

**Policy transfer and policy  
translation: day care for people  
with dementia in Kerala, India**

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## Declaration

I have composed the thesis and the work it embodies has been done by me and has not been included in another thesis

A handwritten signature in black ink, appearing to read "Fran McCabe", with a long, sweeping flourish extending to the right.

## **Acknowledgements**

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## **Abstract**

This thesis explores and explains the development of day care for people with dementia in Kerala, India. The development process is framed within the context of social globalisation. The central aim of the thesis is to further build theory on how and why social policy from one context is transferred and utilised in the development of social policy in another. The theoretical constructs of policy transfer and policy translation are used to explore the development process. Policy transfer is an existing concept within policy and politics literature. Theory on the concept of policy translation is built up within the thesis using theories of literary translation.

Exploration of these processes provides an explanation of the development of day care. Policy transfer and policy translation are found to take place between the UK and Kerala. Policy ideas and information from the UK are transferred and then used within the implementation of day care in Kerala. A two-part research design explores firstly policy transfer and then policy translation. Policy transfer is examined within an analytical framework developed from existing models of policy transfer. Policy translation is investigated through a comparative analysis of day care for people with dementia between the UK and Kerala. The differences between day care in the two contexts represent the changes caused by the processes of policy transfer and policy translation.

The main findings of the thesis are that policy transfer and policy translation have taken place within the development of day care in Kerala. The two concepts are found to complement each other. The theoretical construct of policy translation

provides additional detail and clarity on the process of policy development to that provided by policy transfer. Policy transfer and policy translation can be described as mechanisms by which social globalisation is taking place and in turn globalisation promotes these processes. The thesis concludes that the theoretical constructs of policy transfer and policy translation as developed here could be used within other research to explore the processes of globalisation.

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## Glossary of terms and synonyms

<b>ADI</b>	Alzheimer's Disease International
<b>ARDSI</b>	Alzheimer's and Related Disorders Society of India
<b>AS-AD</b>	Alzheimer Scotland – Action on Dementia
<b>CGN</b>	community geriatric nurse – terminology for the care staff at the day care centres in Kerala
<b>NGO</b>	non-governmental organisation
<i>Ayurvedic</i>	a traditional system of Indian medicine
<i>Chinnan</i>	<i>Malayalam</i> term for an older person who shows signs of cognitive deterioration, for example, an older person who may speak to people who are already dead – see chapter 7
<i>Churidar</i>	Indian dress for women comprising a tunic and trouser suit with tight ruffled trousers and a scarf
<i>Malayalam</i>	local language spoken in Kerala
<i>Malayalee</i>	a person from Kerala
<i>Medhashayam</i>	an <i>Ayurvedic</i> term for brain disease – see chapter 7
<i>Mundu</i>	South Indian dress for men or women comprising a long cloth which is wrapped around the waist to form a skirt. The cloth may be fold up around the waist to shorten the skirt for ease of walking
<i>Salwar kameez</i>	Indian dress for women comprising a tunic and trouser suit with loose trousers and a scarf
<i>Sanyasa</i>	the final life-stage within traditional Hindu culture – see chapter

# **Chapter 1**

## **Introduction to the thesis**

### **Background**

This research developed following my experience working as a volunteer for the Alzheimer's and Related Disorders Society of India (ARDSI) in 1999. I spent six months working in Cochin and spent some of my time at the ARDSI day care centre for people with dementia. While there I became aware of the importance given to both people and literature from outside India, particularly from the UK and USA. I became interested in how information from outside India influenced the design of the day care centre. It also became apparent that although many aspects of the day centre were similar to those I had seen in the UK, there were more subtle differences. This led to the design of this thesis.

Demographic changes are taking place leading to an increase in the number of people with dementia around the world. They are also leading to changes in family and social organisation, which may affect the amount of informal care for vulnerable groups such as people with dementia. These changes are of greater magnitude and

are expected to have more of an impact in less developed regions. India is within a less developed region as defined by the United Nations (United Nations 2002). Demographic changes may lead to an increasing need for formal policy and formal care for people with dementia in India.

New services are being developed for people with dementia in India led by the ARDSI. Policy development is taking place within an unusual context. Individuals and organisations in less developed regions are developing policy and services in areas where there were none previously. These individuals and organisations have access to huge amounts of information from around the world. Access to this information has become easier with better communication and the development of the Internet. It is of interest to researchers and policy makers both how these individuals and organisations make choices about which information to use and how they use this information.

The specific focus of this thesis is the development of day care services for people with dementia recently established in Kerala, India. These services are run by a non-governmental organisation (NGO), the ARDSI. The research investigates the influence of policy and information from other countries on the development of day care in Kerala and the process through which this information was transferred and used to develop services.

## **Overall aim**

The central research aim is to develop theory on how and why social policy and service models from one context are transferred and then utilised within the development of social policy and services in a new context.

The wider aims of the thesis are to contribute to the body of knowledge regarding policy transfer and related processes and to provide useful information for actors engaged in the policy process in both less developed and developed regions.

The thesis is exploratory in nature and provides a rigorous investigation of one example of policy development. The research tracks the development of day care for people with dementia in Kerala from the initial perceived need for new policy through to the implementation of policy ideas and services. Policy transfer is described as 'the process by which actors borrow policies developed in one setting to develop programmes and policies within another' (Dolowitz and Marsh 1996:357). This research tests an analytical framework for the process of policy transfer in order to develop evidence-based theory regarding policy transfer. I argue that policy transfer is the fundamental process by which information is transferred between the UK and Kerala and that by using an analytical framework for policy transfer the process can be explained. I further argue, however, that the concept of policy transfer is limited in its ability to fully describe and explain the processes involved. The thesis goes on to develop the concept of policy translation to further explain the development and day to day functioning of day care for people with dementia in Kerala. I define policy translation as the process by which policy is altered and adapted as it is transferred and then implemented in a new context.

In the policy transfer literature the term 'policy' is used loosely and refers to social policy content and documents as well as services and practice. Within this thesis the term 'policy' is also used loosely within the definitions of policy transfer and policy translation as this allows them to be used flexibly within the analysis. However, attention is drawn to the specific meaning of the term as it is used. This thesis traces how social policy influences the development and functioning of services and investigates the relationship between policy, services and practice.

### **Specific objectives**

The thesis has two specific objectives. Firstly to investigate and then explain the process of development of day care for people with dementia in Kerala, India. Secondly to develop evidence-based theory on the processes of policy transfer and policy translation.

These objectives are met firstly by investigating how social policy and service models are transferred from the UK and other countries to Kerala. This represents the exploration of the process of policy transfer. Secondly by examining how policy and practice are adapted and enacted by the key actors in Kerala the process of policy translation is investigated.

### **Research questions**

The aims and objectives of the thesis are met by answering a series of specific research questions. These questions frame the research process and influence the

research design. The thesis investigates the process of policy transfer using an analytical framework developed from existing literature on policy transfer. The concept of policy translation is developed through this thesis. The research is split into two sections. The first section focusing on policy transfer and the second on policy translation.

1. What happened during the development of day care for people with dementia in Kerala, India?
2. What does this tell us about the process of policy transfer?
3. What happens at day care for people with dementia in Kerala?
4. What happens at day care for people with dementia in the UK?
5. What do the differences between the two contexts tell us about the process of adaptation and implementation in Kerala and, therefore, the concept of policy translation?

The first two research questions allow investigation and explanation of the process of policy transfer. The key actors in Kerala who were involved in the development of the ARDSI and its day centres are the main source of information regarding the policy transfer process. Data from interviews with these individuals are analysed alongside documentary evidence and the physical evidence of the day care services to elucidate the policy transfer process. I argue that policy transfer was the fundamental process observed during the research. It is expected that the UK is a key source for policy within the policy transfer process. However, the existing theoretical construct of policy transfer does not provide a complete explanation for what is observed.



The remaining questions are answered by looking in detail at day centres in Kerala and the UK. It is confirmed through the investigation of policy transfer that the UK is the main source of information and ideas for the development of the day care centres in Kerala. There is no specific model of day centre transferred rather an image of day care is transferred. This image is built up by the key actors using information and ideas from the UK. Within this research the day centres in the UK are used to represent the model of day care that the key actors in Kerala use during the policy transfer process.

When an existing policy is implemented within a new context factors within that context lead to changes in the policy. I argue that these changes include adaptations made by key actors as well as 'natural' changes that take place due to the culture of the target context. Social and cultural factors within the new context influence the new policy and alter it as the implementation process takes place. These changes to policy within Kerala are elucidated through comparison with services in the UK. The differences between day care in the two contexts represent these adaptations. These adaptations represent the process of policy translation.

A comparison is undertaken between day care in Kerala and the UK. This comparison takes place, therefore, between a state and a country. The choice to make the comparison in this manner was, as far as possible, to compare like with like. The population and size of India are too large for it to be considered as a single context in this thesis. There are wide cultural and social differences found across India and so I chose a single state as a suitable context for comparison. The other half of the comparison is the UK, a whole country, but the breadth of cultural differences across the UK is probably similar to those found across the single state of

Kerala in India. The specific day centres investigated in the UK are located in Scotland. I argue that the differences between Scotland the rest of the UK are insignificant compared with the differences between the UK and Kerala.

## **The thesis**

The thesis is split into three main sections. Chapters 2 to 5 comprise the literature and policy analysis. Chapter 6 outlines the methodology and research methods. The final five chapters provide analysis and discussion of the data collected.

The processes of policy transfer and policy translation provide a theoretical framework within which it is possible to describe and explain the process of development of the day care services in Kerala. These processes are discussed in chapter 2. This chapter also situates the thesis within the wider context of globalisation. There is a wide body of literature on the concept of policy transfer and other concepts relating to information transfer and policy learning. The policy transfer literature supports my argument that policy transfer is the relevant process within this thesis. An analytical framework of policy transfer is developed within this chapter. This is used within the analysis to explain the observed example of policy transfer. The review of the policy transfer literature exposes some shortcomings in the ability of the concept of policy transfer to explain what is observed within this thesis. In order to fully explain what is observed I develop the concept of policy translation. Theories of literary translation are used to develop the concept of policy translation. I argue that this concept enables a full explanation of what is observed.

The processes of policy transfer and policy translation take place between the UK and Kerala. They take place between two very different cultures. The culture of each permeates the social organisation and therefore the social policy, services and experiences of the people with dementia. The culture of each context, therefore, influences the processes of policy transfer and policy translation through the actions of the individuals involved and the social organisation within which they operate. I argue that the concept of culture is key within this thesis. Chapter 3 focuses on the concept of culture in particular with regard to ageing and dementia. The definition of culture is complex and contentious and a working definition for culture is developed. Culture affects the experience of people with dementia and the types of care they receive. Culture also affects the understanding and use of the concept of dementia. This chapter continues with a discussion on the different models of dementia and their relevance in the two contexts.

Chapter 4 develops the discussion of dementia and looks in detail at the experiences and situation of people with dementia in Kerala and the UK. Dementia has an age-related prevalence and therefore the situation of older people is also of interest within the thesis. Demographic changes are affecting 'culture' and through this the situation of people with dementia. The current situation of people with dementia in each context affects how and why services are developed. The situation of people with dementia is different in the two contexts due to differences in family structure and formal and informal care provision that is differences in the 'culture of care'.

Chapter 5 looks in detail at services and policy for people with dementia in the two contexts. Again these are shaped by 'culture'. Formal policy in each context

influences service provision for people with dementia and the role of day care within that. The development of day care in the UK has taken place over the past fifty years and the UK is often seen as a leader in this field. This may be one reason the key actors in Kerala chose the UK as a source of information and ideas. A comparative policy analysis provides more information on the 'culture of care' in each context. The 'culture of care' is a central component within the comparative analysis in this thesis.

Chapter 6 discusses the methodological stance of this thesis and the research design. The thesis is an ethnography of the development of day care for people with dementia in Kerala, India. The cross-national nature of the research is an important dimension of the research and presents challenges for the research design and for data collection. I aimed to be a good 'comparativist' within the thesis (Øyen 1990:5). The research involves people from different cultures and people with dementia and within this chapter I raise important issues concerning ethics and informed consent. An interpreter was used for part of the research in Kerala and this was an interesting part of the research process.

The remaining chapters comprise the analysis and discussion of the field data. The analysis begins by looking at the process of policy transfer. The analysis is based on a series of interviews with key actors in Kerala. The driving force for the process of policy transfer is identified, in essence, as one individual: Roy. Roy's own motivations and aspirations met with a growing awareness of dementia in India. This led to the development of the ARDSI and the subsequent development of day care services for people with dementia. The process of policy transfer, which initially led to the development of the ARDSI, continues over time and is central in the development and design of day care centres in Kerala. The chapter uses the analytical framework

developed in chapter 2. This analysis produces a comprehensive and clear explanation of the policy transfer process that led to the development of day care services in Kerala. The following chapters look more closely at the detail of this policy transfer and the current functioning of the day centres to elucidate the process of policy translation.

The process of policy translation is explored through a comparative analysis of the data from the UK and Kerala. This analysis is discussed in chapters 8 to 10. Each chapter explores a different level of analysis. The discussion in chapter 8 forms a practical comparison. In chapter 9 the behaviour of individuals is compared through exploration of specific aspects of day care. Chapter 10 draws ideas from throughout the thesis to explore the fundamental concepts that have been translated. Progression through these chapters deepens the understanding of policy translation.

