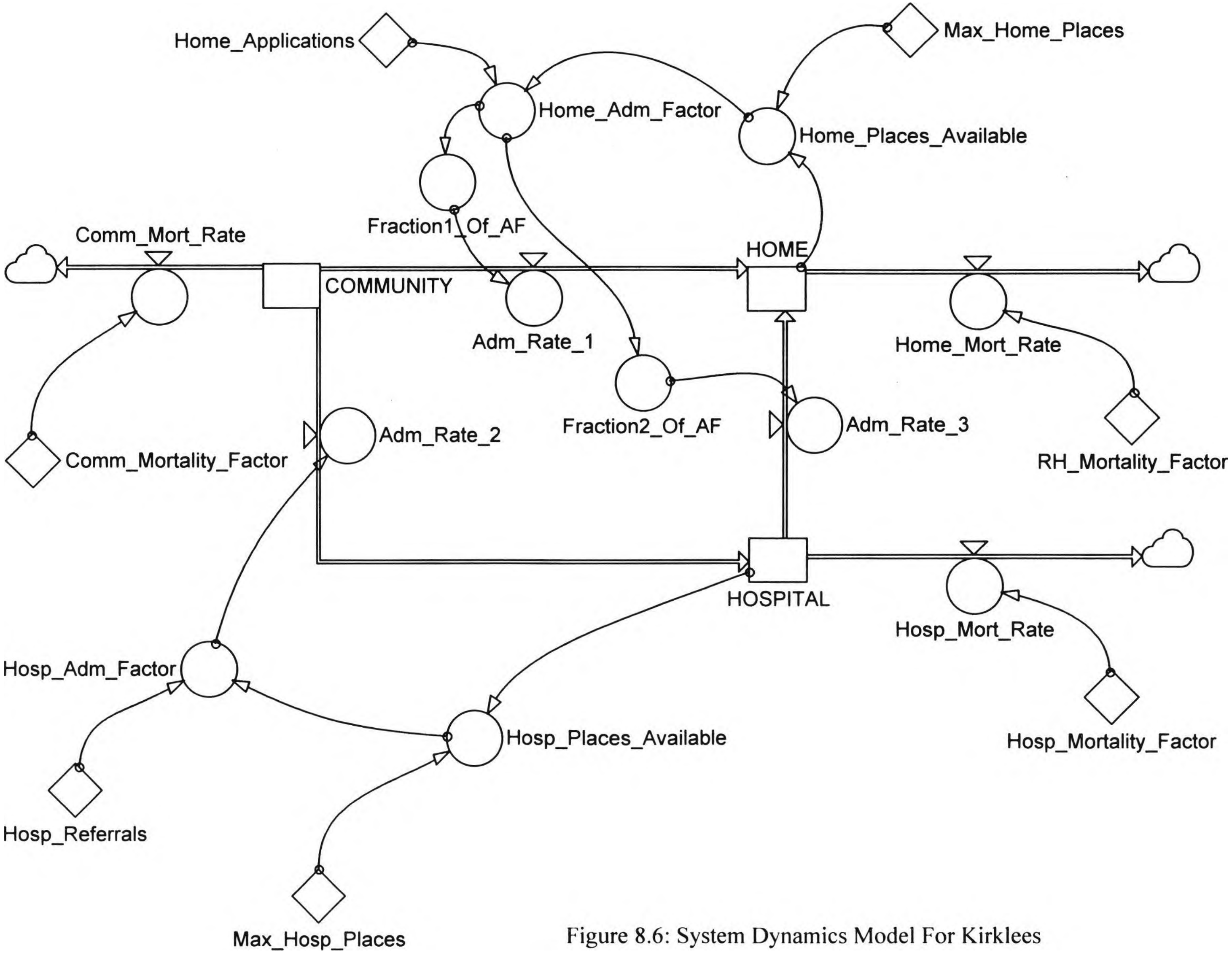

Figure 8.6: System Dynamics Model For Kirklees

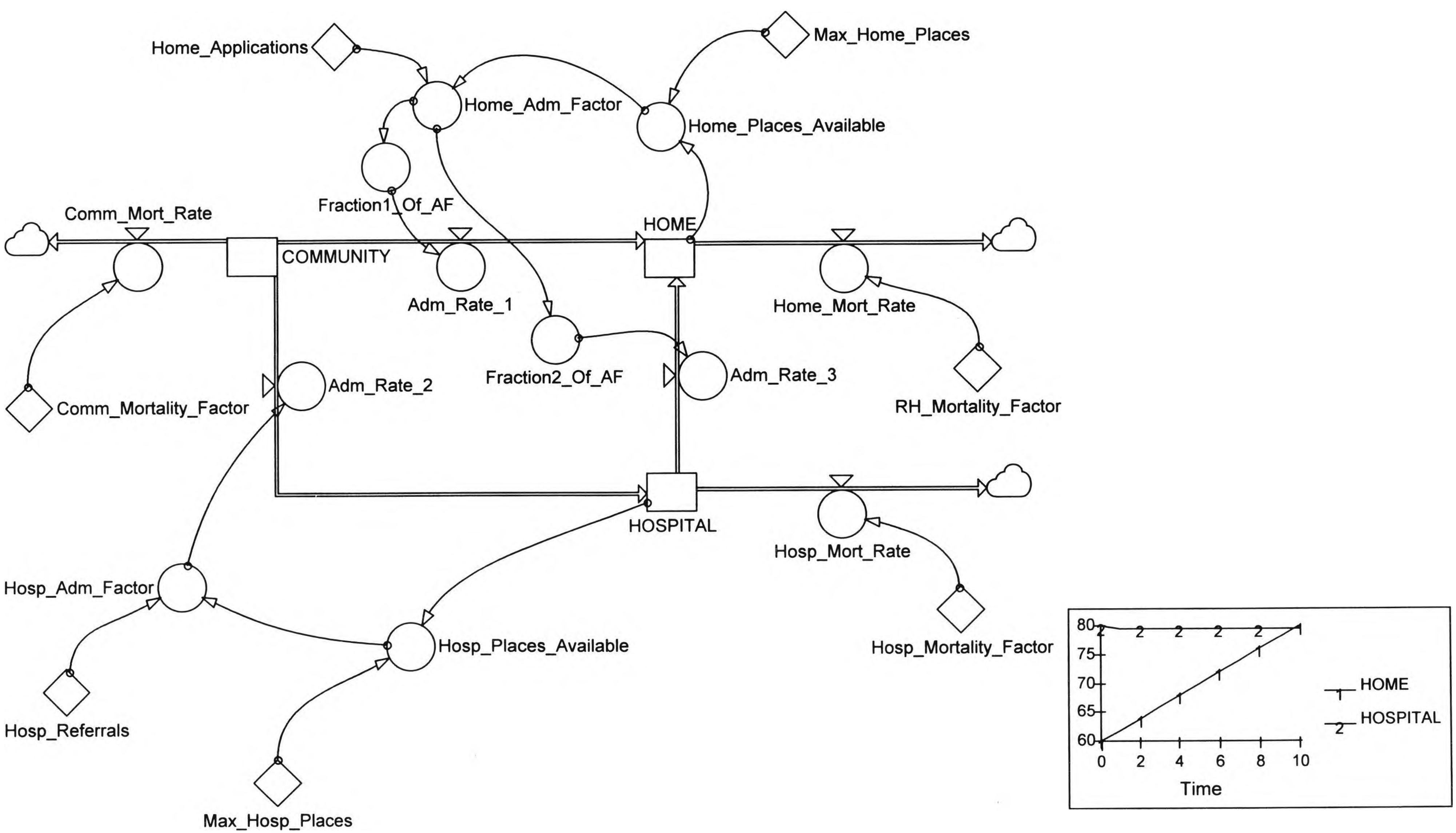

Figure 8.7: Dynamic Behaviour Of The Model

The system runs for 10 cycles: this can be thought of as a period of ten years. Over this period the number of places taken in homes rises to the maximum of 80, while the number of places in hospital drops fractionally. Though the drop would not be significant in practice, the fact that there is a change indicates the interactions occurring in the model. More importantly, perhaps, the model can be shown to replicate the behaviour of Figure 8.4.

8.5.3 Simulation

The next step is to change the features of the model to reflect possible changes in the domain itself. Consultation with professionals and managers in Kirklees suggested that two changes were probable: an increase in the numbers of places available to people with dementia in homes, and a reduction in the number of hospital places.

Figure 8.8 shows the results of increasing the numbers of places in homes by 50%, from 80 to 120, and an increase in applications to 20 per cycle, while keeping all other features of the model constant. This is intended to capture the idea of an increase in availability of places leading to an increase in the number of applications. (In principle it is possible to write an equation for the relationship between available places and rate of applications, but in practice there are no data that allow one to write the equation. Hence the 'manual' approach was deemed appropriate here.) The graphs show that as the new places are filled, there is drop in the numbers of people with dementia living in the community. Once the places are filled, numbers in the community begin to climb again.

Figure 8.9 shows what might happen if the number of places in hospital were to be reduced - this has actually happened in Kirklees - all other things being equal. The result is that the numbers of people with dementia living in the community rises, from 405 in Figure 8.7 to 425 in Figure 8.9.