The transfer of information involves communication between different groups of actors. The key actors in Kerala interpret and transfer information from the UK. They then pass this information on to the staff working in the day centres. The staff interpret this information and convert it into action as they enact their roles within the day care. Each of these processes involves communication. Communication is dependent on the knowledge and perception of each individual and as such is an inexact process. As each group interprets information a translation process takes place. The concept of policy translation is revisited in chapter 8 and the framework for its exploration is set out. The chapter continues by comparing practical aspects of day care. The practical differences start to elucidate the process of policy translation. They also link the analysis of policy transfer with that of policy translation.

Chapter 9 looks in detail at specific aspects of day care. These discussions allow detailed analysis of the day care centres and their functioning. The detail within the descriptions of activities at day care provides clear evidence for the process and cause of policy translation. The differences between the two contexts are further illustrated in the views and attitudes of the staff at each centre.

Chapters 8 and 9 highlight key concepts which have been transferred and translated within the development of day care for people with dementia in Kerala. The translation of these is explored in chapter 10. The translation of the concept of dementia is fundamental to the thesis. How dementia is conceptualised affects how the different actors behave and consequently the enactment of day care. The key actors and the day care workers use their own concept of dementia to define what day care is and what their roles are at day care. The conceptualisation of dementia is influenced by the culture of both the UK, from where the concept comes, and Kerala, where the concept is used.

The thesis concludes by returning to the research questions and central aim of the research. The final chapter further draws out the main conclusions from the research regarding the theoretical constructs of policy transfer and policy translation. It continues with discussion of the usefulness of the research and its relevance within the wider context of policy development in less developed regions of the world. The conclusion finishes with discussion of the issues highlighted by the thesis for further research.

## **Chapter 2**

### **The processes of policy transfer and policy translation**

#### **Introduction**

I argue that the theoretical constructs of policy transfer and policy translation provide a theoretical framework within which it is possible to describe and explain the process of development of day care in Kerala. I argue that the processes of policy transfer and policy translation are fundamental in this development.

The theory of policy transfer is explored within this thesis. The relevance of policy transfer within this thesis is illustrated by comparing it with similar concepts. These concepts are framed within a discussion on globalisation. The theoretical construct of policy transfer describes the process by which information moves between countries. It also offers an explanation of why this happens. The analytical framework developed here is evaluated through analysis of the data and from this analysis theory on policy transfer is further developed. The thesis provides a full and detailed analysis of an example of policy transfer.

I argue, however, that the concept of policy transfer is limited in its ability to describe the implementation and development processes of the transferred policy in the new context. In addition it does not offer an explanation of what happens to the information as it travels from one place to another, from one person to another. The policy transfer literature does not see this as problematic. It assumes that information is transferred as it is. The passing of information is communication. I argue that all communication is dependent on the perspectives of those involved. I further argue, therefore, that each stage in which information is transferred involves some form of translation. Translations take place even when the two people involved have the same natural language. If the two people come from different cultures and are speaking in a shared language these translation processes have more impact on the information. The different cultural perspectives of the people involved, therefore, affect the implementation of policy in a new context. When these translation processes result in the transfer of policy from one context to another it can be referred to as policy translation. The concept of policy translation is developed within this thesis<sup>1</sup>. The concept of translation is rarely used within social policy research. Freeman (2003b) discusses the process of translation in research on managed competition. Wilson also highlights translation processes within comparative social policy research (2001b). Theory is developed on policy translation taking ideas and inspiration from theories of literary translation.

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<sup>1</sup> The idea of policy translation originated from discussions with Dr. Richard Freeman, School of Social and Political Studies, University of Edinburgh.



## **Policy transfer and related concepts**

Policy transfer (Dolowitz and Marsh 1996:343) describes a process by which policy is transferred between different contexts. Policy transfer is one of a group of terms used to describe the movement of policies and ideas between countries and regions. These include convergence (Bennett 1991; Pollitt 2001), diffusion (Rogers 1962; Eyestone 1977) and lesson-drawing (Rose 1991). These concepts are related but differ in focus and the aspects of transfer they describe. In summary, convergence and diffusion refer to patterns of policy adoption, which can take place by a number of mechanisms. Lesson-drawing and policy transfer are mechanisms by which learning and transfer take place. These concepts may be generally described as policy learning (Freeman 2003c). Groups of transfers could lead to the patterns described by convergence and diffusion. All of the concepts discussed within this chapter, except for policy translation, are used within social policy literature. There is a lack of consistency between different sources in how the different concepts are used and this is often confusing. Within the following section I have tried to clarify these concepts and describe their relations to each other. Table 1 provides a summary and brief comparison of these concepts. The field of social care for people with dementia is the focus of this research but few studies are available which look at this in relation to policy transfer. One paper discusses policy transfer in the field of social care for older people in Europe (Tester and Freeman 1996). It is also unusual to examine an example of policy transfer between contexts as diverse as the UK and India. Most studies of policy transfer and related concepts within this field are undertaken within more developed regions (e.g. Dolowitz et al 1999; Jacobs and Barnett 2000).

**Table 1. Policy transfer and related concepts**

<b>Concept</b>	<b>Description</b>	<b>Relation to other concepts</b>
Policy Transfer	The transfer of ideas, information and other components of policy from one location to another. This transfer can be undertaken by a range of individuals and groups and can be voluntary or involuntary.	Policy transfer is mechanistic and is described within a single timeframe. Voluntary policy transfer relates closely to lesson-drawing. Policy transfer may be a mechanism by which convergence or diffusion takes place.
Convergence	A concept describing a pattern of policy development across time and across different countries whereby different countries or regions develop similar policies.	Convergence is closely related to diffusion, which also describes patterns of policy adoption. Convergence may occur as a result of policy transfer or lesson-drawing between different countries or regions.
Diffusion	This describes the pattern of spread of policies across different countries or regions. Policies are adopted by different countries and thus 'diffuse' across borders.	Diffusion is closely related to convergence as stated above. Again, policy transfer and lesson-drawing may be seen as mechanisms of diffusion.
Lesson-drawing	This describes a voluntary process of policy learning taking place between regions or countries. Actors or groups in one country actively search for policy solutions in different countries or regions.	Lesson-drawing is closely related to policy transfer, it could be described as voluntary policy transfer. Lesson-drawing could be a mechanism by which convergence or diffusion takes place.

Examples of policy transfer and its related concepts are becoming more common with increasing globalisation (Evans and Davies 1999; Common 1998; Dolowitz 2000). The definition of globalisation is contentious and much debated. Giddens describes globalisation as 'the intensification of world wide social relations' (1990:64). Globalisation is often thought of as the compression of time and space allowing closer relations across wide distances (Hoogvelt 2001; Kiely 1998). In summary 'globalisation refers to a world in which societies, cultures, politics and

economies have, in some sense, come closer together' (Kiely 1998:3). Although the definition of the term globalisation is contentious there are changes that are taking place across the world which are resulting in similarities between nations and could be said to constitute globalisation (Evans and Davies 1999).

Globalisation can be described on different levels, as economic, political or social (Hoogvelt 2001). Within this thesis it is the idea of social globalisation that is relevant. Globalisation in general has 'increased the demand for policy transfer' (Wilson 2001b). Social globalisation encourages transfer and provides an environment in which transfer and learning between countries can take place. The development of day care for people with dementia in Kerala came about following and because of the development of social relations between countries. Globalisation increases the opportunities for policy transfer and policy transfer itself facilitates globalisation (Evans and Davies 1999:371). In the same way globalisation affects the individual but it may also be that the individual affects globalisation (Kong 1999:219). The ability to participate in globalisation depends, however, on access to the global world and is thus not possible for everyone (Hoogvelt 2001; Kiely 1998). This thesis frames policy transfer within the context of globalisation and looks at the ability of individuals to participate in and influence social globalisation.

It is widely accepted that learning and policy transfer take place between and within regions and countries. There are two common misconceptions about policy transfer and related concepts that affect how it is studied and identified. These can be described as the 'world cup' fallacy and the 'comparative difference' fallacy (Marmor 1997:348). The world cup fallacy assumes that countries are free to pick and choose the best policies available. At the other extreme the comparative fallacy denies that

there is any possibility of policy transfer or learning due to the social, cultural and historical differences found between countries (Marmor 1997). It seems probable that the actual situation is somewhere between the two. A growing number of studies have found evidence of policy transfer between countries (e.g. Common 1998; Dolowitz et al. 1999; Tester and Freeman 1996; Jacobs and Barnett 2000).

The study of policy transfer is a multi-disciplinary process and this can be advantageous as well as disadvantageous. It is a disadvantage in that policy transfer could be said to lack a common theoretical standpoint (Evans and Davies 1999). Policy transfer can, however, provide a framework to study common concerns across nations and disciplines. For example, the transfer of public health policies is of interest to health professionals, politicians and economists (Evans and Davies 1999). Policy transfer allows investigation of global, international, trans-national, and domestic structures and their influence on policy development (Evans and Davies 1999:367). Evans and Davies clarify their definition of policy transfer as 'an action-orientated intentional activity' involving an 'agent of transfer' (1999:366). They stress that analysis of policy transfer should be limited to these types of transfer and this thesis explores such an example. Further discussion on the related concepts of convergence, diffusion and lesson-drawing helps to clarify and illustrate the concept of policy transfer.

## Convergence

'Convergence' is often used at the macro level to describe wide ranging similarities found across countries. It is defined as 'the tendency of societies to grow more alike, to develop similarities in structures, processes and performance' (Kerr

1983:3). The process of modernisation following industrialisation is seen as a convergent process with a possible outcome being that all countries will reach a similar endpoint (Bennett 1991). Statistics are often used to show patterns of convergence across countries and figures of economic development can be used to support the theory of convergence (Bennett 1991). More recent arguments question the extent of convergence as a real phenomenon but agree that it does take place to some extent (Pollitt 2001). Some of the processes of convergence involve policy transfer, lesson-drawing or diffusion. It is also possible to use the term convergence at a policy level, policy convergence, to describe the adoption of similar policies by different countries. It is important to make the distinction that convergence relates to a process, not a state of being, so it must be studied over time.

A review of studies of policy convergence in advanced industrialised states found four processes through which convergence takes place (Bennett 1991). The four processes identified as processes of convergence are emulation, elite networking, harmonisation and penetration (Bennett 1991:215). Emulation is most relevant here as it involves lesson-drawing and could be thought of as a type of policy transfer. The concepts of convergence and policy transfer are, therefore, not unrelated but describe different aspects of policy change. Policy transfer could be described as a mechanism of convergence.

### Diffusion

The concept of diffusion relates to 'any pattern of successive adoptions of a policy innovation' (Eyestone 1977:441). Studies of diffusion look at patterns of policy adoption with little reference to underlying mechanisms. Diffusion is used to describe

patterns at both a micro and macro level. Diffusion studies assume common problems and the appropriate common responses and do not account for values and political cultures (Rose 1991:9). The neglect of culture and process means that diffusion does not provide a useful concept for research. As with convergence diffusion relates to a process happening in more than one place and policy transfer may be described as a mechanism of diffusion.

### Lesson-drawing

'Lesson-drawing' describes a deliberate choice to learn about policy from another country (Rose 1991:7). Lesson-drawing implies that the actors involved have choice in the adoption of policy and that they learn the new policy voluntarily (Rose 1991). Policy transfer as a concept includes both voluntary and involuntary adoption of policy. Lesson-drawing, therefore, could be described as voluntary policy transfer (Dolowitz and Marsh 1996). Lesson-drawing need not result in the transfer of ideas or policy. A negative lesson may be drawn on what not to do (Dolowitz and Marsh 1996). Lessons are sought across time and/or place to provide new solutions for existing problems (Rose 1991). Lesson-drawing takes place at the level of policy programmes, that is, at the micro level.

The discussion of lesson-drawing by Rose (1991) introduces some important points about the process of policy transfer. Rose (1991) argues that it is not normal for policy makers to look elsewhere for ideas for policy change. A high degree of dissatisfaction with existing policies leads policy makers to risk uncertainties in adopting policies from other countries (Rose 1991). Policy makers are more likely to look to countries or organisations with a lot of experience with a particular programme

or within a particular field. Rose argues that the search for new policy is expected to follow the path of least resistance as time and capacity of policy makers is generally very limited (1991:13). This may be the case but I argue that the individuals involved in lesson-drawing each have their own perspective and motivations. These may influence their search for policy ideas more strongly than simply following the path of least resistance. Where to search may be driven by similarity between countries. A subjective identification with another region is more important than physical proximity (Rose 1991:14). Individuals in the UK are more likely to look to the USA rather than physically closer European countries as there is felt to be more common ground in policy and politics (Dolowitz et al. 1999). 'In East Asia the colonial legacy remains strong enough for policy transfers to occur between the former colonising powers and the territories they used to dominate' (Common 1998:447). Thus in this example individuals in India may look to the UK for policy ideas.

Creating new policy using information from another country is seldom as simple as copying. The policy needs to be adapted to fit the new context. This seems an important point and one central to this thesis. Rose describes four levels or degrees of lesson-drawing from emulation through to inspiration (1991:22). These are similar to the degrees of policy transfer discussed below. In this thesis the process of policy adaptation and implementation is described as one of policy translation and is discussed below. Degrees of lesson-drawing may be analogous with degrees or types of translation.

## **Policy transfer**

Policy transfer is described as:

'a process in which knowledge about policies, administrative arrangements, institutions etc. in one time and/or place is used in the development of policies, administration arrangements, institutions etc. in another time and/or place' (Dolowitz and Marsh 1996:344).

This definition appeared to fit with what I thought had happened in the development of day care for people with dementia in Kerala. I expected that policy transfer would be a fundamental process within the development of day care. The choice of the concept of policy transfer for use in this thesis was also related to the multi-disciplinary nature of the concept and the models of policy transfer proposed by Dolowitz (2000) and Evans and Davies (1999).

Both models allow investigation of the whole process of policy transfer (Dolowitz 2000; Evans and Davies 1999). The models both describe the process of policy transfer and illustrate how policy transfer can help to explain the development of policy. A good study of policy transfer places it within a framework of 'agency and structure' and using these models allows such a study to be completed (Evans and Davies 1999:373). Evans and Davies' (1999) model comprises a multi-level analysis and a twelve step model of the policy transfer process. Dolowitz's (2000) model consists of nine questions which when answered provide a full description and explanation of an example of policy transfer. These models provide a useful theoretical context within which to analyse policy transfer.

Dolowitz's (2000:9) nine questions are:

- Why and when do actors engage in policy transfer?
- Who transfers policy?
- What is transferred?



- From where are lessons drawn?
- Are there different degrees of transfer?
- When do actors engage in policy transfer and how does this affect the policy making and policy transfer processes?
- What restricts policy transfer?
- How can researchers begin demonstrating the occurrence of policy transfer?
- How can policy transfer help our understanding of policy failure?

Each of these questions highlights an element of policy transfer and the model provides one approach to analysing the process of policy transfer. This model appears useful in clarifying and elucidating the policy transfer process (2000). It makes sense to ask who was involved in the policy transfer and to investigate their motivations. It also seems important to ask when the transfer took place and what was transferred. The two contexts between which the policy transfer takes place are also important in explaining the process of policy transfer. The two contexts and the individuals involved may either facilitate or restrain the policy transfer process. It also seems important to ask about the degree to which the transfer takes place. Thus the first seven questions of Dolowitz's (2000) model appear useful. Within this thesis these seven questions are slightly simplified to aid empirical investigation and they provide the basis for the analytical framework of policy transfer used here. The details of how each question contributes to the overall analysis of the policy transfer process are discussed below.

I have not included Dolowitz's (2000) final two questions. The question of how researchers can begin demonstrating the occurrence of policy transfer is answered by

this research. The thesis provides an example of a full and detailed analysis of an example of policy transfer. The approach taken within this thesis could be used within other empirical work. Dolowitz also asks how policy transfer can help our understanding of policy failure. This thesis does not begin to answer this question. An evaluative component would need to be added to the research design in order to assess the success or failure of the transferred policy. Dolowitz also asks how policy transfer affects the policy making process. The policy making and implementation processes are examined in detail through the concept of policy translation. More detail on how the two concepts relate to each other is given in a later section on policy translation.

The model developed by Evans and Davies (1999) is quite different in nature from that of Dolowitz (2000) but the two models complement each other. While Dolowitz's model looks at the elements of the policy transfer process in turn Evans and Davies' model describes a twelve step pathway along which the policy transfer process progresses (Evans and Davies 1999). The twelve steps are: recognition, search, contact, emergence of information feeder network, cognition and reception, emergence of transfer network, elite and cognitive mobilization, interaction, evaluation, decision enters policy stream, process and outcome (Evans and Davies 1999:378). The specific steps of this model are discussed below within the analytical framework developed for this thesis. Evans and Davies (1999) introduce two interesting concepts, the policy transfer network and the agent of policy transfer. A policy transfer network is similar to an epistemic community and both are discussed further below. Evans and Davies talk of both the agent of transfer and the client of transfer (1999). The agent is the individual or group who collects information and presents it to the client persuading them to go ahead with the policy transfer process. Within this

research it is not clear that different people fill these roles. It appears that the agent and client maybe the same individual. Evans and Davies model also includes the different levels at which policy transfer takes place. These are global, international, trans-national and domestic (1999:367). These different levels and their relevance are considered within the analysis.

Evans and Davies (1999) also start to talk about how policy transfer takes place. The question of 'how' is also highlighted within Dolowitz's (2000) discussion. I argue that for a full understanding of policy transfer the question of how it takes place should be answered and, therefore, include this question within the analytical framework used in this thesis. Eight questions form the analytical framework. Each of these questions is discussed below and detail is given on their importance and how they would fit into a pathway model of policy transfer like that of Evans and Davies (1999). The eight questions are:

- Who is involved in the transfer?
- What influences the timing of the transfer?
- Why does the transfer take place?
- What is transferred?
- From where is the policy transferred?
- How does the transfer take place?
- What constrains or facilitates the transfer?
- To what degree does the transfer take place?

## Who is involved in the transfer?

The question of who transfers policy relates to Evans and Davies' 'agent of transfer' (1999:368). Dolowitz proposes nine categories of actors and organisations who may be an agent of transfer: elected officials, bureaucrats and civil servants, policy entrepreneurs and experts, consultants, political parties, pressure groups, think tanks, corporations and both governmental and non-governmental international organisations and institutions (Dolowitz 2000:17). It is likely that a combination of these categories is involved in any example of policy transfer. Political parties may also use policy transfer. For example the use of ideas from the USA by the UK Labour party in the late 1990s to increase electoral appeal (Dolowitz et al. 1999). Policy transfer can be a top-down or bottom-up process. In the field of care for older people innovations by individuals involved in organisations providing care may lead to changes in policy at a higher level (Tester and Freeman 1996). International NGOs are also becoming more influential in the spread of ideas and policy around the world (Clarke 1998; Koehn and Rosenau 2002; Dolowitz 2000). International NGOs may be influential in guiding how issues become of global concern (Koehn and Rosenau 2002). In this example Alzheimer's Disease International (ADI) may influence the development of policy in different countries. It is expected that the role of policy entrepreneurs rather than government policy makers will be important in this thesis.

There are various kinds of networks involved in the spread of policy and they can be influential. Epistemic communities are an example of this (Haas 1992:1). An epistemic community

'is a network of professionals with recognised expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue area' (Haas 1992:3).

These communities are becoming increasingly relevant in policy development (Adler and Haas 1992). An epistemic community may act as an agent of transfer. Some evidence from the field of social care for older people suggests that informal networks of actors may be more influential in policy development than formal national or international organisations (Tester and Freeman 1996:16). Evans and Davies propose the idea of policy transfer networks (1999). These link policy communities with epistemic communities for the duration of the policy transfer process and facilitate information transfer between different groups and individuals.

### What influences the timing of the transfer?

The timing of policy transfer relates to the third question, which asks why policy transfer takes place. The two questions are closely related. Why an individual or group undertake policy transfer influences when this transfer takes place. Conversely the timing of policy transfer may provide information on the motivations of the individuals involved.

### Why does the transfer take place?

The reasons why policy transfer takes place can be described as a continuum from voluntary transfer to coercive transfer (Dolowitz and Marsh 1996). Voluntary transfer is the same as positive lesson-drawing and occurs in response to dissatisfaction with the status quo (Rose 1991; Dolowitz and Marsh 1996). Coercive transfer describes situations where external actors impose a change in policy. A single example of policy transfer may occur for a variety of reasons both voluntary and coercive. The pressure to undertake policy transfer is subjective and takes place in

response to a need for change and dissatisfaction with the status quo. This relates to the 'recognition' element of the Evans and Davies model wherein a need for policy change is recognised, initiating a search for ideas (1999:377). Actors involved in policy transfer work from their own viewpoint with limited information and under time and capacity pressures. This affects why a specific policy transfer takes place (Haas 1992; Marmor 1997; Dolowitz 2000).

International generalisations exist which are often more influential on policy than regional variations and may initiate the search for policy ideas in different countries leading to policy transfer (Marmor 1997). 'Crisis mongering' about policy issues can increase policy transfer if a nation feels it may be facing a similar crisis as other countries (Marmor 1997:350). An example of this is the spread of privatisation across Europe. The increasing numbers of older people around the world is often associated with a crisis. This may well be influential in the spread of policies between countries. All industrial countries face similar issues with respect to older people and so similar policies may be adopted (Tester and Freeman 1996).

### What is transferred?

What is transferred can be split into six general categories. These are policy goals, policy content and instruments, programmes, institutions, ideologies, ideas and attitudes and negative lessons (Dolowitz 2000:23). The term policy used in policy transfer refers to one or more of these categories. One or more may be transferred in any example of policy transfer. In this thesis it is expected that several of these categories have been transferred to enable the establishment of a range of programmes and services. The evaluation element of Evans and Davies' pathway is

where the client decides what should be transferred (1999:379). They place this decision late on in the pathway once the policy transfer network is established.

### From where is the policy transferred?

Policy can be drawn from international, national or local sources. It is also possible to search in time (Rose 1991). As discussed above a 'subjective definition of proximity' guides where to look for new policy (Rose 1991:3). The transfer in this research takes place between the UK and India. Developing countries have an advantage in that they can learn from both more developed and less developed countries (Mishra 1998:488). This relates to Evans and Davies' search element within their pathway (1999). Evans and Davies stress there are different levels at which policy transfer takes place and also stress that it is often an interdisciplinary process (1999). Agents of policy transfer may draw information and ideas from a wide range of sources. Freeman (2003b) concludes that simple transfer between two points is less common than thought. He describes a 'policy bagatelle' within which policy ideas and information 'bounce' between different people and different locations (2003b:2).

### How does the transfer take place?

Dolowitz (2000) does not specifically discuss how policy transfer takes place. Within his model the question of how the transfer takes place is answered through the other questions. Evans and Davies (1999) discuss the formation of a policy network as the mechanism by which transfer takes place. Freeman (2003c) looks in more detail at how transfer takes place in a study of cross-national learning. Voluntary policy transfer is similar to lesson-drawing and policy learning. Freeman finds four

methods by which cross-national learning takes place (2003c). Firstly individuals learn from other countries through literature, particularly academic journals. Secondly individuals learn through attending conferences. Thirdly they learn through informal visits to services in other countries or by being visited by others. The final method by which learning takes place is through formal exchange programmes. In any example of policy transfer one or more of these methods may be relevant.

### What constrains or facilitates the transfer?

Policy transfer is facilitated and/or constrained by various factors both within and outwith individual nations. Each nation has an inherent social, political and cultural structure, which affects which policies are transferred and how this takes place (Dolowitz 2000). Dolowitz suggests seven broad categories that restrain or facilitate policy transfer: policy complexity, interactive effects, institutional constraints, feasibility constraints, past relationships and language constraints (2000:26). Institutional and structural constraints may either facilitate or restrict policy transfer depending on the similarity of the countries between which the policy transfer is taking place (Marmor 1997). Germany's complex public policy structure inhibits their ability to transfer policy from other countries (Tester and Freeman 1996:14). Political ideology can produce resistance to transfer policy from particular countries. Ireland is reluctant to transfer policy from the UK for historical reasons (Tester and Freeman 1996:14). It is also necessary to have the technical ability in the receiving country as well as the necessary skills and resources to implement and run the new policy (Koehn and Rosenau 2002). Language is very important as, even in countries with the same language, there may not be equivalence of terms within the policy literature (Tester and Freeman 1996; Tester 1999; Wilson 2001b). Where different languages are



involved then the policy transfer process is more complex and limited due to the language constraints. This question begins to suggest the influence of culture on the process of policy transfer although this idea is rarely emphasised within the literature. This appears to be a shortcoming of the concept of policy transfer that is addressed within this thesis through the development of the concept of policy translation.

### To what degree does the transfer take place?

Transfer is rarely all or nothing; policies may be adapted to fit their new context and may not be transferred in full. There are four levels of transfer given, which relate loosely to the degrees of lesson-drawing (Dolowitz 2000; Rose 1991). These are copying, emulation, combinations and inspiration (Dolowitz 2000:25). There is some debate as to whether copying can actually take place when a policy is transferred as there are inherent differences in the new context which affect the policy transferred. Actors within a policy transfer network may decide not to transfer a complete policy but may transfer just parts of it (e.g. Hulme 2000). Discussion of examples of policy transfer and related concepts may also be overstated in many incidences and may only reflect adoption of particular words and phrases without adoption of an actual policy (Marmor 1997; Pollitt 2001). I conclude that policy transfer, therefore, may not be a purely free and rational process but is possible in some form. Again the cultures of the two contexts between which policy is transferred affect to what degree policy is transferred.

The degree to which policy transfer takes place relates to the implementation process, the process element in Evans and Davies model (1999:379). Dolowitz also mentions the effect policy transfer has on the policy making process (2000). The

manner in which policy is implemented following transfer is not, however, emphasised within the policy transfer literature. I argue that this should be emphasised and that the process of transfer strongly affects the policy as it is transferred and implemented.