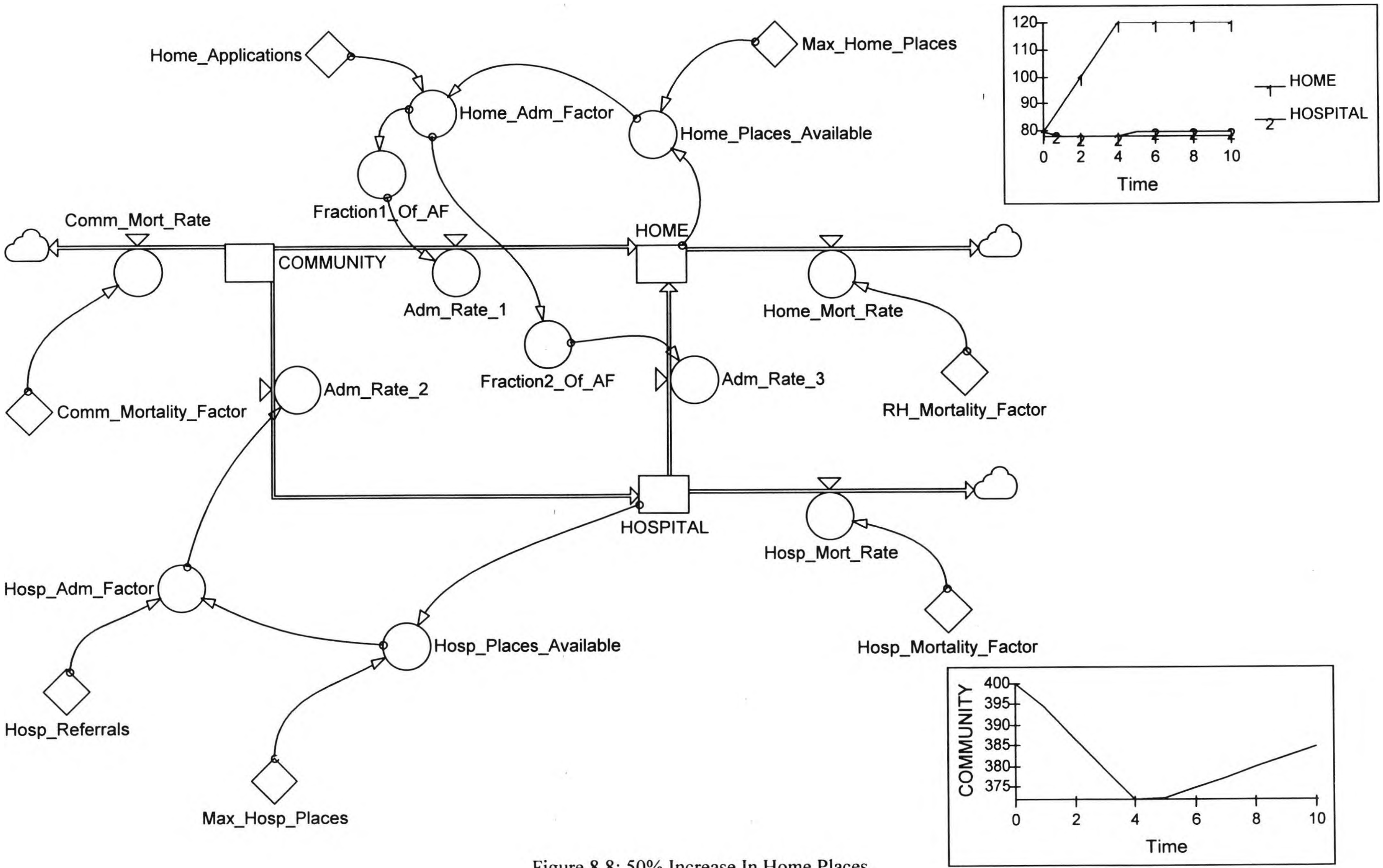

Figure 8.8: 50% Increase In Home Places

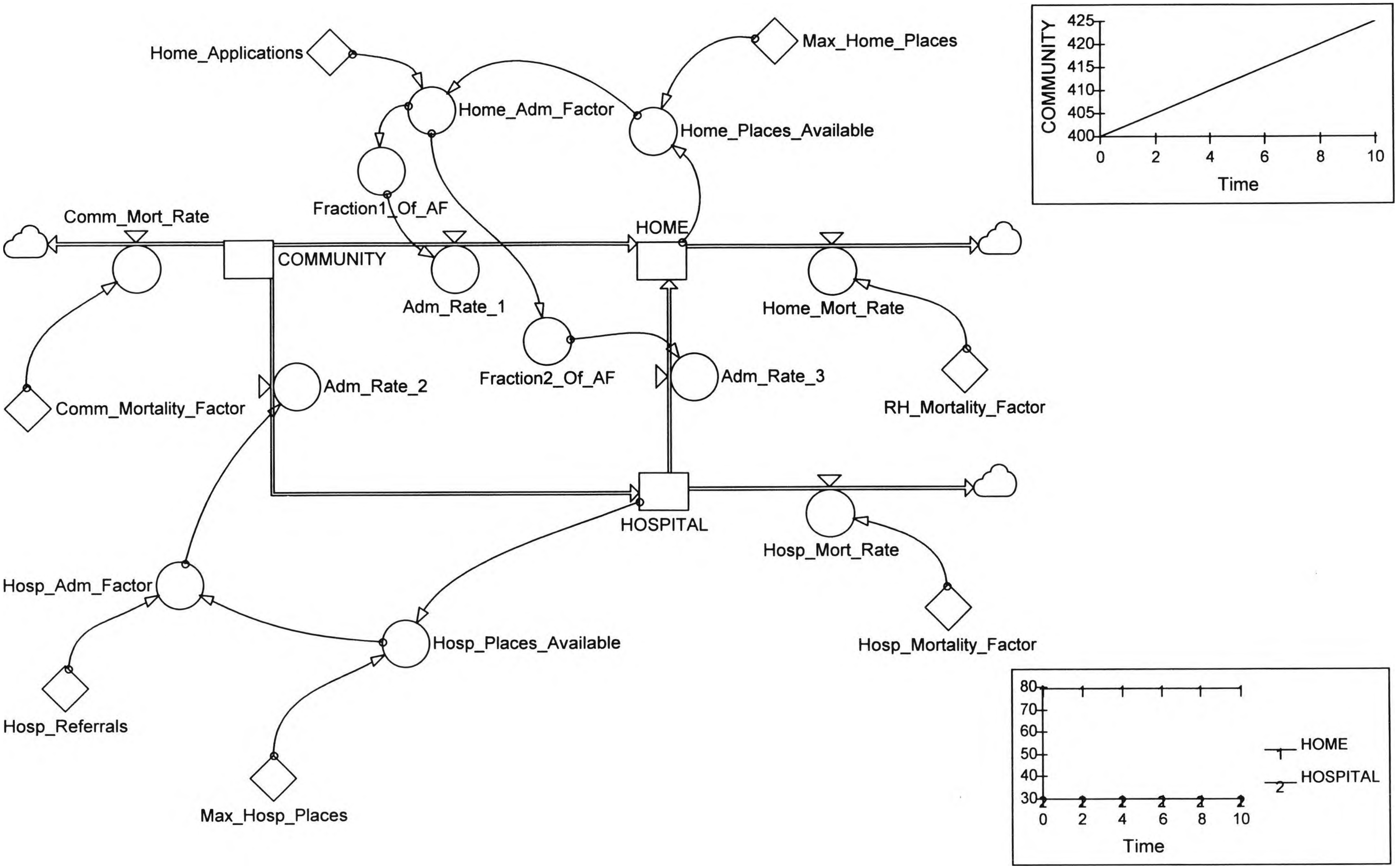

Figure 8.9: Reduction Of Hospital Places

8.6 Conclusions

The models presented in this chapter provide insights into the effects of service capacity on the domain. Two key points can be made. The first is that the model developed is stable over a wide range of assumptions: changing states does not lead to chaotic behaviour.

The second point is that there is a simple relationship between the numbers of people in the community and in institutions. Now that the rate of increase in people with dementia in the population is relatively modest, as shown in Chapter 3, it appears that the current system, with all its imperfections, may cope with demand in the short term. This said, given that NHS and social services budgets are currently tight and hospital places are falling, combined with the increase in prevalence of dementia, will place ever-increasing strains on a system that already appears to be under-resourced.

Looking forward, there are two broad scenarios that might be expected to affect the system:

- A large increase in demand, which might occur if there is substantial unmet need, which begins to drain resources. Lewis and Glennerster (1996) suggest that, so far, the community care reforms have not stimulated a substantial increase in demand;
- A breakthrough in treatment, which would reduce the demand for institutional provision. This is possible, but does not seem likely in the next few years.

In the absence of either of these, and assuming that the assumptions built into the models are plausible, the system may well survive in its current form for some time to come.

It is also worth reflecting on the differences between the models presented here and those developed by Wolstenholme. The key difference lies in the treatment of resources. Wolstenholme assumes that it is possible to model financial resource flows, whereas the arguments presented in this thesis (including the Appendix) suggest that this is not the case: these flows are not at all well understood. The approach taken here has been to model resource constraints by incorporating upper limits to the numbers of places in hospital and homes. This does not provide insights into the financial implications of changing policies in the domain, but does show how resource constraints may affect patterns of service delivery.

CHAPTER 9

FLEXIBILITY

9.1 Introduction

The empirical investigations of the last three chapters were designed to satisfy the first two objectives of the thesis, being concerned with understanding the nature of the domain and the extent to which systems science methodologies could be used to enhance that understanding. The focus of the thesis now moves onto the third of the three objectives identified in Chapter 1, and explores the impact of two key concepts embedded in current community care policies, flexibility and collaboration.

Community care policies, which were outlined in Chapter 4, propose substantial changes in the structure and financing of community-based services. The policies have several distinct aims, prominent among which are increased consumer choice, a shift from institutional to community-based services and the introduction of a mixed economy of care. These are to be achieved over a period of years in an evolutionary fashion, and the ramifications of the new framework are as yet unclear. (It is also possible that the new Labour government will introduce further changes, thoguh at the time of writing it has not indicated its intentions.) So while it is possible to paint a general picture of developments, many fundamental questions remain, both for the academic and the practitioner. Individual health and social service organisations have to deal with uncertainty in the development of their community care strategies, and in particular balance short-term pressures on resources for existing services with the long-term shift to new ways of working. Two possible organisational responses to this uncertainty are the creation and exploitation of flexibility, and collaboration; the latter is discussed in Chapter 10.

The treatment of these concepts is mainly theoretical, the purpose being to inform discussions of different approaches to understanding the domain in Chapter 11 - though this chapter and the next do draw on some of the evidence presented in Chapters 6-8. The key to the approach is the identification of specific systemic characteristics of the domain which appear to be important. In this context, a characteristic is important if it can be manifested in different ways in different settings, and those differences can lead to substantial differences in process or performance. This approach has been used by some authors in systems science and operational research, though relatively seldom. It is more often used in management science, in situations where authors are seeking to understand particular aspects of organisations, and phenomena such as co-ordination and control are operationalised as quantitative variables (Sharfman and Dean, 1997).

Some authors, however, use a different approach, where they focus on specific characteristics but collect data about them and interpret it qualitatively (Sharma, 1997; Uzzi, 1997). That is the approach used here and in the next chapter. It should be noted that other choices were available here, notably the possibility of using ideas drawn from organisation theory, such as Mintzberg's (1983, 1989) ideas on organisation and management, Simon's (1982) concept of bounded rationality and Linblom's concept of 'muddling through (Linblom, 1959; Lindblom and Cohen, 1979). It was felt that the domain was not yet sufficiently well understood from a systems point of view to allow use of a general theoretical framework with any great confidence. This more general theoretical approach may well, however, pay dividends if used in the domain in the future.

The next section of this chapter notes the perceived importance of flexibility in community care policies. Then, the nature of flexibility is investigated: the literature is large but fragmented, with various definitions and conceptualisations, and key references relevant to the domain are identified.

A way of synthesising some of the interpretations of flexibility is proposed. The last part of the chapter discusses the extent to which flexibility is desirable and attainable in services for people with dementia and their carers.

9.2 Flexibility In Community Care Policies

In the report which presaged the new legislation, Sir Roy Griffiths (1988) set out a broad, long-term framework for the development of community care, focusing on new financing mechanisms and more generally on the creation of clear incentive structures to shape service delivery. Sir Roy's framework was endorsed by the government in Caring for People and related guidance, though the latter tended to focus on short- rather than long-term issues (Davies, 1993). Two particular issues were left unresolved, namely how to deal with the uncertainties new ways of working were bound to bring, and how to balance short- and long-term pressures on resources.

An important clue about the resolution of these issues can be found in the government's response. In its view, community care required services which, "respond flexibly and sensitively to the needs of individuals and their carers" (Secretaries of State, 1989: page 5). Traditional bureaucracies delivering standardised services were to be transformed into more consumer-oriented organisations: this and other new service characteristics will require flexibility in service delivery. Flexibility may, then, be an important determinant of the success of community care in general and the performance of services in the domain, and in turn analysis of the way in which flexibility might operate in the domain might provide insights into the likely success of current policies.

This issue does not appear to have been explored by empirical researchers or policy analysts. Indeed, they (for example Challis et al., 1995; Lewis and Glennerster, 1995) use the term freely, without defining it - it is assumed that flexibility is a desirable property of health and social services. This may be the case, given the precedents of inflexible and badly managed services: but it is worth exploring the concept in greater depth.

9.3 Types Of Uncertainty

In a management context, the term flexibility is generally used to describe the ability to do something other than that which was originally intended (Evans, 1991). Marschak and Nelson (1962) argued that one position was more flexible than another if it left open a larger set of future positions than the other. Implicit in these definitions is the notion that flexibility is desirable in conditions of uncertainty, and Mascenharas (1981) proposed that low flexibility was appropriate in stable environments, whereas high flexibility is appropriate in unstable or highly uncertain environments. Accordingly, this discussion starts with consideration of the types of uncertainty present in the domain.

The empirical evidence presented in earlier chapters suggests that there are three distinct types of uncertainty that strategies for services within the domain must address. Each one reflects a particular order of future uncertainty. The first is the uncertainty surrounding the achievement of specific goals. Some objectives within the domain can be specified, and the purpose of a strategy is to work out how to achieve them. An example here would be reduction of the number of long-stay NHS beds in a locality. The characteristics of such a service can be planned, and risks of failure - such as difficulty of relocating staff, or community-based services proving more expensive than expected - identified. The uncertainty lies only in the extent to which a clear plan can be realised in practice.

The second type of uncertainty occurs when specific goals can not be specified, though the general direction of strategy can (see Rosenhead, 1989). The domain is in a state of flux, though is not in any sense chaotic.

Community care policies are explicitly developmental in nature, and so long-term goals are difficult to specify: local goals will be general rather than specific in nature (see Lewis and Glennerster, 1996). For example, purchasers are charged with becoming enablers of services, but the precise nature of the enabling role and its consequences for relationships with providers and the services they deliver is only emerging over time. There is also uncertainty surrounding the most appropriate trade-offs between the various objectives of community care, which will be in competition with one another and so likely to be realised to different degrees. Health and social services organisations must nevertheless make progress towards these general objectives.