So far I have argued that policy transfer is a useful field for study as it helps to increase understanding of the policy making process and extends the focus of policy analysis. Policy transfer provides a mechanistic framework for understanding the processes involved. The policy transfer literature provides a good theoretical background in which to develop the analysis in this thesis. I argue, however, that there are limits to the current understanding of the concept of policy transfer. The mechanistic approach limits understanding of the policy development process as it treats it as a rational process and does not allow for the emergent nature of policy. The concept of policy transfer and the models discussed above do not allow for detailed investigation of policy implementation and development. The questions of degree of policy transfer and what constrains policy transfer go some way to thinking about the process of policy implementation. I did not feel, however, they would be sufficient in explaining my data. Therefore I developed the concept of policy translation to further develop my analysis.

The concept of policy transfer draws attention to how the transfer and implementation processes alter what is being transferred. These changes are a result of the communication processes involved, which in turn are influenced by the perspectives of the individuals involved. Communication itself is an imperfect process which is influenced by individual interpretation. The interpretation process alters the information being communicated and this process could be described as translation. Each step in a chain of communications involves some sort of translation. In this

research, information about day care in the UK was translated in two steps to produce day care centres in Kerala. Firstly the information and ideas in the UK are interpreted and learnt by key actors from Kerala. These individuals form their own images of what day care is. They in turn communicate these to the staff who are involved in the running of the day care centres. The staff running the centres then interpret this information and put it into action. The first step runs along side the policy transfer process described above and the second step follows on from it. A full discussion of the concept of translation is undertaken below with a final definition developed for it.

## **Policy translation**

Policy translation is defined within this thesis as the process by which policy is altered and adapted as it is transferred and then implemented in a new context. The theoretical construct of policy translation is developed using literary translation as an analogy. The changes made to the policy as it is transferred involve both deliberate adaptations by the individuals involved and 'natural' changes that occur due to the differences in the new context. Literary translation theories are used to help to elucidate and explain what is meant by policy translation. There are many different types of translation and different approaches to the process.

Translation is most commonly thought of within literature, the translation of the written word of one language into another. Put simply to translate is to 'express the sense of (words or text) in another language' (Oxford English Dictionary 1999). Translation also has a secondary meaning as 'the process of moving something from one place to another' (Oxford English Dictionary 1999). So there is both a language or meaning component and one of movement between two contexts.

'The single movement of adoption/adaptation (of policy) can be described as translation' (Freeman 2003b:5).

'The critical element in translation, crucial to understanding it, is the change it brings about: change in the substance or significance of the source and in the character of the target' (Freeman 2003a:6).

The process of translation alters the text as it is translated. In the same way the process of policy translation alters the policy as it is translated.

Translation involves communication and change. Communication takes place through a system of signs, which are determined by social convention (Freeman 2003a:6). Each individual interprets communication from their own perspective and in a unique manner. Communication is, therefore, inexact. Communication could be described as a series of translations, each person translating what they are told or what they see. Communication between two people who do not share the same first language probably involves more of a translation process and is less accurate than communication between two people with the same first language. The steps in the policy transfer and policy translation processes all involve communication and therefore, translation. Translation is an active process within which the translator 'creates' the new text (Freeman 2003b). In the same manner the policy translators in this thesis create new policy in Kerala as they translate the UK policy.

Translation is not a straightforward process and is influenced by the perspective of the translator. Translation methods relate to ideology and therefore to the individual translator's culture (Toury 1995:65). How a text is translated depends on the original context/culture and the target context/culture. The concept of culture is explored fully in chapter 3. The relationship between the two contexts affects the approach to translation and the resulting translated text. Thinking about the process

of policy transfer it is possible to see how culture has influenced the process. The questions of where individuals look for ideas and information and the choices they make about what to transfer are all related to their cultural perspectives. In the same way the approach taken by a policy translator on how they translate the information depends on their cultural perspective. They find information and ideas and translate these into their own culture. They then pass on this information to others involved in the policy and further translation processes take place. Some of these translations are cross-national and involve translation from one language to another, from one culture to another. Other translations are within one language and one culture but from different perspectives within those.

Translation is much debated and many theories have been put forward to explain and provide methods for translation (France 2000). It is possible to describe these as a continuum from word-for-word translation and literal translation through to free translation and adaptation (Newmark 1988:45). These extremes are also described as 'pedantic literalism' and 'licentious imitation' (France 2000:4). Word-for-word translation means that the words in the original are kept in the same order and translated singly using their most common meanings. The main use of this approach is to understand the mechanics of the original or as a first stage in translation. Adaptation is the 'freest form of translation' often used for plays and poetry where themes and plots within the original are preserved while the detail is not (Newmark 1988:46). To think of these in service terms word-for-word translation might represent a situation where each element of a service is copied in the target context. An adaptation would represent the development of a new service in the target context based on the general aims and outcomes of the original service. An ideal translation is one that 'meets the original as an equal' (Steiner cited in France 2000:6).

The different approaches to translation may reflect different aims of translators. In this research there are different levels at which translation takes place and the actors at each level have different motivations and aims and, therefore, use different methods of translation. The main agent in the translation process, the translator, is the source of that particular text for the target context or audience. The translation proceeds according to what the translator decides is appropriate and feasible dependent on culture and ideology (Hermans 2000:11). The policy maker in the new context translates the policy in a manner that is appropriate and feasible for his/her culture and ideology. The translated text has to find a place within the target culture while 'it points back towards the source text about which and for which it speaks' (Hermans 2000:13). The translated text must fit in the new culture, although it is unlikely that the 'otherness' of the source will be lost altogether (Hermans 2000:13). The new policy or service should fit in the target culture, which in this research is Kerala. It seems likely, however, that it will retain some accent from the original source, the UK. 'Translated texts invariably signal to textual models of at least two cultures at once' (Hermans 2000:13). The day care centres in Kerala will have elements of the culture of both Kerala and the UK.

The different types of translation result in very different outcomes. When using an approach like word-for-word translation the outcome does not look familiar within the target context, it looks foreign. This type of outcome results from a translation aim known as 'foreignisation' (France 2000:8). This approach to translation results in a product that is somewhere between the two languages but with a strong sense of the original language. This approach is more commonly used for translations of poetry rather than fiction for which the story is more important than the structure and detail of

the text (France 2000). Maintaining aspects of the original language and trying to replicate specific features of the original results in a text that may strike the reader in the target language as odd. Foreignisation may be a product of poor translation but it may also be a deliberate choice of the translator. The translator may want to 'confront the reader with a new or alien world' (France 2000:9.). This approach to translation suggests a respect for the original text and a desire to maintain as much of the original as possible within the translated text. It may also issue a challenge to the norms of the target culture (France 2000:9).

When using this analogy for services it could be the case that policy makers in the target context think that services in other places are better than those in their context. Alternatively there may be no such services in their context. Policy makers would be expected to pursue a process of foreignisation if they want to produce something new and original for their country and to produce something that would stand out from what other people were doing. It may also imply that they have more respect for other countries and so seek to emulate services in another country rather than produce services which fit comfortably in their local culture. When describing a translation process where the translator has respect for the original some would say that there is subjugation to the original. There is a power relationship with the original text where its author subjugates the translator (France 2000). Others argue that this respect implies dialogue with the original rather than subjugation to it (Masson 1995 cited in France 2000:8). Translation generally, however, can be described as a hierarchical relationship whereby the original author of the text is above the translator (Simon 2000).

At the opposite end of the continuum of approaches to translation there is adaptation. Where a process of adaptation is used the translated text fits within the target culture. The text looks familiar in the new context. This type of approach relates to the ideas of 'acceptability', 'annexation' and 'domestication' and is a common approach to translation (France 2000:9). These terms all relate to the fact that the translated text fits well within the target culture. The result of such an approach is a text which creates the illusion 'of a text originally, 'naturally' written in the target language' (France 2000:4). In this type of translation the original source is hidden and the resultant text familiar and culturally appropriate. It, however, lacks all elements of the original. The motivation of a translator using this approach is to produce a user-friendly text, which can be widely read and appreciated in the target culture. If we think about services the motivation may be similar. To produce a service that is popular and useful in the target context. Another reason is that the translator is trying to make sense of the original text. They translate it so that it is easier to understand and makes sense in the target context. The staff within day care in Kerala are trying to understand the information they are given about day care in the UK. They 'domesticate' this information to produce a day care service that makes sense to them.

These two extremes of translation provide two illustrations of approaches to the process of policy translation. The terms suggest a tension between the original and the translated text. Translators could be described as either resisting the original, in the case of domestication, or having an affinity with the original, in the case of foreignisation. These tensions affect the outcome, in this case the enactment of day care in Kerala. The terms foreignisation and domestication are used within the analysis of the data to describe and explain the processes of translation. The terms



are used to further explore the process of policy translation and explain what is observed.

## **Conclusion**

Within this chapter I argue that the concepts of policy transfer and policy translation provide a theoretical basis from which to explain the development of day care for people with dementia in Kerala. The development of day care in Kerala takes place within the wider context of globalisation. I argue that the process of policy transfer is on one hand encouraged by globalisation and on the other it is a process by which globalisation takes place. By framing my thesis within the construct of globalisation I place my research within a wide context. I have used the existing models of policy transfer proposed by Dolowitz (2000) and Evans and Davies (1999) to provide the background for the analytical framework developed and used within this thesis. I conclude that by using this analytical framework it is possible to further understand the development of day care. The analysis also assess the usefulness of such an approach to the study of policy transfer.

However, I argue that policy transfer does not provide a complete explanation for what is observed in the development of day care for people with dementia in Kerala. Within the existing literature on policy transfer little is said about the actual processes involved and the influence of the transfer process on what is being transferred. I argue that the process of transfer and the following process of implementation alter the information and ideas being transferred. I conclude that these alterations are the result of translation processes, which take place alongside and following on from the policy transfer process.

Policy translation is a process which occurs through the policy transfer process and then continues as a service is developed and implemented in a new location. The ideas acquired through policy transfer are implemented in a new location and during this process translation takes place. I have shown that this translation process is analogous with literary translation. Literary translation theories help to elucidate and explain what is meant by policy translation. I argue that concepts such as foreignisation and domestication deepen the analysis in this thesis and have explanatory power. The changes made to the policy as it is transferred involve both deliberate adaptations by the individuals involved and 'natural' changes that occur due to the differences in the new context. These processes involve communication and are dependent on language and culture and I conclude that this makes the literary analogy useful and apposite. However, I argue that there are limits to this analogy. Services are complex and involve a variety of individuals making the translation process for services more complicated than that for text. This thesis explores this definition of policy translation and assesses its usefulness.

Throughout this chapter I argue that the influence of culture within the two contexts, both on policy and on the individuals and groups involved, is fundamental but rarely mentioned within the policy transfer literature. I conclude that culture is an important influence within the processes of policy transfer and policy translation. This chapter has outlined the theoretical framework within which the development of day care for people with dementia in Kerala is explored. The following three chapters provide the details of the two contexts between which the transfer and translation processes have taken place. They provide discussions on the culture of the two

contexts. These discussions are central to gaining a full understanding of the processes of transfer and translation.

## **Chapter 3**

### **Culture – ageing and dementia**

#### **Introduction**

I have established that culture is a fundamental influence on the processes of policy transfer and policy translation. The culture of the two contexts between which transfer and translation take place is central within this analysis. The relationship between these two cultures is important in determining the processes observed. As discussed in the previous chapter the influence of culture is central to the theoretical construct of policy translation and it is also important in determining different aspects of the policy transfer process. I argue that understanding the cultural context is a basic requirement to understanding these two processes. Without a full description and investigation of the cultural background of the two contexts it is not possible to fully explain the processes of policy transfer and policy translation. The different actors involved, the agents of transfer and the translators work from their own perspectives, within their own cultural frameworks.

This and the following two chapters provide a comprehensive picture of the two cultures in relation to day care for people with dementia. These chapters describe the cultural context in which the day centres and the individuals who work in them are embedded. Culture influences the development and functioning of day care through the actions of individuals involved and through the social organisation within which day care is situated. This chapter looks at the concept of culture and how it relates to ageing and dementia in the two contexts. Chapter 4 brings the focus down onto the situation of people with dementia in the two contexts and the role of culture within them. Chapter 5 discusses formal care and social policy for people with dementia in the two contexts again emphasising the role of culture within them.

This chapter begins with a discussion on the concept of culture. This is not a simple concept to define and a working definition is developed from the literature for use in this thesis. In this chapter the focus is on how culture influences the image and experiences of older people and people with dementia in the UK and Kerala. Central to this discussion is how dementia is conceptualised in each context and different models of dementia are examined in this light. Most discussion on models of dementia has taken place in developed regions of the world. The chapter ends with a discussion of their relevance in less developed countries such as India. The chapter concludes by comparing the culture of each context and looking at its influence on the image of people with dementia and the relevance of this within the development and functioning of day care for people with dementia.

## **The concept of culture**

There is an extensive literature on what constitutes culture. It is a complex concept and is not fixed in time or place. It is problematic and contentious to define and is, therefore, defined in many different ways (Frow and Morris 2000). These problems are illustrated by the definition given by Lisle (1985:16):

'culture comprises institutions, customs, traditions, value systems, life styles, language(s), mindset etc. which characterise a human society and which govern the behaviour of its members.'

This definition illustrates the breadth of 'culture' but is of little use as it includes a range of concepts which themselves require more careful definition such as 'mindset' and 'traditions'.

Geertz (1973) discusses many different possible definitions of culture. Two definitions from the work of Kluckhohn (cited in Geertz 1973:4) illustrate an all encompassing, simple approach to culture. These are 'the total way of life of a people' and 'the social legacy the individual acquires from his group.' Both definitions are useful for clarifying what is meant by the concept of culture. Sokolovsky (1990:2) defines culture as 'patterns of created ideology, social organisation and the ways people produce and distribute valued objects.' Victor (1994) also discusses the formation of social organisation as being dependent on dominant cultural values. It is accepted that social organisation forms an important part of culture (Frow and Morris 2000). The way in which families and social groups are structured and maintained is influenced by culture and affects the experience of individuals.

Geertz discusses defining culture as consisting of 'webs of significance' woven by the individual (1973:5). He states that when exploring culture the researcher

should undertake an interpretative exercise to seek to understand the significance of culture for the individual. Geertz does not, however, define culture as purely subjective. There has been much debate on whether culture is subjective or objective (Geertz 1973:10). I would agree with Geertz and others that culture is both a part of the individual but also part of the structure of their society (1973). Mehta (1997:253) states that culture is both an internal and external force. Its influence works both through individuals and through social organisation.

Culture refers to the formation and maintenance of social groups and also to their definition against other groups (Frow and Morris 2000:317). This suggests that there is unity within each cultural group. It is important to think about the boundaries of culture and whether we can talk of a culture of India or, as in this case, a culture of Kerala or the UK. Culture may operate at different levels, as discussed above, but these levels may not then fit together. Differences in 'class, gender, race, sexuality, age, ethnicity and community' may create significant differences between individuals within one culture (Frow and Morris 2000:317). The suggestion above that culture refers to a unity within each cultural grouping relates to the choice of the UK and Kerala as comparable contexts as discussed in chapter 1. It is assumed within this thesis that we can talk about a culture of Kerala or of the UK when talking about the situation of older people and people with dementia. It is possible to be more specific about what is meant by this by looking at ageing and culture in more detail.

As discussed above culture can act at different levels of social organisation from the macro to the individual. The term culture is also used to describe aspects of these different levels. For example, in this thesis I discuss the 'culture of care' for people with dementia. This relates to the social, political and religious institutions,

beliefs and norms which affect how people with dementia are cared for within a particular context.

Culture is not fixed in time. Berting (1987:1) describes culture as

‘historically developed institutional arrangements of countries...values or value systems, styles of collaboration and communication, language, patterns of thought.’

This definition introduces history as an important factor in the development of culture and this is a central issue to understanding specific cultures. Historical change in religion, politics, economics and social organisation influences the development of specific cultures. It also illustrates how culture influences all aspects of functioning including how individuals think. Factors such as globalisation, modernisation, migration and urbanisation are influencing and changing culture in different contexts (Tout 1989). These chapters try to capture an image of the culture of the two contexts during the research period and take into account historical and demographic factors.

Before moving on to discuss the culture of ageing I return again to the work of Geertz (1973). He highlights another important issue regarding culture, which is illustrated in the quotation below.

‘Culture is not a power, something to which social events, behaviours, institutions or processes can be causally attributed; it is a context, something within which they can be intelligibly – that is thickly – described (Geertz 1973:14).

Within this thesis I aim to ‘thickly describe’ the cultures of the UK and Kerala with specific regard to care for people with dementia. The role of culture within this thesis is to provide the context within which policy transfer and policy translation take place. My descriptions of the ‘cultures of care’, both in the literature review and later in the



data analysis, form a fundamental part of the thesis. As a working definition in this thesis culture is defined as patterns of religious, political and societal values, which act at both an individual level and at societal level to form and maintain social organisation within a given context. Cultural traditions interact with individual socio-economic circumstances to affect individuals' experiences and status.

'Ageing happens in a cultural context' (Fry 2000:751). Culture affects the experiences of older people and people with dementia through traditional family structure, attitudes towards older people and their care as well as individuals' expectations about ageing. There are culture specific aspects to ageing and culture which provide 'guidelines' for ageing and being an older person (Mehta 1997:253). Across the world there are a huge range of responses to ageing dependent on local cultures (Barker 1994; Wilson 1991; Wilson 2000a). Cultural traditions interact with individual circumstances to influence the experience of individuals and concepts such as gender and class may be more influential on the particular experiences of older people than the ageing process itself (Wilson 2000a; Victor 1994).

By looking in detail at the formation of social organisation in the two contexts within this thesis it is possible to assess the influence of culture on the process and experience of ageing. Dementia has age-related prevalence and therefore the culture of ageing is relevant for people with dementia.

A fundamental element of social organisation for older people is the family. Cultural values and traditions as well as individual socio-economic factors influence family structure. Western societies, particularly the USA, promote the pursuit of independence and older people aim to provide for themselves in later life and most

older people live alone or with a spouse (Wilson 2000a; Tinker 1997; Victor 1994). This can be compared with cultures where families are interdependent units providing support on a mutual basis such as China and India (Wilson 2000a). The situation for older people is very different in India and the UK due to widely different religious and social traditions that is different cultures. There does, however, appear to be some universality about the low status of older people in different countries (Martin 1990; Victor 1994). The following sections look in detail at the culture of ageing in the UK and Kerala before comparing the two contexts.

## **Culture – ageing and dementia in the UK**

The west is often thought of as ‘culture free’ (Wilson 2000a:19), with western societies following a purely scientific approach to ageing. This is a limited view and denies the influence of social organisation within families and communities, which continue to affect the process and experience of ageing. In the UK culture favours nuclear families and older people usually live alone when their children leave the family home to set up their own. Values such as independence mean that older people are expected and encouraged to look after themselves in later life. This western cultural norm may make people with dementia increasingly vulnerable as they need care and support in later life. However, with the existence of the welfare state and a long cultural tradition of formal care for vulnerable groups in the UK there is an apparent provision for people with dementia.

Older people in the UK are a diverse group with a wide range of roles and experiences. Many older people lead active and independent lives and provide valuable support to their families with tasks such as caring for grandchildren. Older

people are also encouraged to be self-sufficient and independent through private pension schemes and private care services (Tinker 1997). An increasing number of retired people have sufficient money to financially manage their own retirements (Gilleard 1996). The Conservative government of 1979 to 1997 encouraged individuality and self-reliance. This may change the identity of older people in the longer term but is a recent change and older people in general are still regarded within the culture of ageing described below (Gilleard 1996). There are different images of older people in the UK but they are overwhelmingly negative due to an excessive fear of ageing (Victor 1994:81). Most of the negative associations with ageing are related to culture and mediated by it (Fry 2000:751).

Currently the dominant view in the UK of older people is that they are a burden on society. With the ageing of the population older people are seen to be the cause of a 'crisis' in terms of costs for pensions and care (Innes 2002; Arber and Ginn 1998; Vincent 1996:3). This crisis is often highlighted and over emphasised within the media (Arber and Ginn 1998; Innes 2002). This promotes negative images of older people and supports and reflects a culture of ageism (Bytheway 1995). Older people are more often associated with their need for care than with their contributions within the family and community (Arber and Ginn 1998). Ageism operates through the dominant image of older people as dependent (Featherstone and Wernick 1995:7). Ageing is seen as an ongoing decline with increasing dependency although this is often not the case (Wilson 1991). The image of older people today is also influenced by comparison with perceptions of older people from the past. Pre-industrial times in the UK are often described as a 'golden age' for older people when they were respected and cared for (Victor 1994:61). It seems unlikely that this was the case and more

probable that these images reflected the situation for older people from affluent classes (Victor 1994:61).

In some ways the negative image of older people and their perceived dependency contradicts the earlier paragraph where it was argued that the culture of the UK promotes independence as an ideal for older people. It is perhaps the perceived failure of older people to achieve this independence that contributes to the negative image of older people. It is also the case that there are many different types of older people in the UK and these different perceptions fit different groups.

People with dementia suffer a double negative image, both ageism and a negative image of people with mental health problems. Innes (2002:488) discusses the idea that in the UK dementia is seen as a 'condition worse than death'. This has implications for the experience of people with dementia and for policy makers in this field.

Culture influences the individual and the family and in turn it influences policy development. Social policy is developed within the cultural norms of the country in which the social policy is developed. If a culture promotes family care at home for older people then policy makers might be expected to focus on day and home support services rather than residential care. In the UK there has been a policy shift, described in detail in Chapter 5, from institutional care towards community care. Whether this illustrates a change in the cultural construction of older people and ageing or whether it is related to funding and fear of crisis is not clear and is discussed further in chapter 5. In the UK in general the image of older people is negative with ageism a strong attitude within the culture of ageing. This is amplified for people with

dementia who also experience stigma associated with mental health problems. There have, however, been positive changes in the perception of people with dementia and a reduction in the stigma associated with dementia (Kitwood 1997; Kitwood 1995).

## **Culture – ageing and dementia in Kerala**

India encompasses an incredibly diverse range of cultures and traditions. However, there is an 'inherent unity created from a rich cultural heritage accumulated over 5000 years' (Dutt and Noble 1982:1). Hindu religious traditions and values typify Indian society with Hindus comprising four-fifths of the population (Census of India 1991). The culture of ageing in India is strongly tied to Hindu religious traditions. Currently the influence of Hinduism within India is strong as the current ruling party in government, the Bharatiya Janata Party, is defined within religious boundaries.

Mehta (1997:256) discusses three main principles of ageing found within Asian culture. These are reciprocity, older people as transmitters of cultural heritage and as keepers of the social significance of festivals. Older people contribute to family and community life through teaching and passing on cultural heritage and they have central roles in auspicious days and festivals. In India the most important feature is 'family centredness' where individuals place family needs over their own (Mehta 1997:259). In one Indian study older people stated that younger generations should care for them because they continue to participate in family life (Patel and Prince 2001). In India 'intergenerational relations are essential keys to a satisfactory old age' (Vatuk 1980:127). The culture of ageing in Kerala, therefore, is shaped by the individual's place within the family.

Cohen states that current Indian gerontology is often based on the theme that 'Westernization' and modernisation have led to the decline of the joint family and a consequent decline in the status and experience of older people (1995:315). Popular opinion is that in the past older people were venerated and well cared for, a golden age similar to that proposed for industrialised countries. When asked, older people state that respect for them is declining and many do not wish to live with children who may not respect and care for them (Patel and Prince 2001). Older people prefer to remain independent and fear times when they will become dependent on children or others for care and financial support (Yadava et al. 1997; Patel and Prince 2001; Dharmalingam 1994). Older people are worried about modern ideas from industrialised countries particularly the focus on individualism and consumerism. These are seen to contribute to the breaking of the joint family system, which in turn can make older people seem superfluous and unwanted (Yadava et al. 1997). Older people see the breakdown of the extended family system as real. Evidence shows that most older people remain within extended family groups but a decline in this appears to be a real fear of older people (Van Willigen and Chadha 1990; Yadava et al. 1997). There is also some evidence that the traditional extended family in India is becoming less common (Irudaya Rajan 2000).

Traditionally it is said that older people were of a high status in India with the oldest man being the head of the household (Cohen 1998). In more recent times the earning male has become the head of the household as more older men retire (Desai 1998). The Indian tradition is to venerate and respect older people within the household although they may not hold power (Irudaya Rajan 2000:35). Cohen talks of veneration for older people and images of men of 60 being seen as wiser and stronger than younger men (1995:325). The experiential wisdom of older people was

respected and valued but it is felt that a change is taking place in traditional hierarchies leading to an ambiguity of roles within families in India (Desai 1998:675). There is, however, little evidence that the status and experiences of older people were better at an earlier time and it seems likely that their situation was always poor and more dependent on gender and class than age (Cohen 1998; Martin 1990).

For older people the Hindu and Indian tradition is for older parents to live within an extended family with one of their children usually the youngest son (Tout 1989). The extended family networks in developing countries are often assumed to provide older people with 'clear social roles, security and care' (Heslop 1999:5). A study on family size and social networks in Delhi concludes that social ageing is defined by power, the acquisition and then loss of power within the family and social network (Van Willigen and Chadha 1990). Older people hand over their power and responsibility to younger members of their family and in ideal circumstances can enjoy a degree of freedom in old age (Vatuk 1980).

The Hindu ideal is to approach old age and dying consciously, to spend more time in prayer and meditation and to detach yourself from the world (Caplan 1985; Dharmalingam 1994; Vatuk 1980). *Sanyasa* is a Hindu term, which describes later life and the process of withdrawal from the world (Mehta 1997:255). Personal religiosity, spiritual realisation and withdrawal from worldly concerns characterise this period (Mehta 1997:255). These changes traditionally take place within an extended family setting. They characterise self-centredness in older age, which contrasts with the importance of family-centredness discussed above. Studies show that entering *sanyasa* is often no longer possible as older people need to continue to work for as

long as they are physically able (Dharmalingam 1994; National Sample Survey Organisation 1998; Chilima 2000).

In summary, the culture of ageing in India seems to reflect change, or a perception of change. The fear described by older people is focused on the break down in the extended family and the problems this may cause for older people. In comparison in the UK the fear seems to be among other people who conceptualise older people as a burden on society. Both cultures share a fear of the future but in India this is about the breakdown of the extended family network. In the UK it is about the assumed burden of an increasing population of older people. More specific to this thesis is the culture of dementia in the two contexts and this is explored below.

## **Culture and dementia**

‘Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple cortical functions, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation’ (Jacques and Jackson 2000:2).