The third type of uncertainty occurs where uncertainty about the future is very high and the value of planning is called into question. It can also occur when 'the market decides', where markets replace organisations (Knapp et al., 1993). While community care does not aspire to the ideal of the perfect market, market-like activities may render some planning processes redundant. Further, Harrison et al. (1994) point out that one source of chaos in the NHS in the last few years has been the government's changing political agenda. At different times the government has promoted competition, then sought to limit perceived adverse outcomes of competition, promoted performance measures such as the Efficiency Index and the Patient's Charter, and so on. The rapidly changing objectives make it difficult for purchasers and providers to know where to focus their efforts. Harrison and colleagues argue that this has created the 'wrong kind of chaos', since purchasers and providers have little chance of influencing or exploiting it. They state that:

> ".. our analysis suggests that innovation and patient responsiveness are of little relevance in keeping government satisfied, while empowerment and decentralisation may be a positive handicap, and the kind of performance measurement systems which are

> appropriate on one day may not be on the next." (Harrison et al., 1994: pages 45-6)

This situation, if replicated in community care, makes planning for uncertainty problematic. The sensible response might in principle be to wait for the government to move and then act, though this might only lead to paralysis. This raises questions about the nature of strategies which will take account of these different types of uncertainty.

9.4 Balancing Short- And Long-Term Considerations

Another issue noted above concerns the balancing of short- and long-term pressures on resources. In any public sector policy, where resources are scarce, there will always be a danger that immediate problems will crowd out longer term considerations. Further, decisions made now may 'lock in' services to undesirable patterns in the longer term. This tendency might be explained, in part, by the uncertainty just referred to, since it is easier for people to focus on clearly defined short-term issues rather than the genuinely difficult task of judging future trends in policy and practice. Unsurprisingly, in the face of a very long and difficult agenda, many NHS and social service providers have focused on immediate details of the new financing arrangements that affect the maintenance of current services, and on getting new structures for purchasing, joint working and so on in place. Nevertheless, decision-makers have to attempt to make sensible decisions about the future patterns of service delivery. One way of doing this is to examine the extent to which different strategies keep desirable options open or close them off - that is, the extent to which they retain flexibility.

The term flexibility is used in many different literatures to describe a desirable property of systems and organisations. As will be shown below, there is broad agreement that flexibility is: an intrinsic property of a system; a multi-dimensional concept; and is a crucial element of an organisation's response to uncertainty. However, it is also clear that the nature of flexibility remains elusive. This is not to say, though, that it is beyond definition, and what follows here is one possible way of characterising flexibility. The literature has two major strands: those papers which focus on flexibility as a strategic issue; and those which treat it in operational terms, notably in the context of flexible manufacturing systems.

	Defensive	*Aggressive*
Internal	**Internal-defensive**	**Internal-aggressive**
External	External-defensive	External-aggressive

Table 9.1
Ansoff's classification
Source: Ansoff (1984)

9.5 Flexibility As Strategy

Many authors who have discussed flexibility as a strategic issue have focused on the link between flexibility and uncertainty, and in so doing have identified a number of possible strategies for dealing with environmental uncertainty. For example, Ansoff (1984) provides a simple classification (Table 9.1) of internal/external and defensive/aggressive strategies. However, the classification does not, of itself, help to clarify the nature of flexibility: rather, it suggests what to do with it when it is available.

Three papers serve to illustrate insights from the literature about strategic flexibility. The first is by Carlsson (1989), who presents an account broadly similar to the earlier identification of three types of uncertainty, but operating over three different timescales. Carlsson identified:

- Operational flexibility (short term), where changes are made to operational procedures, particularly enabling rapid responses to external changes;
- Tactical flexibility (medium term), where flexibility is 'built into' processes; and,
- Strategic flexibility (long term), which is the ability of an organisation to reposition or reshape itself.

The importance of the time dimension is emphasised, as is the insight that responses over different time periods require different types of action at different levels of an organisation.

The second paper is by Mascenharas (1981), who related flexibility to the nature of the external environment. He argued that:

- In stable environments flexibility is not a priority, and specialisation and standardisation should be pursued;
- In unstable environments flexibility is a high priority and should be incorporated into operations; and,
- Where stability varies over time, organisations' strategies should also vary.

Mascenharas draws attention to the concept that flexibility is not necessarily inherently desirable, but should be optimised according to external circumstances.

The third paper is by Evans (1991), who developed a framework based on the temporal and intentional dimensions of flexibility (Table 9.2), arguing that organisations adopt strategies which incorporate flexibility, with the nature of the flexibility depending on the nature of the opportunities and threats in their external environments. Evans also links general strategies (eg. offensive/defensive) with specific *types* of flexibility. For example, a firm that adopts a defensive posture and elects to respond to events as they occur may decide to keep key assets liquid or maintain 'elasticity' in structures and processes.

	Ex ante	**Ex post**
Offence	Agility	Liquidity
	Versatility	Elasticity
Defence	Robustness	Corrigibility
	Hedging	Resilience

Table 9.2
Flexibility: Strategic Dimensions
Source: Evans (1991)

Type of uncertainty	**Strategic objectives**	**Flexibility dimension**
Market acceptance of kinds of products	Diverse Product Line	Mix
Length of product life cycles	Product Innovation	Changeover
Specific product characteristics	Responsiveness to customer specifications	Modification
Aggregate product demand	Market Share	Volume
Machine downtime	Customers' Due Dates	Rerouting
Characteristics of materials	Product Quality	Material
Changes in the above uncertainties	Strategic Adaptability	Flexibility, Responsiveness

Table 9.3
Dimensions Of Flexibility
Source: Gerwin (1992)

Taken together, these three representative papers suggest that flexibility may be an important characteristic to possess in uncertain environments. They emphasise the importance of the time dimension, and the fact that organisations should decide to what extent flexibility is desirable in a particular environment. All of this leaves open, though, the question of what flexibility actually means in practice: that is, what internal structures or processes are consistent with particular strategies.

9.6 Flexibility As Action

The literature on flexibility which deals with internal processes points to the importance of two dimensions, time and range. Perhaps the most complete account is by Gerwin (1992), who identified a number of dimensions of flexibility (Table 9.3), and pointed out that most of the literature focused on the time periods and ranges of operations over which organisations respond to actual or anticipated events.

For an organisation to be flexible it must respond within an appropriate timescale. If an organisation responds too slowly then opportunities are missed or it risks being unable to respond to a threat. The other dimension is range of responses, which is not explicitly defined by Gerwin, though his meaning is clear - it is concerned with the *nature and scope* of a plan for, or response to, a change in the environment.

The flexibility dimensions listed in Table 9.3 include examples of actions that organisations can take. It is possible to link the different examples together by identifying the variables that are affected by each action. If one thinks, for a moment, of a manufacturing process then rerouting and changeovers in production can be described in terms of the *volume* and *mix* of parts or products involved. Modification of a product involves either change in the *internal relationships* between existing components or the use of a new *mixture* of components, or both. Further, the relationship between the elements used or produced is also crucial. Range can therefore be expressed as a function of volume, mix and internal relationships. Flexibility can be expressed in terms of four dimensions: time, volume, mix and internal relationships.

The identification of these four dimensions is not, in itself, sufficient to characterise flexibility, even for well defined manufacturing processes. The dimensions can, after all, be used as a general framework for describing many processes. The essence of flexibility is that there are changes along *at least two dimensions*. In practice most changes will take place over a period of time, suggesting that flexibility involves the capacity to change along the time and range dimensions at the same time. This interpretation is consistent with Gerwin's observations about range and time - it refine's Gerwin's framework.

Given that particular situations require specific responses, a flexible response will be reflected in changes along different combinations of dimensions at different times. Decisions about which response is most appropriate in a particular situation will involve *trade-offs* among the four dimensions: so flexibility is the capacity to make different trade-offs in response to changing circumstances.

The use of four dimensions is open to charges of over-simplification. In the domain in this thesis, the extent to which a particular service is flexible will be influenced by the willingness of service providers to keep options open for people with dementia and their carers, by the limitations on co-ordination due to information problems (Sharma, 1997), and by the resources available to allow pursuit of desirable options. These and other factors will influence the extent to which it is possible to make trade-offs along the four dimensions.

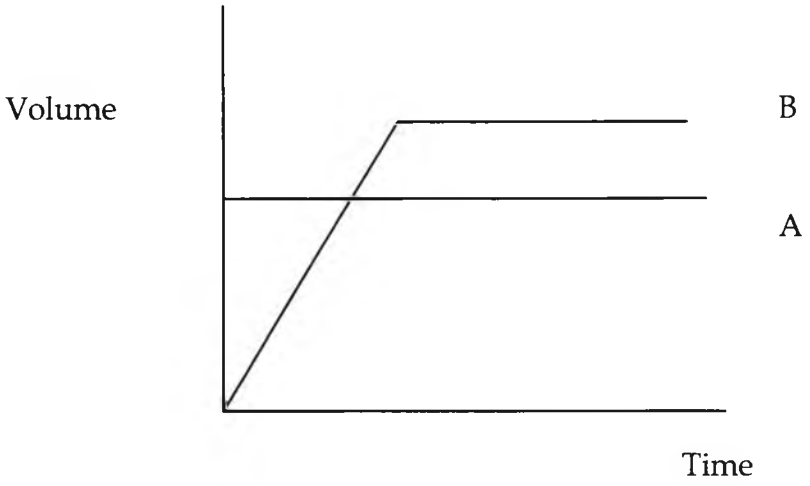

Figure 9.1
Concept Of Flexibility Trade-Offs Along Two Dimensions
(in this case volume and time)

A. Constant volume of service over time
B. Quantity of service provided increases over time, up to a resource-constrained maximum

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Figure 9.1 shows the simplest example, a trade-off along two dimensions. Imagine designing a service package for a person with dementia. Evidence from earlier chapters suggests that services can stay constant over a period of time, or tend to increase up to a resource-constrained maximum. In principle, the options available for constructing the package of care include all of the points on the graph below lines A or B, depending on the initial quantity of service provided and the rate of increase in service needs of the person with dementia and the carer. This point is discussed in the next section.

9.7 The Costs Of Flexibility

Flexibility must in practice be balanced against the costs of achieving flexible structures and processes. Indeed, many authors (including Marschak and Nelson, 1962; Sharma, 1997) stress the trade-off between flexibility and costs. This trade-off with costs emphasises that flexibility is not a discrete, ever-desirable property; it will be more or less valuable depending on the circumstances. To take a simple example, one response to increasing demand for admissions to nursing homes would be to provide as many places as necessary, so that a client could enter at any time. (Indeed, the rise in the number of nursing home places suggests that there has been a tendency in this direction.) From a consumer's point of view this appears to offer real choice between nursing homes.

However, even if individuals contribute to costs, the total resources available within the system are in practice less than the total that might be wanted or needed. In the longer term allocation of more resources to nursing homes may or may not be desirable, since it ties up substantial resources in one type of service, and must close off other service options. Hence commitment of resources (by individuals or statutory agencies) increases flexibility in one potentially useful way but will reduce it in others. Rosenhead (1980a) and Jones and Ostroy (1984) both note the essentially simple relationship between cost and flexibility, where in general the more options are kept open the greater the total cost of keeping them open, either in terms of resources actually committed or reduction in performance. Put another way, and echoing one of the definitions given earlier, one position is more flexible than another if it leaves available a larger set of future options at any given level of cost.

It is worth noting that flexibility is a requisite for providing choice to users of services. The government's intention is that service users should be able to exercise choice, and assumes that services will become more responsive (as noted earlier in the chapter). That is, services should provide choice by providing a greater range of options - which can be conceived in cybernetic terms as greater requisite variety, or as greater flexibility. Because Caring for People (Secretaries of State, 1989) is more a framework document than a detailed set of proposals, it does not specify the nature or extent of flexibility that might be appropriate. In practice, flexibility - and hence choice - in the domain must be limited by the resources available. The resource constraints make it especially important to analyse how resources should be allocated.

In the domain, then, with the direction of long-term developments unclear, a key task is to identify which options can or should be kept open and the financial consequences of keeping them open.

9.8 Keeping Options Open In The Domain

At this point it is worth briefly recapping the arguments made. In essence these are that flexibility is concerned with keeping options open, that one can think about flexibility both in strategic terms and in terms of the ways in which it affects the design of services, and the extent to which flexible services can be provided must be constrained by available resources.

It is now possible to turn to the domain. Two issues need to be considered, namely which options should be kept open, and what strategies can or should be employed to keep them open. From the perspective of an individual with dementia, the main options that need to be kept open are clear from earlier chapters: the possibility of remaining in the community, and entry to a residential/nursing home or hospital. Important secondary options within community care include access to domiciliary, respite and other services for individuals and carers. It was, however, shown in earlier chapters that options are limited in practice through routinisation of professionals' referral decisions and other factors such as availability of places in particular homes. (As Lewis and Glennerster (1996) pointed out, the government explicitly sought to reduce the availability of residential/nursing home places.) The range of available options is therefore smaller in practice than people with dementia and their carers might wish. The fact that many local authorities now charge for some community-based services further reduces the options for some people, if they cannot afford the charges. There is therefore a contradiction at the heart of current policies, which on the face of it seek to increase choice - and keep options open - yet in practice reduce them.