This definition illustrates some of the issues around ‘dementia’. It emphasises the medical aspects of dementia. Within this definition the terms ‘emotional control’ and ‘social behaviour’ are used. These terms are socially constructed and ‘culturally bound’ and suggest there are boundaries between the socially acceptable and unacceptable (Harding and Palfrey 1997:145). This brings in the idea that dementia is pathological and abnormal but does so in a manner that is socially constructed. Thus



this 'medical' definition itself exposes the limitations of defining dementia as a medical condition.

However, dementia has been traditionally seen as a medical condition for which a medical solution will be found. It is described within a biomedical framework. The term dementia is applied to a number of clinical conditions including Alzheimer's disease, multi-infarct dementia and Pick's disease (Bond 1992:397). The biomedical theory of dementia is widely used by different groups involved in care for people with dementia from family carers to hospital consultants. The medical model is limited in its usefulness as illustrated by Harding and Palfrey (1997:34) when they summarise what is known about dementia from empirically based research: 'cause: unknown, diagnosis: very difficult until after death.' Dementia is described as a disease despite a lack of a common cause for the symptoms (Harding and Palfrey 1997). Harding and Palfrey go further, suggesting that the medical community 'constructed' dementia as a cause of the behavioural symptoms that were observed (1997:101). They needed a name for the condition that they had observed. Within social gerontology the medical model has been heavily criticised and a need for a social model of dementia has been emphasised (Lyman 1989; Gubrium 1987; Cheston and Bender 1999).

When using the biomedical model the course of dementia is described as a progressive decline in various cognitive functions and emotional and personality traits (Arendt and Jones 1992). The pattern and rate of these changes is varied and individual although dementia is often described as progressing in stages (Jacques and Jackson 2000:9). Behaviours that are often described as associated with the progression of dementia include wandering, aggression, restlessness, hallucinations, inappropriate sexual behaviour, suspiciousness and repetition (Wilcock 1990). Many

of these words have negative connotations and defining dementia in this way may have a negative outcome for the individual. Cognitive changes such as those described above outline a continuing and degenerative progress of the illness. More recent research challenges these ideas and evidence is growing that the progression of these symptoms can be halted or even reversed by improving the social and psychological environment of a person with dementia (Kitwood 1997; Kitwood and Bredin 1992).

The biomedical model has three main propositions: that dementia is a pathological, abnormal condition, that it is organic in aetiology and progresses through stages and that it is diagnosed using biomedical assessments (Lyman 1989). Each proposition of the medical model can, however, be criticised for its neglect of the social and over emphasis on the medical. To view dementia as pathological it is necessary to define what is normal but it is often difficult to diagnose the early symptoms of the condition. It may be difficult to distinguish between dementia, normal ageing and depression (Jacques and Jackson 2000; Cheston and Bender 1999). There is a fine boundary between what is accepted as normal behaviour and that attributed to a biomedical or psychological condition. It has also been found that the behaviours an individual has displayed throughout her lifetime, following diagnosis, may be attributed to the effects of dementia (Lyman 1989; Cheston and Bender 1999). The label of dementia also changes the way people interact with the person with dementia (Innes 2002; Harding and Palfrey 1997). The behaviour of a person with dementia is not understood within a 'normal' framework and they may become isolated from 'normal social life' (Bond 1992:401).

The stage like progression of dementia has been heavily criticised as progression of symptoms is highly variable and distinct stages are rarely seen (Gubrium 1987). Carers, however, often accept the existence of stages as this offers some explanation for the behaviour of the individual with dementia and a degree of prediction about future events (Kitwood 1997). A tension for the carer may, however, develop when the disease progression does not fit with the given stage (Gubrium 1987). Medical treatment of dementia leads to a power relationship between doctors and carers and the person with dementia. When a carer is under stress they may exert more control on the individual with dementia and this may be done, within the biomedical model, using chemical restraints (Lyman 1989). This power relationship may have a detrimental effect on the behaviour of the person with dementia (Bond 1992; Lyman 1989). It may also have a negative outcome in that the carer may start to expect deterioration in the individual's condition and behaviour. Dementia could become a self-fulfilling prophecy (Lyman 1989). Neglect of the social aspects of dementia has a detrimental impact on the experience of both the person with dementia and her carers (Kitwood and Bredin 1992; Cheston and Bender 1999).

There are positive aspects to the medical model especially for the carer (Bond 1992). The conception of dementia as a medical problem provides a way of coping with the challenges of caring for a person with dementia. It also offers an explanation for what is happening to the person with dementia (Bond 1992:401). Both carers and doctors benefit from a disease label for dementia (Harding and Palfrey 1997:125). In the 1970s in the USA what is described as the 'alzheimerisation' of dementia took place (Kitwood 1997:22). All types of dementia came under the label Alzheimer's and a change in attitude took place leading to dementia being regarded as a disease

rather than senility or insanity. This helped to de-stigmatise the condition and led to increased awareness of it and financial support for research.

There is a growing amount of research on the impact of the social and psychological environment on an individual with dementia (Kitwood and Bredin 1992). Three lines of evidence for the importance of the social environment are found. Firstly, from studies within a care setting it has been found that individuals with serious cognitive impairment can show significant improvement following changes in their social environment (Kitwood and Bredin 1992:278). Secondly, there is evidence of stabilisation of symptoms in individuals diagnosed with dementia following changes in the social environment (Rovner et al. 1990). Thirdly, there is evidence from studies of older rats, which indicate that changes in social environment led to neurological improvement in the rat's brains (Diamond 1985). The effect of an improved social environment has also been associated with biochemical changes in cerebrospinal fluid in people with dementia (Brane et al. 1989). These findings clearly emphasise the importance of the social and psychological environment.

Criticism of the medical model has led to the development of social and psychological models of dementia. One possible model proposed by Lyman is a 'sociogenic' model (1989:604). This frames dementia as socially constructed and people with dementia as 'social actors who live with impairment' (Lyman 1989:604). Within this model account is taken of culture, personal relationships and the experiences of the person with dementia. Knowledge about dementia is socially constructed and affects the way in which social interaction takes place with people with dementia (Lyman 1989). Several psychological and social theories have been applied to explain the behaviour and experience of people with dementia. These often

have the aim of providing better care for people with dementia and reducing the impact of dementia on individuals' lives (Lyman 1989).

Various therapies have been developed since the 1950s for people with dementia based on psychological and social theory (Kitwood 1997). Reminiscence therapy has become a popular tool when working with people with dementia. Reminiscence has been found to help individuals with dementia make sense of their current environment (Woods et al. 1992; Kitwood 1997). Reminiscence therapy in some form is widely used within services for people with dementia in the UK (Kitwood 1997).

Kitwood (1997) describes dementia as a dialectic process, a result of the interplay between neurological damage and social psychological environment. The effect of the social environment can be negative or positive, either increasing the negative impact of the neurological damage or reducing its impact on the individual's cognitive and social abilities. Kitwood's theory of care for people with dementia follows a 'person-centred paradigm' and has been very influential on the way people with dementia are cared for in the UK (Kitwood and Bredin 1992; Kitwood 1993; Cheston and Bender 1999). The concept of people with dementia as somehow different is challenged within the theory and acceptance must be reached that 'the problem' of dementia is caused within interactions where all involved are responsible (Kitwood and Bredin 1992:273). Kitwood proposes that care giving for a person with dementia takes more than common sense and must involve some understanding of the experience of people with dementia (1993).

As a result of the focus on social environment many new activities and care practices have been developed for people with dementia (Kitwood 1997). In response to which, assessment tools have been developed to evaluate the impact of these interventions on the well being of people with dementia. The social model of dementia has been influential on services being developed for people with dementia in the UK. This has taken place due to increasing awareness of the social model and through the training of staff to understand dementia using a social framework. This change could be described as a cultural shift within 'culture of care' in the UK. There has been discussion of the emergence of a new culture of dementia care based around the social model of dementia (see Kitwood and Benson (Eds.) 1995). Evidence for the use of a social model of dementia within day care services is found within this thesis.

These discussions on the models of dementia have taken place in the UK and other countries in developed regions. Within this thesis it is important to ask what relevance the different models have for people with dementia in less developed countries such as India. In the UK the promotion of community care and an emphasis on social care for people with dementia, which is discussed in chapter 5, fits with more recent social models of dementia. In Kerala, however, the cultural context leads to the role of care being situated with the family. It is not formalised as social care but seen as part of traditional family roles. As this is the case a social model of dementia may not be helpful. It may not give clarity about the condition and may be stigmatising. Saying that dementia is somehow related to social interactions may shift the blame for the condition to the main carer, the daughter in law. Within Cohen's work on Alzheimer's disease in India he describes this taking place (1998). There is a long history of allopathic medicine in India and, therefore, the biomedical model is likely to be understood and useful. The culture in India is such that dementia is

conceptualised within the medical model rather than more recent social models of dementia. Discussions through this thesis illustrate the use of the biomedical model of dementia in Kerala.

Dementia is not clearly defined within the different languages of India and within the culture of the country. There is a Hindu word *sathiyana* that can be loosely translated as 'sixtyish' it relates to people becoming 'wilful, stubborn, irritable and hot-brained' (Cohen 1995:325). This might be compared to the term 'senility'. It is not clear if this relates to dementia. When relating an example of a person with Alzheimer's disease Cohen states that Western medicine through psychiatry reduces the stigma associated with the condition (1998). Previously the 'madness' of the older person was related to the 'bad family' particularly the behaviour of his/her children (Cohen 1995:329). He describes visiting a person with Alzheimer's disease in a nursing home and being told by the staff that she had 'a serious medical condition', she was not simply old (Cohen 1995:330). It seems that it was also important for those caring for the person with Alzheimer's disease that dementia is conceptualised as a disease rather than old age.

## **Conclusion**

I argue that an understanding of the cultural contexts of the UK and Kerala is essential to fully explain the processes of policy transfer and policy translation. I have established, however, that the concept of culture is complex and difficult to define. Within this chapter I developed a working definition for culture. I have shown that culture influences the actions of individuals and the social organisation in which they act. The concept of culture also implies a unity within the context it describes.

Looking specifically at the culture of ageing and dementia in the two contexts I found important differences and similarities. I conclude that in the UK the general image of frail older people and people with dementia is negative and focuses on the needs of these groups. In Kerala the image of people with dementia is also negative due to the general perception of mental health problems. The image of older people in Kerala is still positive but this is seen to be changing as globalisation and modernisation change the culture of the region. The ageing of the population is also seen as negative in both contexts but I have shown that the nature of the problem is different. Older people as a group are expected to become a burden on society in the UK due to cost of pensions and care provision. In Kerala the increasing number of older people is seen as a problem due to other changes that are taking place at the same time such as urbanisation and modernisation. Within this chapter I highlighted that culture is not fixed in time and the influence of these changes is discussed in more detail in the following chapter.

I have shown that the way in which dementia is conceptualised within the two contexts is influenced by culture. I argue that how dementia is defined and conceptualised affects how people with dementia are perceived and cared for. I further argue that the different contexts discussed within this thesis place a different emphasis on each of the two main models of dementia. I have established that in the UK the biomedical model is still widely used but a gradual change is taking place leading to more emphasis on the social aspects of dementia. The 'culture of care' for people with dementia is changing. Chapter 5 explores this further by discussing how the development of social policy and services for people with dementia in the UK reflects these ongoing changes. In Kerala, as found in this research, there remains a



strong emphasis on the biomedical model of dementia. The cultures of Kerala and the UK affect how people in the two contexts understand and conceptualise dementia.

This chapter has introduced the concept of culture. It has discussed and explored the culture of ageing and dementia in the two contexts. I have begun to construct a 'culture of care' for people with dementia in each context. I argue that the day centres explored within this thesis are embedded in the 'culture of care' for people with dementia in each context. How the day centres develop and how they function on a day to day basis are shaped by the 'culture of care'. I conclude that to elucidate the development of day care in Kerala it is necessary to understand and fully elucidate the 'culture of care' in each context. The following two chapters provide more detail on these 'cultures of care'. Chapter 4 looks at family structure and the role of the family and informal carers within the culture of care. Chapter 5 follows on from there to discuss social policy and formal care in each context.

## **Chapter 4**

### **People with dementia in the UK and Kerala**

#### **Introduction**

This chapter continues the discussion of the two contexts between which policy transfer and policy translation have taken place. The current situation of people with dementia in both Kerala and the UK is discussed focusing on family structure in each context. Family structure is an important part of 'culture' for people with dementia. Culture influences family structures and, therefore, care for people with dementia. The discussion of the 'culture of care' in each context is continued within this chapter.

The situation of people with dementia is not fixed in time. Historical and ongoing demographic changes are important in determining how care is provided for people with dementia. The current situation of people with dementia in Kerala and the changes taking place to this are important in determining the need for formal care services and the types of service required. The situation in the UK is compared with that in Kerala for two reasons. Firstly, the UK is where the ideas and information for

the policy transfer and policy translation processes came from. Secondly, changes in Kerala are perhaps making it more 'western'<sup>2</sup>. The UK provides an interesting contrast to Kerala. It is also possible to draw conclusions about the suitability of choosing the UK as a source of ideas for developing services in Kerala.