In the terms of the framework presented above, the available options represent trade-offs between the volume of services provided, the local organisational arrangements used, and the costs of the different services. Given the government's desire to reduce its own expenditure on community care, the trade-off will in practice be one between volume and organisation, with constant or declining resources. The only way that some options can be opened up is for people with dementia or their families to opem them by paying for them themselves. This was largely reflected in the case study site, where professionals were in practice making decisions about support for individuals against a background of knowledge of available resources - the issue reduced to a (short-term) trade-off of cost and quantity, with organisational (long-term) form not impinging on local thinking.

This leads into the second issue, which concerns the strategies that are - or might be - employed to keep options open. Returning to Evans's (1991) classification (Table 9.2), providers of services may elect to anticipate events (*ex ante* actions) or may react to them (*ex post*). Services for people with dementia currently exhibit a mix of the two, with the joint planning of services representing a genuine attempt to anticipate demand, but many services being of necessity reactive. Thus the hospital service has to react as new cases arise, and the whole system has to react to changes in local and national community care policies. (This contrasts with other certain other health and social services, where numbers can be predicted with reasonable certainty and policies are not subject to major change in short timescales, such as maternity services or some elective surgical procedures.)

In supporting people with dementia during the period when entry to institutional care is deemed possible, the objective of the team is to keep options open that would otherwise be closed. That is, entry to an institution may be avoided, and hence options that involve staying in one's own home are kept open. An important point here is that keeping options open can be achieved at the financial and/or physical and emotional expense of carers, whose own options are simultaneously reduced. This is a point that seems not to be recognised in the literature: incresing one person's options may reduce others'. Flexibility is generally treated as something that can be observed from a single perspective - but in the domain this is not possible. There is therefore yet another trade-off to be made, between the options available to the different parties involved - though particularly the person with dementia and the carer.

Analysis of flexibility in the domain offers a further observation here: it may lead to changes in the nature of the organisational designs that are deemed desirable, when compared with models deemed desirable for a relatively predictable world. It is conceivable that models should be inherently flexible: that is, they should allow for responses to unpredicted events at any time. In other cases it will not be possible or desirable to be able to respond at any time, not least if the appropriate arrangements are too costly.

It is interesting to note here that the study by Challis et al. (1995), along with other studies by the Personal Social Services Research Unit, do appear to increase the range of options available to elderly mentally ill people, since care management increased the likelihood that people would remain in the community, and thus eligible for a range of community-based services. But the work of von Abendorff et al. (1994) suggested that the same cannot be said of care management for people with dementia. In terms of the framework presented above, it seems that care management for people with dementia:

- Does not affect the costs of service provision;
- Does not influence the likelihood of admission to institutional care.

In short care management, where the pilot sites - admittedly for other groups of elderly people - are clearly effective, seems not to influence the range of options available. So, in the domain it is not clear what organisational forms, if any, might maintain or increase their options.

This section highlights the complexity of the task - the trading-off along several dimensions - of making decisions about formal services for people with dementia. If resources were plentiful then perhaps it would not be necessary to worry too much about these trade-offs: options could be kept open and pursued as necessary, in response to individual needs. But the thrust of the arguments here is that many decisions seem bound to be resource- rather than needs-led.

9.9 Conclusions

It was argued in Chapter 5 that VSM represented a useful approach to modelling of organisation processes, as long as it was used as a way of thinking about organisations rather than as a template for real-world events. The analysis presented in this chapter focuses on a key problem in assumptions underpinning VSM - and other systems science approaches - namely that it is possible to optimise the design of a system. Instead, the most appropriate organisation design in the domain may be one that maximises flexibility - that is, one that keeps options open rather than optimises around one solution.

The domain is characterised by high uncertainty about the future pattern of services and by severely constrained resources. Providers of formal services might therefore respond in one of the following ways:

- Focus on short term problems at the expense of the long term, either because longer term developments cannot easily be predicted or resources are (perceived to be) too scarce or locked up in existing services;
- Provide short term 'quick response' services within an otherwise largely inflexible system;
- Develop an inherently flexible service - if such a service can be designed.

In terms of the four dimensions described earlier, a 'quick response' team that was used in times of crisis when entry to an institution was looming, might be used to keep options open by focusing on the time dimension. Another potential alternative, developing an inherently flexible service, would involve working out new trade-offs between time, service mix and internal relationships.

The empirical data presented in Chapters 6-8 does not provide direct evidence about the merits of different organisational models, although it is possible to imagine further work along the lines of the Markov Cohort in Chapter 7 that investigated the extent to which different models achieve particular objectives such as avoidance of institutionalisation. This chapter does, though, suggest that it is possible to understand the domain in terms of its capacity to respond flexibly to the demands placed upon it, and offers insights into the rationale for different organisational models within community care. The implications of flexibility will be discussed further in Chapter 11, in the overall model of the domain. First, however, it is necessary to turm to another organising principle for community care - collaboration.

CHAPTER 10

COLLABORATION

10.1 Introduction

In Chapter 9, a framework for the assessment of the flexibility of service delivery was presented. The point was made that flexibility is not always a desirable property of organisations, and the degree of flexibility must be tailored to the resources available and the nature of the environment in which the organisation operates. In the domain of interest in this thesis, it is also fair to say that any desired degree of flexibility can only be achieved through proper co-ordination of services.

In this chapter, a similar type of argument is developed to help understand the extent to which collaboration and co-ordination are desirable properties of the service delivery system in the domain. Like flexibility, collaboration is advanced here as an organising principle for the domain. The next section briefly outlines the distinction between the terms collaboration and co-ordination. The background to current policies designed to promote collaboration and co-ordination in community care are then discussed, and then applied to the domain. It is suggested that collaboration and co-ordination are useful organising concepts for thinking about the 'internal relationships' dimension of flexibility presented in Chapter 9.

10.2 Co-ordination, Co-operation And Collaboration

At its simplest, co-ordination is the process of alignment of one body's actions with those of others. Ovretveit (1993) and Nocon (1994) both observed that much of the literature on co-ordination defines it in terms of the organisational forms that can help to promote it, namely bureaucracies and markets. Bureaucracies have properties that are well captured in Beer's VSM (see Chapter 5), while co-ordination in markets is achieved through economic transactions between buyers and sellers - the market acts as a resource allocation mechanism. This is a classic dichotomy described in political and economic texts (see for example Coase, 1960; O. Williamson, 1985). Some authors have argued that the dichotomy is too simplistic, and there are other, distinct organisational forms such as 'clans' (Ouchi, 1980), 'fiefs' (Fairtlough, 1994) or 'associations' (Butler, 1983). This third form is characterised as network-like in nature (Flynn et al., 1996), and less formal in the nature of relationships between individuals and organisations. Control is diffused throughout the network or group.

The terms co-ordination and collaboration can and are used interchangeably, even by authors who have clearly thought carefully about them. Ovretveit (1993) provides a distinction that is useful in the context of this thesis:

- Co-ordination is the bringing together of parts to create a whole;
- Collaboration is joint action between two or more parties.

Thus co-ordination stresses the holistic nature of joint action, whereas the term collaboration stresses conceptually simpler bi- or multi-lateral arrangements. Co-ordination implies intentionality - there is a co-ordinating mechanism at work. Further, co-ordination is a general term, referring to relationships of many types including market transactions, whereas collaboration is used to describe non-market inter-personal and inter-organisational relationships.

There is a third term that might be used here, co-operation: it is the term favoured by game theorists, among others. As Axelrod (1990) notes, co-operative relationships can come about voluntarily or as a result of some external influence, such as the state intervening. Co-operation implies that parties act voluntarily in pursuit of some common objective. Here, collaboration seems to be the appropriate term to use for most of the following discussion: but as will be seen the differences in emphasis between the terms do matter in the domain.

Collaboration can usefully be thought of as a strategy for reducing uncertainty, through pooling of resources to allow a greater range of responses to unknown future events than a single party could manage alone. In practice it involves a range of types and strengths of relationship (Ovretveit, 1993). In the domain in this thesis collaboration is deemed to be desirable because it might in principle:

- Clarify roles and responsibilities in the organisation(s) involved;
- Avoid the isolation experienced by many community-based providers, and so contribute to higher morale;
- Help to avoid duplication and gaps in services;
- Thereby improve the efficiency and effectiveness of service delivery.

As noted in Chapter 4, community care has long been fragmented, and it is difficult to argue that better collaboration between service providers is a bad idea. Like flexibility, however, collaboration is not an end in itself and will only be useful insofar as it promotes better services for people with dementia and their carers.

Huxham (1993, 1996) has reviewed the circumstances under which collaborative working arrangements are likely to be successful, and found that factors such as shared values, trust, willingness to share available resources, and good inter-personal relationships are predictive of success. Her list emphasises how far collaboration is dependent on the people involved, and will not happen simply because it is part of a policy, however strenuously pursued.

10.3 Collaboration In Community Care

Like flexibility, the concept of collaboration - particularly between health and social services - was promoted by the government long before the publication of Caring for People. Traditionally, one of the obstacles to the delivery of appropriate community care services was the division between health and social services: this was discussed in Chapter 4. Yet health and local authorities had a statutory duty to collaborate - in what was termed joint planning - with one another in planning community care following the 1973 NHS Reorganisation Act, so the concept of collaborative planning has been current for over two decades now. From 1973 onwards there were attempts to promote collaboration through creation of joint financing mechanisms - the two sides would have to collaborate in order to allocate community care resources. But Wistow and colleagues (1990), who studied local responses to these policies, concluded that one side generally dominated the other, so that decisions were more unilateral than collaborative. Barriers to collaboration included professional cultures, different budgeting arrangements in health and social services, and different accountability arrangements - which lead to the two sides having different objectives. This confirmed a general picture of failure of local sites to respond to central directives on joint planning during the 1970's and 1980's (Nocon, 1994; Parker, 1988; Webb and Wistow, 1986).

These policies were directed at local authority level planning, rather than at the level of service provision. During the same period the government had also attempted to promote collaboration in service delivery, though rather more in the NHS than in social services, culminating in support of the early initiatives in care management (see Challis et al., 1995). (This was discussed in Chapter 4.)

In 1989 in Caring for People (Secretaries of State, 1989), the government argued that for community care to be successful, there must be collaboration at *both* levels, namely purchasing and service delivery. Thus a whole chapter was concerned with new arrangements for joint planning and financing of community care between NHS purchasers and local authority social services departments. Academic policy analysis suggested that purchasers and providers would be advised to establish long term collaborative relationships with one another, both within the health service (Robinson, 1994) and in community care (Knapp et al, 1993).

On the provider side, care management was endorsed as the preferred model - suggesting that co-ordination of services was to become the norm. As noted in Chapter 4, care management does not require horizontal co-ordination between service providers - a care manager acts as co-ordinator.

There were also to be new, formal arrangements for managing discharge from hospital. These were to be integrated with agreements on policies for the provision of residential/nursing home places. The precise nature of the arrangements was not spelled out - these were to be specified locally. As Lewis and Glennerster (1996) note, the government required health and local authorities to agree formally on procedures before they could receive special transition payments designed to help them change from the old arrangements to the new. Making the allocation of the transitional grant dependent on agreements appears to have acted as a stimulus to collaboration, and helped to overturn the history of failure of previous decades.

In summary, then, Caring for People promoted:

- Collaboration between health and social services in purchasing and in making formal arrangements for discharge from hospital and for planning of residential/nursing home provision;

- Co-ordination of service delivery, principally through the introduction of care management.

10.4 Collaboration In The Domain

At the end of Chapter 4 it was concluded, on the basis of the published literature, that there were three identifiable models of service delivery for people with dementia and their carers. These were:

- The 'traditional' fragmented model, with little collaboration evident;
- Care management, which formalised the care manager as co-ordinator of services;
- Team-based working, with referrals and case discussions between team members.