The question of whether dementia is a significant issue in Kerala is addressed. Several papers were published in the 1990s claiming that there was no dementia in India (Cohen 1998) but more recent research has found a range of prevalence rates for dementia in India. Rising life expectancies and decreasing birth rate are leading to an increase in the number and proportion of older people around the world. These changes also impact on the prevalence of dementia and figures for this in Kerala and the UK are compared. Other developments such as urbanisation, increasing migration, modernisation and globalisation affect the experience and situation of people with dementia. The real effects of these changes on people with dementia in Kerala is discussed in comparison with people with dementia in the UK. The culture of each context is also affected by these changes influencing the manner in which care is provided for people with dementia. The current situation for people with dementia is discussed in each context. There is little information on this in Kerala and so the situation of older people is explored as an equivalent.

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<sup>2</sup> The idea of 'the west' within this thesis is defined as western industrialised countries typified by the USA and UK. During the research period the UK and USA were found to be key images of 'the west' for people in Kerala.

## **Dementia in Kerala**

The need for social care for people with dementia in the developing world is expected to increase due to changes in social, medical and economic factors (Chandra 1998). As countries develop and change so does the epidemiological profile of that country (Larkin 1998). Dementia has age related prevalence and the greying of the world's population is leading to an increase in the number of people with dementia, especially in the developing world (Wilson 2000a). Chandra (1998:7) cites increased life expectancy as a major factor 'leading to the problems and illnesses of old age emerging as major social and medical issues' in the developing world. The epidemiological profile for Asia is not dissimilar to that in more developed regions a century ago (Larkin 1998:92). A decline in fertility rate is predicted across the world leading to an increase in the relative and actual number of older people (United Nations 1998). The increase in the number of people over sixty will be more dramatic in the developing regions. Between 1998 and 2050 this population in the industrialised nations is predicted to increase by 66% but in the developing regions it is predicted to increase by over 800% (United Nations 1998). The numbers of people with AIDS may affect these increases. Kerala, however, has a comparatively low prevalence of AIDS (AVERT 2003).

There are expected to be 100 million people over 60 in India by 2013 and a doubling of this population is expected to take place between 1991 and 2016 (Government of India 1999). The number of older people has been increasing since 1951 and India has a higher proportion of older people than other countries in South Asia (Irudaya Rajan 1989:19). In a survey conducted across India in 1995 and 1996 it was found that there were more older people in rural areas. Seventy-eight percent of

older people live in rural areas compared with just twenty-two percent in urban areas. Until recently there were greater numbers of older men than women but in this survey a shift towards more women is seen and this is more notable in urban areas (National Sample Survey Organisation 1998:12).

The state of Kerala is the focus of this thesis. Kerala is an interesting and appropriate place to undertake research into people with dementia. The number and proportion of older people in Kerala is increasing more rapidly and is higher than in other parts of India (Irudaya Rajan 1999). Kerala is not typical of the rest of India. Most importantly the proportions of the most common religions are markedly different. In India as a whole Hindus comprise around 80% of the population with Christians just over 2% (Census of India 1991:Table 24). In Kerala, Christians and Muslims make up one fifth each respectively of the total population. The remaining three fifths are Hindu (Chiriyankandath 1996). This has had a major effect on the politics and culture of this region. The early breakdown of the caste system and the development of the communist movement in Kerala led to improved education and social welfare systems. These in turn led to high literacy rates and improved health conditions (Chiriyankandath 1996). Literacy rates for India as a whole are 65.38% while in Kerala the rate is 90.92% (Census of India 2001). In 1999 the life expectancies in Kerala were 70 years for men and 76 years for women (Irudaya Rajan 1999:49). There is also a high level of out migration with younger people living and working in other parts of India and abroad, especially in the Gulf States (Irudaya Rajan 1989; Prakash 1999b). Irudaya Rajan (1999:49) describes Kerala as being 25 years ahead of the rest of India in terms of demographic transition.

In industrial regions the expected increase in the number of people with dementia is already impacting on health and social services. In developing regions the increase is faster and has greater effect as until recently the number of people over 65 has been relatively small. The prevalence of dementia has been studied extensively in industrial regions but is less well documented for developing regions. A combined project looked at a sample of the prevalence studies conducted within Europe in the 1990s and found estimated prevalence rates. For people over 65 years of age the overall prevalence of dementia is found to be 6.4% and the prevalence for people aged 65-69 is 0.8%, rising to 28.5% of people over 90 years (Lobo et al. 2000). Prevalence increases with age and most studies included in this project found similar prevalence rates.

Few studies have been undertaken in India looking at the prevalence of dementia and the results from the studies which have been done vary considerably. Three studies are accepted as being rigorous by the 10/66 Dementia Research Group (2000b) and these are: Shaji et al. (1996), Rajkumar et al. (1997) and Chandra et al. (1998). The results in these studies vary from 1.7% of people over 65 (Chandra et al. 1998) to 5.2% of people over 65 have dementia (Shaji et al. 1996). The prevalence rate of 5.2% of people over 65 was found in an epidemiological study of a rural part of Kerala (Shaji et al. 1996). This result may reflect the higher proportion of older people in Kerala and supports the evidence that it is experiencing the ageing of the population ahead of other parts of India.

There are several other reasons as to why such variation is seen between these figures. The definition and diagnostic tools used may differ between studies. As discussed in chapter 3 the definition of dementia is complex. There are also

significant problems with the diagnosis of dementia (Cheston and Bender 1999). The formal medical definition of dementia used for diagnosis is in constant development as illustrated in differences between two editions of the Diagnostic and Statistical Manual (DSM). In the DSM-III-R (1987) dementia is included as a diagnostic term and the entry includes a list of symptoms that are necessary to diagnose dementia and subtypes of dementia. In the DSM-IV (1995) dementia no longer has a diagnostic definition. The separate brain conditions that cause dementia, previously listed as subtypes, are listed with their diagnostic criteria (Cohen 1998). There have also been changes in more recent definitions in the description of dementia with a greater emphasis on the cognitive defects caused by dementia and less emphasis on the emotional and personality changes (Cohen 1998). These changes in definition are important to note, as they effect how dementia is identified and recorded within prevalence studies.

The diagnosis of the different causes of dementia is difficult due to the nature of the conditions. Many conditions affecting the brain can only be given a definite diagnosis at post-mortem. Many diagnostic tools are used in an attempt to diagnose dementia. Some more traditional examples which are used in Kerala are the Mini Mental State Examination (Folstein et al. 1975) and the CAMDEX scales (Roth et al. 1986). These provide a measurement of ability at one time and place and may not, therefore, provide a true indication of an individual's score. They also often rely in part on past information that may be provided by a relative or friend and there is the possibility that this information may be biased (Kitwood 1997). These types of test have been heavily criticised especially when used in different cultures (Chandra et al. 1994). Many of these diagnostic tools for dementia are developed in industrial regions. They rely on cognitive tests, which may not be culturally appropriate in

developing regions, even less so where literacy rates are low (Chandra et al. 1994). Issues of diagnosis affect the calculation of prevalence figures. Diagnosis is also important within day care. A diagnosis of dementia is often needed for an individual to gain a place.

There are also differences in the visibility of people with dementia in developing regions. They may be less likely to be taken to a doctor (Cohen 1998). A final reason may be increased mortality for people with dementia in developing regions resulting in a lower prevalence (10/66 Dementia Research Group 2000b). This is summarised by Cohen (1998:30) 'such findings reflect complex demographic differences in who survives, gender and class specific patterns of which bodies are likely to be presented to a medical gaze'. It is generally accepted however that there are lower prevalence rates of dementia in developing regions and this has important implications for research into the possible causes and aetiology of the causes (10/66 Dementia Research Group 2000a). It also has implications for the development of services for people with dementia and questions whether there is a pressing need to develop them.

## **Demographic change**

The current situation of people with dementia in the UK and in Kerala is affected by ongoing demographic change. The increasing number of older people discussed above is one important change. The process of globalisation, as discussed in chapter 2, is affecting changes in patterns of migration and urbanisation, as are the processes of modernisation and industrialisation in Kerala. Kerala is currently undergoing demographic change similar to that which has already taken place in the



UK. There may be the perception from people in Kerala that their culture is changing and becoming more akin to that in more developed 'western' countries.

### Migration and urbanisation

In India migration and urbanisation are changing traditional family structures (Sen 1994; Martin 1990). Family structure and organisation can be described as a fundamental aspect of culture for people with dementia in both Kerala and the UK. There has been an increase in the urban population compared with the rural population in India since the beginning of the twentieth century (Bose 1971:92). The pace of urbanisation increased through the second half of the twentieth century with the pull of better opportunities in urban areas and the push of poor conditions and little investment in rural areas (The Economist 1996). Kerala underwent rapid urbanisation in the 1980s and this continued into the 1990s (Prakash 1999a). In urban areas dwellings are much smaller so when children move to cities their older relatives often remain in the rural home (Government of India 1999). Generally in developing countries urbanisation leads to a decline in co-habitation of families and increasing numbers of older people left in rural communities without family support (Wilson 2000b; 2001a).

Migration also takes place outwith India. Migration displaces people from their roots and traditional sources of livelihood and community support and affects the context of ageing (Tout 1989). As discussed above, in Kerala there is a high level of out-migration to the Gulf States. The impact of this is greater in developing countries as there is little formal provision for pensions and older people are more dependent on family and informal support (Tout 1989). Urbanisation and migration may isolate older

people but the additional income from sons and daughters living away from home provides important economic compensations (Heslop 1999:20). The effect of these changes can be both positive and negative for older people. Older people may become more isolated but may have greater financial resources. For people with dementia it implies that the situation will be mainly negative. People with dementia need a greater level of care and support and without appropriate services the family are most likely to provide this. If the younger members of a family live away from the family home then there may not be anyone to care for the older members of the family.

Urbanisation and migration are less relevant in the UK. Similar changes took place in the UK but at an earlier date and, therefore, prior to the increase in the proportion and numbers of older people. It is difficult, therefore, to assess what impact the changes had on the current situation of older people. One assumption is that the extended family was the normal family structure in pre-industrial times in the UK. It is unlikely that was ever the case as a lower age of mortality would mean that few people lived long enough to be part of extended or three generational families (Victor 1994). Families were, however, bigger and the number of people available to care for older people was higher (Victor 1994). There is some evidence that the process of urbanisation actually increased family size as there were fewer houses within the new cities and families were more likely to live within three generational families (Victor 1994:171). Internal migration and mobility continues to affect families within the UK (Vickers 1998). Internal migration is slowly increasing with more younger people moving away from their family home (Vickers 1998). Older people are the least likely to migrate (Vickers 1998). There are pockets of older people across Britain as a result of ageing in situ, out migration and some 'retirement migration' (Victor 1994:101).

## Modernisation and industrialisation

The effect of the industrial revolution on social and cultural values has been well documented and industrialisation is seen as having a negative impact on the experience of older people (Tout 1989; Cohen 1998; Cowgill and Holmes 1972). As discussed in chapter 3, in terms of older people, pre-industrial societies were seen as the 'golden age' (Victor 1994:64) while modern societies are seen to neglect older people. A more recent view is that the position of older people has always been generally poor with factors such as gender, class and religion having an impact as well as family structure and culture (Martin 1990; Victor 1994; Cohen 1998).

Modernisation is defined simply as 'a process through which societies are believed to change from less to more developed forms through the introduction of new technology and other social change' (Webref 2003). There is much debate around the concept and its relevance and exact definition. A theory of modernisation was developed by Cowgill and Holmes (1972) which assessed the effect of the process on older people in more developed regions. The research concluded that modernisation had a negative impact on the situation of older people who are said to be devalued within modern societies (Cowgill and Holmes 1972). The influence of modernisation in developing countries was also investigated with the conclusion that it undermines the position of older people within society as it promotes youth and views ageing as a negative process (Neysmith and Edwardh 1984). Modernisation is often described as a major factor in the decrease in the position and experience of older people (Heslop 1999). Older people are not seen as actors within modernisation and this has led to it being described as the cause of the current poor position of older people in the

developing world. Modernisation has also changed the pattern of health and illness. Despite many positive medical advances these have been countered by increases in industrial accidents, homicide and the incidence of alcohol and drug related problems (Sen 1994).

The above studies do not compare the present status and experiences of older people with that found historically and have been widely criticised. In fact there is little historical evidence to support the theory that family care has declined following industrialisation and the rise of the welfare state (Tinker 1997). The status of older people has always been poor and more dependent on individual circumstances rather than simply the fact of being old (Victor 1994).

In India older people are worried about modern ideas from industrialised countries, particularly the focus on individualism and consumerism (Patel and Prince 2001; Desai 1998). Globalisation is seen as having changed the context of ageing and the values associated with it. Increased consumerism is described as putting emphasis on individualism in common with more developed regions of the world (Desai 1998). Individualism affects the social and economic structures which traditionally provide support for older people (Wilson 2001a; 2000b). These assumptions about the impact of globalisation are not clear, as discussed above, and it appears they may be more about the fears and concerns of older people rather than any actual move towards consumerism and 'industrialised attitudes.' However, economic globalisation is described as negatively affecting the situation of older people in developing countries (Wilson 2002; 2001a; 2000b). 'Globalisation has the effect of increasing insecurity and the range and intensity of problems that afflict older men and women' (Wilson 2002:660). Economic globalisation has increased the

movement of money from the poor to the rich and at the same time has reduced the freedom of individual governments to develop their own social policy. There is a disincentive for governments in developing countries to provide social support for their citizens (Wilson 2002; 2001a). Interestingly the state of Kerala is often described as one place where local government has overcome this pressure and provides a level of social support for citizens (Parayil 2000 cited in Wilson 2002).