It remained to be seen, though, which of the models might be found in the domain. The evidence presented in Chapters 6 and 7 indicates that there was:

- Evidence of fragmentation, in the sense that the source of referral was a predictor of one year outcome - suggesting that GPs and social services personnel had different beliefs about the appropriateness of particular services;
- Care management had not, as yet, made an impact on the organisation of services;
- There were no formally constituted teams, though some evidence that there was good informal collaboration between some professionals, notably CPNs and social workers.

Was the situation found in the case study site the best that could be expected, or is more and better collaboration desirable? In simple terms, could care management or more team-based working improve outcomes for people with dementia and their carers? There is no direct evidence from the thesis that can be brought to bear on this question, but as in the last chapter on flexibility it is possible to use collaboration as an organising concept to explore the possibilities. Ideas drawn from systems science and economics are both used.

10.5 Collaboration And Networks

Community care policies since 1993 have been evolutionary in nature. Policy analysis has tended to focus on the market-hierarchy distinction (notably Knapp et al., 1994), or on careful descriptive work (such as Lewis and Glennerster, 1996). Here, a different approach is explored.

Increasingly, public services are delivered by heterogeneous sets of inter-related organisations spanning the public, private and voluntary sectors. This suggests that the key task is to understand the nature of new structures and processes. The task is aided considerably by a body of research and thought concerning the transformation of public administration (see Kaufmann, 1991; Kooiman, 1992). The central thrust of this literature is that the complexity of public administration has led to failures of traditional top-down, bureaucratic control. Organisations have responded by developing new forms and new ways of working. For example, there are examples of new lateral relationships, that is of coordinated or collaborative working; and new ways of achieving control of resource use from the top down. Kooiman observes that these new arrangements could all use the co- prefix: co-ordination, co-management of resources, etc. Some of this thinking was introduced in Chapter 5.

Community care is a striking example of this phenomenon, since it is clearly no longer bureaucratic, but equally market-type mechanisms are limited at present. It is already true that services for a single person may be delivered by public, private and voluntary organisations working independent of one another; and the major contribution of carers and service recipients themselves should not be forgotten. All parties can be viewed as co-producers of packages of care (Wilson, 1994). In short, community care can usefully be conceived as an example of a 'third way' of organising distinct from hierarchies and markets.

One way of conceptualising community care is as a network: organisational sub-systems and individuals are linked to one another by resource flows and information exchanges. No single sub-system can control its internal or external environment by its own actions - hence the necessity of 'co-' arrangements. Here, the domain is conceptualised as simple networks comprising a small number of nodes. The links between them represent directly observable resource flows, movement of clients, etc. They may also represent incentive and power relationships. The network model raises some (fairly obvious but) germane questions about the objectives of each agent and the extent to which the actions of agents are dependent on one another.

10.5.1 Foundations In Agency Theory

While network-based theories have been advanced by many authors in recent years, here it is useful to start with the economic theory of agency, to explore the nature of relationships between small numbers of actors, before moving on to networks of larger numbers of actors. The reason for this is that it is helpful to use a theory that captures both resource- and information-based aspects of relationships. Agency theory has been criticised for being 'undersocialised' (see Granovetter, 1985), but is deemed useful here because it highlights aspects of relationships that happen to be important in the context of the thesis.

In agency theory there are two parties to a contract, principals and agents, where principals engage one or more agents to perform a service. Their interests diverge, and they have different objective functions; that is, the principal will typically want a service to be provided at the best possible price and quality, whereas the agent(s) will seek to maximise their own income and/or minimise the effort they put into their work. The fundamental problem is that the principal cannot directly observe the effort made by the agent, and so must devise contracts to ensure the right level of effort for a given reward. Importantly for this discussion, there are information asymmetries between principal and agents. (Principals are people with dementia and their carers and agents are all actors who provide services to them.)

Various strategies have been identified which can be used to limit the divergence between the interests of principals and agents. However, the act of limiting divergence incurs costs and so tends to reduce efficiency. The costs are of three types: the principal may incur *monitoring* costs in limiting the scope for opportunistic action by the agent; the agent will incur *bonding* costs in guaranteeing to deliver the service being contracted for; and in spite of this there may still be some divergence between the interests of the principal and agent, and the resultant costs (and risk) borne by the principal are her *residual loss*. The sum of these three costs comprise the agency costs.

Agency theory has been applied to the study of organisations by many economists, who realised that it has important implications for theories of the firm. An organisation is conceived as a nexus of contracts, both written and unwritten, between the various parties who have a claim on the resources of an organisation; that is, an organisation is a set of agency relationships (Jensen and Meckling 1976). Fama and Jensen (1983) argued that the separation of ownership and control - more formally the separation of decision management and residual risk bearing - was found in a variety of organisational forms. The main organisational solution to limiting the agency problems raised by this separation lay in allocating decision management (initiation and implementation of decisions) and decision control (ratification and monitoring) to different agents. That is, decision-making was allocated between agents so that no one agent has overall control, and agents are dependent on one another in achieving their own desired payoffs. Moreover, organisations adopt governance (decision management and control) structures which limit agency costs: thus a consideration of agency relationships can inform discussion of organisational forms.

The agency problems are exacerbated in complex organisations, where specific knowledge relevant to different decisions is diffused among agents at all levels of the organisation. In practice, both decision management and control are delegated to agents with relevant knowledge, which serves to reduce agency costs. In the domain, this delegation might be to a care manager or jointly to members of teams.

10.5.2 Agency Relationships In Community Care

The new community care policies can be viewed as seeking to influence the agency relationships in community care. Historically, a central problem in the management of both health and social care has been that management and control are not closely linked. Indeed, hospitals have been modelled as consisting of two firms, with a clear separation of management and service delivery (Harris, 1977). The health-social care divide is perhaps another dual-firm arrangement. (As Sharma (1997) notes, principal-professional relationships may differ from other principal-agent relationships because of the high degree of specialised knowledge of held by the professional, and hence the substantial information asymmetry which is always likely to be present.) It seems reasonable to assume that in this model agency costs were low, with monitoring and bonding consisting of informal relationships based on trust: though information asymmetries will have been high. Unfortunately, the dual firm structure also created co-ordination problems, and the increasing pressures on resources from the mid-1970's made coordination of the allocation and commitment of resources a priority.

Since the early 1980's, the NHS and social services departments have witnessed a variety of initiatives designed to create single firms, mainly through 'managerialisation' of professionals; for example Management Budgeting and Resource Management in hospitals (Packwood et al. 1991), and joint financing of health and social services (Wistow et al., 1990). Care management might also be viewed as an attempt to create a single firm in a situation where there was formerly little formal co-ordination of effort.

These examples can be interpreted as organisational responses to agency problems, and specifically as attempts to align the interests of different agents and thus improve the efficiency of *teams* delivering services (Alchian and Demsetz, 1972). The teams might have been created in order to manage either the inputs to a management process (ie. budgets), as in the case of Resource Management, or to manage the inputs to clinical or social services. There are many examples of the latter in health and social care, including care management, primary health care teams, multi-disciplinary community-based mental health teams, and myriad specialised teams in hospitals.

A key point is that the greater the amount of effort put into aligning diverging interests - or put more simply, in creating collaborative working relationships - the greater the resources that have to be devoted to it. The point made above about the many 'co-' arrangements now found in public services is that they are responses to general pressures on resources. The payoff, though, is that the information asymmetries between parties should be reduced even by a modest degree of communication. It can also be added here that there seem to have been changes in the behaviour of the recipients of services (the principals) and some service providers (agents).

Part of the move to 'co-' relationships is due to changes in attitudes towards the amount of information that clients can and should have about services - now exemplified by the Patient's and other Charters.

10.5.3 Agency In The Domain

Agency costs appear to have increased over time, partly through general economic pressures and partly through specific government policies. It is useful to briefly review government actions. These can be summarised as:

- Focussing on within-social services relationships in care management;
- Focusing on professional-patient relationships, generally through the promotion of the mixed economy and also in the introduction of Charters.

It is interesting to note that there have not been any formal initiatives to promote collaborative working between GPs and social workers, a crucial relationship in the domain. The government has therefore sought to align the interests of some actors while neglecting others.

Within the domain there is a large number of relationships, which are inherently costly to maintain, some of which have become more collaborative over time, while others relationships seem distant even now in the 1990's. To this one can add the binary health-social services divide as afactor which will tend to increase costs, over and above what one might expect in a network comprising people with homogeneous backgrounds working in a single organisation.

Ultimately, an agency-based account of the domain is bound to run into difficulties, if only because of the large number of relationships that have to be considered. There are many overlapping agency relationships, and any one actor may be both a principal and an agent, in respect of different relationships. But the account has helped to highlight some reasons why services in the domain have their current form, in particular the resource- and information-based factors involved. Efforts to promote collaboration where there are substantial information asymmetries - whether between professionals and clients or between any two professionals - will be costly.

10.5.4 The Domain As A Network

The excursion into agency theory has helped to highlight the level of resources required to align interests and reduce information asymmetries in the domain. Returning now to the concept of the network, and that of co-production of care, noted at the start of this section, collaboration will depend upon:

- The extent of information asymmetries, and whether or not service providers communicate effectively with people with dementia and their carers - to use Wilson's (1994) term, whether or not care is co-produced between providers and recipients;
- The extent to which the interests of individual service providers are aligned with one another;
- The organisational barriers, particularly the binary health-social services divide and the different budgetary arrangements used in different sectors of the NHS.

The domain is therefore usefully conceived as a network of relationships between many different actors, where the extent of collaboration is influenced by these three factors. Where communication is difficult or the service provider is a poor communicator, where the interests of professionals diverge, and where there are strong organisational barriers, then collaboration will be poor. Conversely, where there are conscious efforts to overcome these problems then there can be effective collaboration.

The evidence presented in earlier chapters suggests that care management is not conducive to effective collaboration (that is, effective in promoting better services). It remains a moot point whether a more team-based approach might be more appropriate. What one can say, however, is that the main focus of any future policy intervention should be in the relationship between GPs and social workers/care managers. If there is one obvious weakness in the network, it is at the operational level across the primary care/social services divide.

10.6 Collaboration And Flexibility

The discussion to this point emphasises the balancing act that organisations engaged in community care must achieve if they are to implement new policies successfully. This can be represented in the dimensions used to describe flexibility in Chapter 9 can be applied to collaboration. For purchasers, collaboration increases the volume and mix of services that can be provided. It may also make it easier to effect changes in relationships between those previously provided by groups in different sectors. As a result, collaboration will increase the total range of options available to the collaborating purchasers. Similarly, a potential strength of collaboration between providers, under care management or any other arrangement, is that it increases the options available to any one provider; and by extension to any client.

Collaboration helps to increase flexibility by increasing the total pooled volume of services, and in practice will make it easier to change the mix delivered to any one person. However, collaboration also makes internal relationships more complex, and so will tend to reduce flexibility. Similarly, the time to respond to some event in a collaborative relationship will tend to increase.

In order to realise the value of collaboration without compromising too much on flexibility, therefore, it will be important to avoid organisational solutions which involve internal relationships which are too complex or make decision-making too slow to respond in a sensible timescale. Clearly, both are a danger in a mixed economy of care with many purchasers and providers and a historical tendency towards bureaucratic approaches to decision-making. In practice this might be achieved by the collaborating parties agreeing on which areas will be subject to joint discussion and which will be tackled by one or other party. Where the introduction of community care is going smoothly, it is this kind of discussion which is taking place. There is no reason in principle, therefore, why a practical trade-off between collaboration and flexibility can not be achieved.

The simple model outlined here does not, though, take any account of the obstacles that lie in the way of achieving the best trade-offs in practice. As noted earlier, there are power differentials and important cultural differences between the NHS and social services departments, and these need to be tackled if sensible trade-offs are to be made; otherwise, they will tend to militate agianst the achievement of effective collaboration and flexibility. This point notwithstanding, the simple model does serve to highlight the nature of the trade-off between two key objectives of community care.

10.7 Conclusions

This chapter has discussed the extent to which collaboration in the domain is desirable. On the one hand it is clear that more collaboration than has occured historically is desirable, but on the other the network metaphor highlights the point that collaboration between all actors involved will be very costly. The interesting question is therefore about the model which will balance desirable effects of collaboration and the costs of achieving it. At the time of writing it is not obvious what such a model would look like, but it seems reasonable that it must involve better co-ordination between GPs and social workers than currently exists.

Taken together with the discussion of flexibility in Chapter 9, this completes the analysis undertaken in pursuit of the third objective of the thesis, which is concerned with the exploration of underlying systemic issues within the domain. The insights gained in these chapters can now be used to draw overall conclusions about the nature of the domain investigated in this thesis.

CHAPTER 11

OVERVIEW: THE DOMAIN AS A NETWORK

11.1 Introduction

The purpose of this chapter is to draw the lessons together, in order to develop a general model of the domain. The structure of the chapter reflects the three objectives described in Chapter 1.

The first objective concerned systems science approaches. The domain is a complex human system, and provides a test of the value of existing systems science methodologies and methods. The first objective was therefore to understand the extent to which systems science approaches were appropriate and useful in this apparently 'soft' domain, and identify their strengths and weaknesses.

The second objective was to assess the extent to which systems science approaches could be used to describe and explain the patterns of service delivery within the domain. Although there have been some excellent published studies (for example Challis et al., 1995; Levin et al., 1989) the domain has not been extensively investigated, and the thesis has provided an opportunity to advance understanding of the nature of service delivery and the factors that might enhance or inhibit the provision of effective services.

The third objective was to understand the influence of two important elements of government community care policies, namely flexibility and collaboration in the delivery of services. While the first two objectives dealt with the detail of methods and patterns of service delivery, the focus here was on wider sytemic issues. The thesis therefore presented an analysis of two important conceptual planks of community care policies, flexibility and collaboration, and discussed their implications for the domain.

The chapter discusses progress towards each of the three objectives in turn. In doing so, it also discusses the two sub-themes identified in Chapter 1, one concerned with the relative value of different modelling approaches in this domain, and the other with the extent to which systems science can - or should - offer a single integrated methodology or a useful 'toolkit' of methodologies and methods.

11.2 The Value Of Systems Science Approaches

11.2.1 The Value Of The Methods Used

It is difficult to make analytical comments about the particular methodologies and methods used in the thesis. Perhaps two comments summarise the subjective experience of using them. Firstly, each one - except cognitive mapping - contributed insights into the domain. Decision analysis and the Markov cohort analysis highlighted the pathways that were and were not being used in the domain. System Dynamics helped in identifying capacity constraints. VSM and SSM, in their different ways, helped to direct thinking towards particular issues, notably in higlighting the importance of flexibility and collaboration as 'organising principles' for the domain.

Secondly, the use of a number of methods together proved useful. The use of multiple methods is not in itself inherently useful: a different combination might have yielded less - or perhaps more - insight. So, it leaves open the question of whether the particular approaches used were the best that could have been chosen.

11.2.2 The System Of Systems Methodologies

It was noted in Chapter 2 that there has been debate among systems scientists about the extent to which their methodologies and methods can be applied in 'soft' domains such as the one in this thesis. The debate has a

	Unitary	*Pluralist*	*Coercive*
Simple	S-U	S-U	S-C
	Operational Research, Systems analysis, Systems engineering	Social systems design, Strategic assumption surfacing and testing	Critical systems heuristics
Complex	C-U	C-P	C-C
	Cybernetics, General Systems Theory	SSM, Interactive planning	

KEY: S= simple, C= complex, U= unitary.

Table 11.1

Classification: System Of Systems Methodologies

Source: Flood and Jackson (1993)

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long history, and has led to the development of a range of approaches specifically intended for use in 'soft' domains (see Rosenhead, 1989 for the leading examples). While the increase in the number of approaches may have had advantages in allowing the extension of systems science into new areas of inquiry, it also raised a problem: how to choose the most appropriate approach for any given problem?

Flood and Jackson's (1993) System of Systems Methodologies (Table 11.1) is one recent attempt to match methodologies to problems. It was used pragmatically in this thesis as a starting point for exploration of appropriate methods: their framework pointed to interpretive approaches such as SSM (Checkland and Scholes, 1991) for the domain. Put simply, a 'soft' domain was deemed to require a 'soft' methodology. In Chapter 2 the argument was advanced that the System of System Methodologies was flawed on two

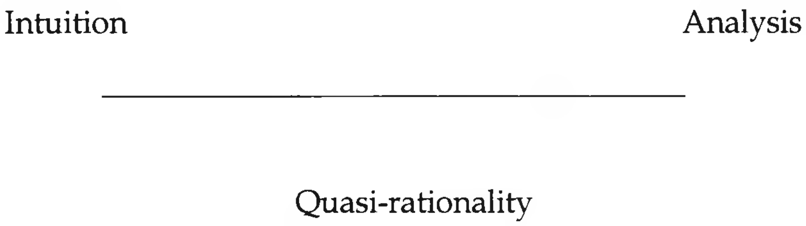

Figure 11.1
The Cognitive Continuum
Source: Hammond (1996)

main grounds: the characteristics of the observer - with particular interests and skills - was not considered, and it implicitly assumed that it was necessary to model the whole of any system using a single methodological framework. The results presented in earlier chapters allow these arguments to be developed.

The role of the observer has not been central to the discussion in the thesis, but some brief comments can be made here. Hammond (1996), discussing the nature of cognition in policy-making, argues that different tasks 'induce' different types of thinking. Hammond posited a cognitive continuum (Figure 11.1), where the line represents different mixes of intuitive and analytical thinking, and the particular mix depends on the problem. Thus some problems are best tackled analytically, and others intuitively - particularly where speed of thought is essential. Most problems in the research and policy spheres will involve a combination of the two.

To this one might add that different people, with particular research interests and skills, will 'shape' this process and tackle it with the tools with which they are comfortable. This seems to be no more than common sense:

Type of problem	*Examples Of methodologies And methods that might be used*
No obvious structure: no one actor comprehends the behaviour of the system, and so even the range of possible perspectives is not obvious at the outset	**SSM, interpretive social science approaches**
Some structure discernable, contained within a system that lacks obvious overall structure: some distinct analytical perspectives can be identified	SSM, System Dynamics: methods may be used in positivist or interpretive mode
Domain appears well structured, and adoption of a particular, identifiable perspective likely to provide useful insights	**'Hard' systems methodologies, statistical analysis (positivist methods)**

Table 11.2

Simple Classification Of Methodologies And Methods For Complex Systems

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any one problem will be tackled in one way by a neo-classical economist, another by a sociologist, and so on. The problem for the systems scientist is to know how to respond to any given task.

Turning to the 'whole system' assumption, the evidence presented in earlier chapters suggests that insights can be gained from approaches which seek 'partial' understanding - the objective is to gain insight into a domain rather than to develop a complete model of its behaviour. Table 11.2, reproduced from Chapter 2, captures this idea. The Table focuses on the perceived degree of structure in a domain rather than on the unitary-pluralist-coercive distinction. The empirical evidence presented in Chapters 6-8 provides useful insights, without attempting to model the domain as a whole.

While SSM might have been useful in the domain, as Flood and Jackson predict, the key observation is that a *decision analytic approach* was also found to be useful. Decision analysis, as an essentially 'unitary' method, would not have been predicted by the System of Systems Methodologies for this domain.

Putting the two problems together, it appears that the choice of methodologies and methods needs to take into account:

- The perception of the degree of structure in a domain;
- Whether the objective is to develop a model or to gain (rich, partial) insights.

Those systems scientists who are principally interested in mathematical modelling will tend to perceive problems as ones requiring mathematical models to solve them, and those who perceive problems as essentially soft in nature will tend to assume that SSM and other methodologies are appropriate. (They may also tend to select problems that lend themselves to analysis by their own preferred approaches, so the risk of mismatches of problems and methodologies may not be as great as this analysis suggests.) This hints at an alternative way of thinking about linking problems and methodologies.

11.2.3 Towards An Alternative Selection Process

This thesis does not, of itself, provide sufficient evidence and argument for the development of an alternative to the System of Systems Methodologies. It does, though, provide some useful clues about the nature of an alternative.

There are two dimensions involved. The first stems from the discussion in Chapter 5 about the ways in which VSM might be used in a 'soft' domain.

A distinction was drawn between the use of the VSM as a way of capturing directly qualities of the world 'out there', and as a way of gaining insights into key structures and processes - without assuming that VSM could itself be used as a model of the domain. One way of formalising the distinction is in the contrast between successionist and generative theories of causation (Harre, 1972). The distinction is between:

- Successionists, who believe that causation is unobservable and its presence can only be inferred from experimental data. This view underpins the experimental method, where causation is shown to exist through application of an ('external' or 'extra-system') intervention to experimental and control groups. If the design is right, then differences in observed effects can be attributed to the intervention.
- Generative theorists, who may also point to an 'external' cause of some event - such as reductions in central funding leading to hospital bed closures - but also to internal characteristics of a system that is changed - such as the ability of local staff to manage the consequences of bed reductions (see Pawson and Tilley, 1997: pages 32-33). Generative theories see causation as acting internally as well as externally for any given system.

The key point here is that generative theories provide a means of thinking about the *potential* of any system for transformation. Thus care management worked in pilot sites because the local (internal) conditions were right, so that the arrival of (external) people charged with implementing it was able to succeed. Equally, the external change agency failed in other places because the internal system conditions were wrong. (Interestingly, writers such as Checkland and Scholes (1991) and others who

Causation/ Judgement	*Successionist*	*Generative*
Correspondence		**Cognitive Mapping, Inference Diagrams**
Coherence	VSM as presented by Beer	SSM, VSM as used in this thesis, Decision Analysis as used in this thesis, Flexibility and Collaboration as organising concepts

Table 11.3

Towards An Alternative Classification: Causation And Judgement Criteria

are concerned with methodological issues in systems science and OR (Rosenhead, 1989) do not refer to this distinction in their writings.)

The second dimension originates in the work of Hammond (1996). In addition to positing the cognitive continuum, he argued that there were two fundamental ways of arriving at judgements, based on:

- Empirical accuracy - so judgements correspond to observed facts;
- Internal logical or mathematical coherence.

Broadly speaking, systems science approaches can be characterised as seeking coherent explanations for events. In their different ways, VSM, SSM and other approaches are all designed to attain coherent descriptions and explanations.

Table 11.3 shows the two dimensions, causation and judgement, as a 2*2 grid. In this thesis the approaches used have tended to be in the generative-coherence square, though the methods used in Chapter 6 could be termed generative-correspondence. These dimensions do not, of themselves, provide a means of matching problems and methodologies and problems. They do, though, highlight issues that are not tackled by Flood and Jackson, and - hopefully - point to a way forward, that takes account of the fact that approaches such as VSM can be used in more than one way. It may be that the only way of distinguishing between different systems science methodologies and methods is - as Checkland and Scholes (1991) argue - through empirical testing. The most appropriate approaches are those that are shown to work in particular circumstances.

In summary, the thesis has not provided a ready solution to questions concerning the feasibility of an integrated methodology - one of the two sub-issues identified in Chapter 1. It has, however, posed serious questions about the value of TSI's System of System Methodologies, and suggested alternative dimensions that could be used as the basis for an alternative approach to identifying methodologies and methods.

The arguments presented in this section also provide a partial answer to questions about the value of the concept of a 'toolkit' of methodologies and methods - the second of the two sub-issues. Following Pawson and Tilley (1997), the evidence and arguments presented here point to the importance of the *problem* and the characteristics of the *practitioner* as important factors in selcting methods from any toolkit. Focusing on the concept of the toolkit alone draws attention away from these other factors. This is where the cognitive continuum concept noted above is useful - the toolkit is not a neutral entity, but something that will inevitably be drawn on in different ways by different practitioners. The toolkit concept therefore implies an objectivity about the selection of methodologies and methods that does not exist in practice - at least at the moment.

11.2.4 Hard Methods and Soft Domains

This leaves the question of the applicability of systems science methodologies and methods in soft domains. As Rosenhead (1992) has observed, the related discipline of OR has often run into problems when applied in soft settings. Systems science appears to have had a little more success (see Midgley, 1996), and there is a literature discussing experiences in soft areas, but there is still considerable uncertainty about how best to proceed.

The conclusion to be drawn from this thesis is that a variety of methods that have been termed both hard and soft can be employed to explore the domain. Table 11.2 suggests why. The most important feature of a domain is the degree to which it is structured - in effect, the degree to which its key characteristics are amenable to analysis using particular methods. Sometimes a domain is 'all structure', and is properly analysed using mathematical modelling techniques. At other times a domain appears to be devoid of any structure - note this will be an observer's view, and may not be shared by all observers. Moreover, there may be variation in the extent to which there are useful insights that can be derived from theory - sometimes decision structures are apparent and can be investigated using decision analysis, while at other times the locus of decision-making is unclear or too diffused to be easily analysed.

The most common situation, though, is likely to fall between these two extremes - 'soft' domains are characterised by a mix of factors which are usefully conceived as structured and others where there is no obvious organising principle at work. The approach taken in this thesis hinges on this concept of partial structuring within the domain. This approach may, to borrow Rosenhead's (1992) phrase, provide a way 'into the swamp', using both 'hard' and 'soft' methods in 'soft' domains.

11.3 The Nature Of The Domain

The thesis explored the domain in three ways. Chapter 6 looked at individual actors, and began to explore relationships between professionals and clients. Chapter 7 investigated the pathways taken by people with dementia over a crucial year in their lives - and traced what happened to them, which was at least in part due to the actions of health and social service professionals. Chapter 8 looked at issues of structure and capacity, tying them back to consequences for people with dementia. Overall, the strategy was to adopt different views, each of which would provide illumination about the experiences of people with dementia.

It must be stressed that there are many things that the thesis did not attempt to study, and cannot therefore be commented upon. For example, no detailed data were collected about the nature of the population in the case study area - as argued in earlier chapters, good qualitative (Glendinning, 1992) and quantitative (Levin et al., 1989) studies had previously been conducted. Similarly, the study did not attempt to identify all people in the local community who had dementia, but only those who were assumed to be candidates, sooner rather than later, for institutionalisation.

In spite of these limitations, useful insights were gained in the course of the studies. Chapter 6 showed that the attitudes and actions of profesionals influenced the services provided to people with dementia. By itself, however, the behaviour of any one individual - even crucial actors such as GPs - was only part of the story. The decision analysis and the Markov Cohort model in Chapter 7 built on the evidence of Chapter 6 by showing that the behaviour of service providers did indeed have effects on the services received by people with dementia, and influenced the probability of entry to institutional care. The System Dynamics model presented in Chapter 8 provided additional insights about the capacity of the system - and the extent to which the service delivery system is tailored to available service and physical capacity.

One way of assembling the evidence from these chapters is by using a network metaphor. This will be discussed in detail in Section 11.5, but suffice to say here that overall conclusions need to be drawn about the experiences of people with dementia within the domain. There are two main conclusions. Firstly, experiences in the community varied depending on the pattern of contacts with health and social services personnel. Those people in the cohort who were still living in the community after one year had been referred down different pathways, and the (admittedly limited) evidence of the inference diagrams in Chapter 6 suggested that different people in broadly similar circumstances received, or were offered, different support and services. This thesis therefore contributes to the evidence of unexplained variation in patterns of services in community care.

Secondly, a relatively small proportion of the cohort was likely to enter either residential/nursing home care or a long-stay hospital bed, but again, the probability of entry appears to be dependent at least in part on the nature of the referrals made. This is not the whole story - the characteristics of people with dementia and their home circumstances must also influence outcomes (Levin et al., 1989) - but it is an important part that has not been told in detail before.

A key observation in the context of this thesis is that the experiences of people with dementia appeared to depend on *both* the behaviour of individuals and the structure of the formal system within which they were working.

11.4 Flexibility And Collaboration

The evidence and argument in Chapters 9 and 10 highlighted a number of issues about the domain that are important in coming to any view about the efficiency and effectiveness of the organisation of services in the case study site or the domain in general. Following on from comments made in Section 11.2, the use of 'organising concepts' can be conceived as a way of 'creating structure' in a relatively unstructured domain. In contrast with VSM, which is external to any particular domain, the use of these concepts flowed from well-grounded reasons for believing that they were important in the local context. The dominant policy document discussed both flexibility and collaboration at some length, and examination of the concepts confirmed that they were indeed important, and not simply rhetorical devices.

Taking flexibility first, the discussion in Chapter 9 emphasised the importance of considering flexibility as a design criterion when a domain is characterised as facing high uncertainty. The broad conclusion was that the domain in the case study site was fairly inflexible, at least at the operational level. The allocation of resources was fixed within any one year, and the attitudes and behaviour of key professionals including GPs and social workers was - so far as one could tell - relatively insensitive to external exhortation for change.

Beyond the immediate concerns of service delivery, Lewis and Glennerster (1996) concluded that there had in fact been important changes in financing mechanisms, and these were leading to real change on the ground. But these changes were not observed in the case study site - this may simply have been because it was too early in the reform process for such change to be observed.

With regard to collaboration, discussed in Chapter 10, the picture was found to be variable. There were some instances of collaboration, backed up by some of the pathways observed in Chapter 7. Yet the key relationship in the domain, between GPs and social workers, was anything but collaborative. This led to observations about the health-social service divide - the data clearly manifested the persistence of the divide on the ground.

The metaphor of the domain as a network was introduced in this chapter. One could say that the individual network links within the domain vary in the extent to which they represent collaboration - sharing of information, carefully planned referrals or joint action - and this affects the fate of people with dementia.

It is also worth noting that the data from the case study site emphasised a lacuna in policy making. The arms-length relationship between GPs and social workers seems to be an obvious target for policy in this area, but has not been addressed directly. Important innovations have been supported by the government in adjacent areas, including care management and primary health care teams, but this particular link remains to be addressed directly.

11.5 Overview: The Domain As A Network

The remaining task is to draw together the evidence and argument presented in the course of the thesis. As noted at the start of the chapter, the metaphor of a network is used here.

In common with other public services, the domain is composed of a mixture of the public and private, to the extent that the traditional public/private sector dichotomy has lost its value. Services may be delivered by any of a range of individuals and organisations. The domain is too complex for any one agent to control effectively, so that a variety of diffused control mechanisms and strategies for collaboration have been developed.

There are three steps in the development of a simple network model. The first involves characterisation of the relationships between the different actors in the domain. The various trust relations, value systems and other factors influence referral patterns - the patterns revealed in Chapter 7. Some of these relationships are good, in the sense that there is sufficient trust for referrals to occur. Others, notably the GP-social worker relationship, are poor. The result is that the domain is composed of network relationships of different types, some involving transfer or sharing of information and resources and others involving 'arms-length' relationships (Uzzi, 1997).

The second step is to define the boundaries of the network, and the influence of organisational structures. For the purposes of this thesis, the boundaries have been drawn around service providers, people with dementia and their carers. Purchasers of services lie outside the boundary, though their influence is acknowledged.

Notwithstanding the seriousness with which the 1993 community care policies were pursued, pre-existing institutional structures played a major role in helping to preserve the *status quo*. Lewis and Glennerster's (1996) evidence suggests that change may well be on the way, but key features of the terrain look much the same now as they did five years ago. Borrowing a term from economic sociology, we can say that the various actors are deeply embedded in social networks (Granovetter, 1985). To give an example, the poor relations between GPs and social workers are well established, and preserved in part by the nature of their relationships with other actors across the network. The fact that many GPs have good relationships with hospital consultants means that they have relatively little incentive to improve relations with - or increase referrals to - social workers.

The third step is to posit a mechanism whereby relationships might be changed, or resistance encountered when change is attempted. One implication of the network view of the domain is that innovation will involve changing the actors, the nature of existing relationships or creating new relationships. Thus the new community care policies sought to change the nature of the actors at some nodes (eg. social workers to care managers), relationships within social services departments, and the environment surrounding the network. They also converted some relationships from state-funded services to consumer-based ones, by allowing charging for day care and other services. At the same time, the NHS reforms changed the roles and incentives for GPs and other health service professionals.

In spite of the fundamental nature of some of these new policies, the deeply embedded nature of some relations has meant that change has been at best modest. GPs are at the centre of a web of complex relationships, involving not only people with dementia but many others, and one expect change to be difficult to achieve.

Finally, some comment is required about the most appropriate organisational form for services for people with dementia. This thesis has advanced understanding a little, but there are still major gaps in understanding, so any comments have to be cautious. What one can say is that the current preferred model of care management is not the most obvious one for people with dementia. It fails to address the question of GP-social worker relationships. Any alternative needs to address this relationship above all. There are two broad ways of achieving this. One is to make GPs the main co-ordinators of care - which, it could be argued, is simply an extension of policies designed to promote the creation of primary health care teams. This does not solve the GP-social worker problem, so additional measures would need to be introduced to encourage the two to collaborate. If such measures could be devised, then in effect the social worker - or care manager - would become a member of the primary health care team.

The second way of solving the problem is to address the wider structural issue alluded to at several points in the thesis - dissolve the health-social services divide. In network terms, fundamental changes in the network environment are the pre-condition for the necessary changes in the domain. There seems to be no immediate prospect of this happening, but it would seem to be a pre-requisite for effective care of a very important group of people and their carers.

11.6 Conclusions

This chapter has sought to draw together lessons learned during the course of the thesis. The lessons relate to the use of systems science methodologies and methods in 'soft' domains, understanding the domain itself, and the nature of flexibility and collaboration in the domain.

CHAPTER 12
CONCLUSIONS

12.1 Introduction

This thesis was organised around three main objectives, identified in Chapter 1. These objectives were:

1. To advance understanding of the value of systems science methods in a 'soft' domain;
2. To advance understanding of the domain itself;
3. To investigate two particular characteristics of the domain, namely the extent to which services were flexible and based on collaborative working.

The thesis has contributed to understanding in each of these three areas. Firstly, it has shown that systems science methods can be applied in the domain, and suggested a better strategy than currently available for matching problems to approaches and methods. Secondly, the use of a particular combination of methods has yielded insights into the nature of the domain. In particular, the results have revealed something of the dynamic behaviour of service delivery systems as a whole: previous studies, though excellent, have investigated only parts of these systems, rather than health and social services together. Thirdly, the analysis of flexibility and collaboration in the domain yielded additional information about the current organisation of services. If viewed as a network, it is possible to understand current organisation as being shaped by differences in values and objectives of the various actors, and by long-standing institutional barriers.

It is therefore possible to answer the question posed in the hypothesis in Chapter 1. The question was: Can a systems science approach be applied in this apparently 'soft' domain, to produce new insights and knowledge? The answer is that it can, as long as careful thought is given to the ways in which methods are used, and it is appreciated that the process is essentially interpretive in nature.

12.2 Conclusions

Just over 450000 people of 65 years or over in the UK have dementia, though a rather smaller number have moderate or severe dementia. The majority live in their own homes. Many of them will live in their own homes for the duration of their lives, but a proportion will enter an institution - either a residential or nursing home or a long-stay hospital. The thesis sought to provide insights into the processes and decisions surrounding entry to institutional care.

12.2.1 Systems Science In 'Soft' Domains

In order to provide these insights it was necessary to address methodological issues, relating to the extent to which systems science methods were appropriate, in what many would term a 'soft' domain. It was observed that there was no convincing formal process for identifying appropriate methodologies and methods. One framework for identification, Flood and Jackson's TSI, was presented. It was criticised for assuming simple relationships between perceived characteristics of a domain and appropriate methodologies. A decision was made to adopt a pluralistic approach to the selection of methodologies and methods, and then to review them to assess their usefulness in the light of experience.

The experience of the use of different approaches reported in Chapters 5-10 indicated that systems science approaches can indeed be used fruitfully in 'soft' domains, as long as they are used to gain insights into aspects of those domains, rather than model the domain as a whole. While a number of authors have long argued that this is the case, the literature on the process of applying systems thinking is more developed than practical ways of matching problems and approaches. The thesis has suggested ways in which this matching process can be undertaken, and provided examples of the results, which show how different methods, used in combination, can yield useful insights.

Two insights were central to the progress made. The first was that modelling should proceed on the assumption that it facilitates interpretive insights. Thus VSM, and the 'organising principles' of flexibility and collaboration, were valuable as conceptual tools rather than direct representations of the domain. The second insight was that even very soft domains have some structure, and it is possible to study this structure using systems science methods. In this thesis, for example, it was possible to use decision analytic methods to model the movements of the cohort of people with dementia over one year.

12.2.2 Understanding The Domain

The published literature suggested that there are problems in the domain stemming both from scarcity of resources and historically poor co-ordination of services. There is evidence that some community-based professionals do collaborate, but two key groups - GPs and social workers - still do not work well together. The binary health-social services divide has long been recognised as a major institutional barrier to co-ordination. The data presented in Chapters 6-8 represent one of the first comprehensive studies of services across the health and social services divide, and for the first time provides insights into the dynamic behaviour of service delivery systems for people with dementia. Work focused on the actions of professionals in the community that pre-date entry to an institution, and on entry itself.

In Chapter 6 a version of cognitive mapping, developed by Eden and colleagues at Strathclyde, was used. It was concluded that it was difficult to assess the validity of the data obtained using the method, and doubts were expressed about its value. Inference diagrams, based on seven individual case studies, were also presented. These provided initial information about the relationship between professionals, people with dementia and their carers. This largely confirmed the evidence in the published literature, particularly concerning the lack of co-ordination across the health-social services divide. There were, though, indications that there were good informal collaborative relationships, notably between CPNs and social workers.

Chapter 7 presented data from a detailed single site case study, where data were collected from a variety of health and social services sources, and a picture built up of the patterns of service delivery in the locality. A cohort of people believed to have dementia was identified, and their one year outcome established. The cohort was defined in terms of referral to a 'secondary' service - either a hospital-based service, or a referral to a social worker for formal assessment. A simple decision analysis was used to show that the initial point of contact with a service was a strong predictor of one year outcome. GPs almost always referred people to hospital-based services, and social services staff generally referred to social workers - though the latter might also refer to hospital-based services.

The data were used to construct a Markov Cohort model, which suggested the likely pattern of demand for institutional care over a fifteen year period. The prediction was that, for the cohort studied, there would be a peak demand for institutional care at about three years, and then demand would tail off. This said, the majority of people in the cohort would not enter an institution. At the end of fifteen years most people in the cohort would have died.

While the Markov Cohort results hinted at the dynamic nature of the domain over time, it did not include any information about the capacity of the hospital and social services systems. A System Dynamics model was developed, based on cross-sectional data collected at the same case study site. The analysis suggested that reductions in the availability of both hospital and residential/nursing home places would increase the demand for community services. Reductions in the numbers of hospital places alone - which has been happening over the last few years - will lead either to more demand for community services, or increases in the numbers of people with dementia entering homes, or both.

12.2.3 Flexibility and Collaboration

Flexibility and collaboration were introduced as 'organising principles', central to government policies relating to the domain. A novel framework for thinking about the flexibility of services in the domain was presented. This emphasised the extent to which the design of services involved trade-offs, along a number of dimensions. Key concepts relating to collaboration in service delivery were also presented. It was argued that the domain was characterised by two types of relationship - either good informal collaboration, or arms-length relationships. Taken together, the application of these 'organising concepts' emphasised the extent to which professional and institutional factors may reduce the efficiency and effectiveness of services for people with dementia.

12.2.4 Drawing The Strands Together

What can be said about the overall approach taken in the thesis? The domain has proved to be a proper testing ground of the applicability of systems science methodologies and methods in a 'soft' domain. Each of the different frameworks and methods has furnished partial insights. This has revealed, for example, the effects of referral patterns on the services provided to people with dementia. In a domain that is not well understood, these partial insights have produced useful knowledge.

If there is a weakness in the approach used, perhaps it lies in the difficulty of piecing these insights together into a coherent whole. There was no obvious way of linking or integrating the different lines of thinking and analysis in Chapters 5-10. The way - or ways - in which this might be achieved in this and other soft domains is a task for the future.

12.2.5 Future Directions For Research

Studies of services for people with dementia have in the main focused on either health or social services, and not the two together. The results presented in this thesis show that it is both possible and useful to do so. One area for further work is to investigate the systemic nature of the domain in more detail, to establish whether the results presented here are confirmed in other localities. Is it generally true that GPs do not refer people to social workers, and that social services staff do not refer to NHS services? Does the organisation of teams actually affect outcomes - defined here as entry to an institution - for people with dementia, or not?

Beyond this, it would be very helpful to understand the relationship between the personal and social characteristics of people with dementia on the one hand and the organisation of services on the other. It was not possible in this thesis to relate the two, but other research has shown that factors such as severity of dementia and the presence of a carer influence the probability of entry to an institution. Linking the person-based variables to wider organisational factors, so that their relative contributions were known, would greatly enhance our understanding of the domain, and provide a sound basis for the design of new policies.

APPENDIX
THE USE OF RESOURCES

A1 Introduction

The importance of resource use issues was stressed at several points throughout the thesis. For example, the question was raised in Chapter 4 about the status of claims that community care was under-resourced - though it is certainly a widely held view. In Chapter 8 the System Dynamics modelling raised questions about the extent to which resources might constrain the available solutions. This thesis has not investigated the matter, since it has focused on movements of people rather than on the resource consequences of those movements, but this Appendix outlines evidence that bears on the issues raised in the main text.

A2 The Economic Impact Of Dementia

Dementia clearly has a major economic impact both on society as a whole and on individuals and their families. But what are the scale and nature of this impact? What is the relationship between resources provided and effects on dementing people and their carers?

2.1 Impact On The National Economy

The impact of dementia on society as a whole can in principle be deduced from the costs of the services that are provided, and the costs falling on people with dementia and their carers. The costs over and above those delivered to the generality of elderly people represent the additional cost to society of dementia. Unfortunately, good resource use and cost data are scarce:

> "It should be noted that we have found few relevant studies in the UK or elsewhere to assist our costings, and the need for more research in this area is considerable." (Schneider et al., 1993: page 30)

What is more, it was emphasised in Chapter 3 that care is needed in identifying relevant populations, so as to arrive at useful estimates of the prevalence of dementia. The figures used will have a direct effect on estimates of costs. In the US, for example, published studies relate only to Alzheimer's disease, and the range of estimates is great, reflecting a number of different assumptions made in their calculation (see Hay and Ernst, 1987; Huang et al., 1988; Rice et al., 1991).

The most careful study of total costs in England is by Schneider and colleagues (1993). In their study they:

- Operationally defined dementia and cognitive impairment, using OPCS definitions;
- Estimated the prevalence of dementia and cognitive impairment - treated as a single group;
- Specified the resources used by this group, using a variety of data sources, for different care settings (in the community, in nursing homes, etc.);
- As far as possible, valued the resources at their long-run marginal opportunity costs;
- Examined who funded the different types of care available, to establish the burden on each sector (personal, NHS, social services, etc.).

The main results are shown in Table A1. The value of the data are limited because they reflect the pre-1993 arrangements, when social security payments still provided a large proportion of the money spent, but they are helpful in providing an idea of the order of costs incurred.

Package	*Private Households, Living Alone*	*Private Households, Living With Others*	*Local Authority Residential Home*	*Non-Statutory Residential Home*	*Non-Statutory Nursing Home*	*NHS Hospital*	*TOTAL*
TOTAL COST P.A. (£M.)	**378**	**1749**	**729**	**167**	**377**	**1284**	**4684**
Health Authority/ FHSA (%)	9.7	13.2	3.0	3.0	3.0	98.6	32.6
Social Services Department (%)	**14.8**	**8.6**	**80.2**	**2.0**	**2.0**	**0**	**17.0**
Client/Social Security Transfer Payment (%)	75.5	78.2	16.8	95.0	95.0	1.4	49.1

Table A1
Cost Burden Of Different Forms Of Care
Source: Schneider et al. (1993)

Note: Figures reflect pre-1993 arrangements, with Social Security payments included. Column totals do not add up to 100% in original paper due to rounding error.

2.2 Costs and consequences for individuals and their carers

Chapter 4 outlined the services provided - and not provided - to people with dementia in the UK. This gave information about the resources committed, but not about the costs of those resources. During the 1980's there was detailed research into the outcomes of care for elderly people in general: unfortunately, the costs of dementia were often not isolated, but some useful data were produced.

Firstly, for elderly people in general there is a rank ordering of costs according to where they live: broadly, hospital provision is most expensive, followed by residential care, with community-based care being least expensive (Wright et al., 1981). And also generally, private residential care is less expensive than care in local authority homes (Judge and Sinclair, 1986). However, for each setting costs vary from place to place, so that (for example) the costs of community care can at times approach or exceed those of residential care. In addition, the basis for calculation of costs is different in different studies, so care is needed in interpreting results from small numbers of sites.

Secondly, evidence from the Kent Community Care Project shows that confused people are more costly than elderly people in general, both because they receive higher levels of support in their own homes and because they are at greater risk of admission to residential care (Challis and Davies, 1986). The Kent model was extended and refined in a subsequent project in Darlington which focused on frail elderly people (Challis et al., 1991, 1995). Almost one third of the people in the study were confused, so that the results are at least suggestive of the cost-effectiveness of services for people with dementia. The community-based service had lower total costs than the alternative of long-stay hospital provision; within the total, there were lower health service costs but higher social service costs than would have been incurred in hospital.

Thirdly, since the thrust of government policy is that people should remain in their own homes as long as possible, and most people with dementia live at home, the costs of maintaining them there are of considerable interest. The Kent project provides some data (Table A2). The Home Support Project (Askham and Thompson, 1990) suggested that specially designed support for people at home could be cheaper than hospital care and (usually also) residential care. Conversely, an innovative scheme for elderly mentally infirm people and their carers proved to be almost three times more costly than services which would otherwise be provided (Donaldson and Gregson, 1989). It did, though, result in avoidance of admission to institutional care.

To these financial costs must be added non-financial costs. It is the psychic and physical burden of caring which necessitates the more visible financial costs of respite care and in some cases long-term institutional care. Given that these costs can be high, it is important to know the value of caring. Traditionally, governments have viewed informal care as a free good, a position which appears to be unaltered by the new community care proposals where support will be provided to unpaid carers, organised by care managers. Some commentators argue that informal care should be explicitly valued, and carers ensured a basic income (perhaps through income supplements) so that they have a measure of control over decisions about what support they receive: they can be more active consumers. These costs have not been quantified, though they have been graphically described by many authors (see for example Glendinning, 1992).

2.3 The Costs of Residential Care

The thesis has emphasised the importance of the decision to enter an institution: there have been major shifts in provision over the last decade, which presumably imply shifts for people with dementia. Davies and

Client type		No change		Some improvement (10% Morale; 20% Quality of Care)		Substantial improvement (30% Morale; 60% Quality of Care)	
		Community care £	Standard provision £	Community care £	Standard provision £	Community care £	Standard provision £
1.	Extremely frail, mentally impaired, very poor health, reliant on spouse, otherwise isolated and lonely	363	1,140	519	1,334	1,202	2,617
2.	Mentally frail, depressed, lives with spouse, support from relatives, unrealistic about capacity to cope	331	70	415	380	880	1,894
3.	As Type 2 but less depressed, lacks any social support	725	214	809	524	1,274	2,038
4.	Lonely, depressed, lives alone, mentally pressured, lacks social support, at risk of falling	965	352	927	512	1,073	1,723

Table A2

Estimated costs to the social services department of combinations of subjective well-being and quality of care for recipients of community care and standard provision, £ at 1977 prices

Source: Davies and Challis (1986)

Knapp (1988) reviewed the evidence available on the relative costs of residential care for elderly people, both within and between sectors. They found that within-sector variations were large, but cited data which suggested that if one looked only at direct costs to residents then private homes were most expensive, followed by voluntary and then local authority homes. But they cautioned that cross-sector comparisons were based on fairly crude averages, and did not include factors such as facilities provided or the mix of residents (or indeed evidence of outcomes for residents). If one takes a broader view of costs, then the rank order is reversed, and it is this ordering for which evidence is strongest. Once again, cost data for the subset of dementing people is not available, so that it is not possible to state the financial consequences of each residential care option.

The costs of NHS nursing home care have been studied (Donaldson and Bond, 1991), with the results suggesting that they are comparable with hospital care. They appear to be more costly than private sector nursing homes, although the latter cater for a less disabled (less expensive) mix of residents. There are very few NHS nursing homes, and numbers seem unlikely to increase in the near future.

2.4 Underprovision

In summary, the evidence for costs and effectiveness of services for dementing individuals is far smaller than that for elderly people in general. Cost data is based on small samples, and deals mainly with innovative schemes rather than 'typical' services. Nevertheless, combined with the information from chapter 4 it is clear that people who are confused or dementing and their carers are a relatively expensive group, many of whom require intensive support and often are not receiving the support they require. This gap between need and provision will have to be quantified in order for the potential future impact of dementia on local services and national economies to be calculated.

2.5 Summary

There are limited data available about resource use and costs of services for people with dementia, and much of what is available is somewhat dated. The evidence is still interesting, though, in that it demonstrates the great variability in costs, where the variation is as great between geographical locations as between care setting. It is not, therefore, possible to state that community care or residential/nursing home care is the costlier option. What one *can* say, however, is that the costs fall on different parties. Thus the costs of private nursing home care fall on individuals or the state via the benefits system, whereas the NHS pays hospital costs. It is these differences in who pays, rather than total costs, which will influence the development of community and residential/nursing home care for people with dementia.

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