In conclusion, older people and people with dementia in Kerala do appear to be facing a changing future. Demographic, social and economic changes have reduced the capacity of the family to provide support (Heslop 1999:6). Urbanisation and migration are changing traditional family structures and leading to a reduction in family size (Sen 1994; Martin 1990). There is debate on the actual effect that these changes have had on the experience of older people and people with dementia in Kerala. This reflects a similar debate in the UK as to whether there was a pre-industrial 'golden age' for older people (Victor 1994:64). It seems clear that changes are taking place in family structures in India with family size decreasing. What is not clear is whether this is decreasing the quality of life of older people or whether their situation was always poor and more dependent on class and gender rather than on being old. The decrease in family size might be perceived as a shift towards a more 'western' style of family. This perception might therefore lead to the idea that western style services will become appropriate for people with dementia in Kerala. By looking in detail at the current situation of people with dementia in the UK and Kerala it is possible to develop this comparison further.

## **People with dementia in the UK**

There are estimated to be 600,000 people with dementia in the UK and of these 154,000 live alone (Department of Health 2001:97). A survey in Scotland found 47% of people with dementia living in ordinary housing, 8% in sheltered housing and the rest in a mixture of residential accommodation and hospital wards (Gordon et al. 1997:755). Another survey in Scotland found similar figures and estimated a rough distribution of 40% of people with dementia living in institutions and 60% in the community (Spicker and Gordon 1997:19). One study looking at people with dementia who were referred to social service departments found that at the time of referral nearly 80% of people with dementia were living at home and of these 60% lived alone (Moriarty and Webb 2000:25-28). The position of people with dementia changes fairly rapidly as the condition progresses and as their needs change. Many move from the community into residential care (Spicker and Gordon 1997:19; Moriarty and Webb 2000). There is less movement through services once an individual moves into residential care. Family members care for most people with dementia. Many carers of people with dementia are also older people and more than 60% are spouses (Audit Commission 2000). Carers of people with dementia often experience higher levels of stress than carers of other groups of people and ask for more support from services (Gordon et al. 1997; Philp et al. 1995).

In one study it was estimated that 40% of people with dementia living in the community were not in touch with any services (Gordon et al. 1997:755). Therefore, many people with dementia living in the community are in contact with services of one type or another. Some studies estimate as low as 50% but most find around 60% (Spicker and Gordon 1997:58). The longer an individual has had dementia, the more

likely they are to be in contact with services. The proportion of people with dementia in different types of institution varies but they can make up to 90% of the population of long-stay psychogeriatric wards (Spicker and Gordon 1997:59). People with dementia, therefore, live in a variety of settings with most living in the community at the early stages of the condition and many moving on to residential care of some kind when the condition progresses. Problems with diagnosis of dementia are still relatively common. These may mean that individuals do not get a correct diagnosis and may not be able to access specialised dementia services (Audit Commission 2000).

As illustrated above many people with dementia in the UK are in touch with formal care services of one kind or another. People with dementia are more likely to move into long term residential care than other older people (Moriarty and Webb 2000:5). Family care and support is however still important especially for those living at home. In a comprehensive European report on older people a major research finding was that the family remains the leading provider of support for older people who are dependent and living at home (Jani-Le Bris 1993). Family structure, therefore, is a fundamental aspect of culture for people with dementia. The number of older people living within two and three generational families has decreased through the twentieth century and family size has also decreased (Victor 1994:174; Haskey 1996; Murphy and Berrington 1993). Family structure is changing due to increased divorce rates, lower marriage rates and lower fertility leading to a diverse range of family structures within the UK (Haskey 1996). Evidence suggests, however, that the nuclear family has been the most common form in Britain since pre-industrial times and remains so (Tinker 1997). However, older people are now more likely to live alone or with a spouse (Miret 1995; Haskey 1996; Murphy and Berrington 1993) but

still maintain high levels of contact with family members (Victor 1994:176). The number of older people living alone increased dramatically during the 1960s and 1970s (Victor 1994:97). The high number of older people living alone or with a spouse appears to reflect the preference of older people to live independently rather than the situation being forced on them (Victor 1994; Murphy and Berrington 1993; Haskey 1996).

Moriarty and Webb looked in detail at people with dementia who had been referred to social service departments in England (2000). This study found that people with dementia in the UK depend on both formal care services and family care. There are individual differences related to class, gender, location and extent of family support. They also found that formal services are accessed either following a crisis or when a family member seeks additional support to care for the individual with dementia (Moriarty and Webb 2000). There is an emerging recognition in social policy in the UK that family and informal carers are an increasingly important source of care and support for older people and people with dementia (Tinker 1997).

The situation of people with dementia in the UK is varied. Care is provided both by family, other informal carers and formal care services. As shown above many people with dementia are in contact with formal services. A discussion of these services and the policy that shapes them takes place in the following chapter. The discussion in this chapter suggests that the 'culture of care' in the UK could be described as a culture of partnership between family carers and formal care services. This partnership is seldom equal and the situation is far from ideal. Chamberlayne and King (1996; 2000) undertook comparative research into 'cultures of care' in the UK and Germany. Their 'cultures of care' formed conceptual frameworks that



highlighted the differences between the different contexts (Chamberlayne and King 1996). In a similar way I am developing 'cultures of care' for people with dementia in the UK and Kerala. These constructs frame my data analysis and are fully constructed within chapter 5. My discussion of the 'culture of care' in the UK focuses on people with dementia as there is enough information available on this. In Kerala the 'culture of care' is more general to older people as there is little available information on people with dementia.

### **People with dementia in Kerala**

There are few studies of people with dementia in India or Kerala and so in this section there is also a focus on the situation of older people as this is the closest fit to the situation of people with dementia. In India there is little formal provision for care of older people so the most common situation for older people is that they live with family members (Martin 1990; Dharmalingam 1994). People with dementia also live with family members and are cared for within the family home usually by a daughter-in-law (Heslop 1999). Traditionally care is provided by the family and often lack of money prohibits any alternative (HelpAge International 2002:45).

'The family operates as a site for labour, a source of shelter and material and emotional support and, in the last resort, as a provider of care' (Wilson 2002:649).

The extended family networks in developing countries are often assumed to provide older people with 'clear social roles, security and care' (Heslop 1999:5). These assumptions cannot be taken as completely true even when the extended family network is secure and even less so when the extended family network begins to break down. The family is still preferred by older people in the developing world as the provider of care for older people (Heslop 1999).

Extended and three generational families have traditionally been the norm in India (Sriram 1993; Irudaya Rajan 2000). The Indian ideal is for older parents to live with a married son although there are notable groups within India where a matriarchal system means parents live with their daughters (Tout 1989). Older people prefer to live with their sons rather than daughters despite finding they get better care from daughters (Irudaya Rajan 2000:39). This emphasises the strength of the traditional system. Although it is still the norm for older people to live with children there is increasing variability in their living arrangements (Martin 1990; Tout 1989; Sriram 1993; Chilima 2000).

The demographic changes discussed earlier are raised again here in relation to family structure in India. There has been a decline in family size in India, which seems to indicate a reduction in the number of extended families and a rise in nuclear families (Irudaya Rajan 2000:32; Government of India 1999). As well as changing patterns of migration and increased urbanisation other aspects of modernisation are also affecting family size in India. The role of women in India has changed considerably in recent years taking them away from traditional caring roles and into the work place (Irudaya Rajan 2000:30; Heslop 1999). Contraception has provided the ability for couples to have smaller families and they are now becoming more common. Therefore, fewer children are available to care for their parents in old age (Government of India 1999). These changes may mean that sons and daughters are able to provide economic support for their parents but not practical and emotional support (Irudaya Rajan 2000:31). Migration and urbanisation do not necessarily lead to the isolation of older people but may reduce a family's ability to provide care (Heslop 1999:18). In Kerala due to high levels of out migration some older people live

alone but with financial security provided by their children. This suggests there are a group of older people in Kerala who are in a position to need and pay for formal care services.

Evidence suggests that families are still the main providers of care for older people (Heslop 1999:19). A recent survey found that only 4-5% of older people in India, defined as those over 60, live alone and 8-10% live with their spouse only. This indicates that only 14% of older people live outwith an extended family group (National Sample Survey Organisation 1998:13). Another study found that 15.3% of older people do not live with children (Irudaya Rajan 2000:39). Living with other family members does not, however, guarantee the provision of care or well being for the older person (Martin 1990).

The quality of older people's relationships with their sons and daughters often decides their economic situation and their health and well-being (Yadava et al. 1997). Around 70% of older people in India are economically dependent and of these 77% are dependent on their children. The economic status of older people is found to be improving in urban areas but decreasing in rural areas (National Sample Survey Organisation 1998:15). A rising number of cases of neglect are found among older people where family members have either not been able, or have not wanted, to provide care and support for older relatives (Patel and Prince 2001).

A growing number of older people are within middle and upper income groups and so have better financial security (Government of India 1999). However, the majority of older people are in low-income groups or below the poverty line. Two thirds of older people are financially vulnerable, particularly those in rural areas

(Government of India 1999:24). In poor families if older people are not able to contribute they are seen as a burden and in slum communities 20% of older people live alone (Irudaya Rajan 2000:30-31). Rao and colleagues found more negative attitudes towards older people within low incomes and poor families where the cost of caring was more of a burden (2000). Many older people are still economically active. In India 16.4 % of men and 4.6% of women between 60 and 69 years old are economically active. This is predicted to rise considerably. By 2030 it is predicted that 37.8% of men and 12% of women in this age group will be economically active (HelpAge International 2002:31). An Indian survey found much higher figures. It found that 40% of older people, those over 60, are still working in India and this figure is higher for rural compared with urban areas (National Sample Survey Organisation 1998:16). In urban areas people are more likely to be protected by retirement benefits. Around 65% of older people in urban areas receive some sort of retirement benefit but this figure is only 21% in rural areas (National Sample Survey Organisation 1998:16). In Kerala half of older men and one tenth of older women are part of the workforce (Irudaya Rajan 1999:57).

Some older people in India move into 'old age homes' but there are few of these and only in urban areas. Overall the idea of them is not popular (Irudaya Rajan 2000:31). However, one study found that older people were satisfied with their stay in an old age home and had moved there due to lack of care in the family home (Dandekar 1993 cited in Irudaya Rajan 2000:32). There has been a steady rise in institutional care for older people since 1950 and the highest number of homes is found in Kerala and Tamil Nadu (Irudaya Rajan 2000:42). The evidence seems to point to a limited shift in the living arrangements of older people with fewer living in extended families and more in institutions (Irudaya Rajan 2000:42). This may be due

to an increase in choice and financial ability or limitations in family care provision. Again Kerala is highlighted as an area where formal care is more common than in other parts of India.

The 'culture of care' of people with dementia in Kerala appears to be a traditional one. Older people live within an extended family system and are cared for by family members. As described in the previous chapter a culture of family centredness ensures care for people with dementia. There are changes taking place to this system. Migration, urbanisation, industrialisation and modernisation are affecting family structures in Kerala. Family sizes are becoming smaller and more older people live alone. This is reducing the ability of family members to provide practical and emotional support to older people but they may be able to provide financial support. In Kerala many young people live and work in the Gulf States and so are able financially to support their parents who remain in the family home in Kerala. Kerala is among the most developed states within India. It seems likely that family sizes are decreasing more quickly in Kerala and therefore the need for formal care may be increasing. The perception of these changes seems to be more dramatic than the actual changes taking place. There is a perception that a breakdown of the traditional extended family is taking place and that family care for older people is no longer guaranteed. This leads to a perceived need for formal services for older people and people with dementia. These discussions begin to clarify the background and reasons for the processes of policy transfer and policy translation investigated within this thesis.

## **Conclusion**

I conclude that exploring the situation of people with dementia in Kerala and the UK provides important insights into the 'culture of care' in each context. I have established from the demographic evidence of changing life expectancy and the ageing of the population around the world that the numbers of people with dementia in Kerala are likely to be rising. The prevalence of dementia in Kerala has been investigated and found to be similar to that in the UK. These studies, however, are difficult to assess due to the problems with identification of people with dementia highlighted in this chapter. However, I conclude that the prevalence rates for dementia are lower in less developed countries than in developed countries. I further conclude that despite a lower prevalence the relatively high number of older people in Kerala suggests there are a substantial number of people with dementia. I have shown that other changes such as globalisation and increasing urbanisation are changing family structures in India and may be leading to a need for formal care services to replace care previously provided by the family.

The demographic changes described in this chapter continue in Kerala, and I argue that their influence is important with regards to the 'culture of care' for people with dementia. I have shown that similar demographic changes took place in the UK but they took place earlier and are of less relevance today. They did, however, contribute to the current situation of people with dementia in the UK. It is not clear whether the demographic changes continuing in Kerala today will result in a society that resembles a modern 'western' society. I have established that there is an apparent perception that this is the case. Concerns about the breakdown of the

traditional extended family and the increase in consumerism discussed above reflect this. If this perception is true then it makes sense for individuals in Kerala to look towards 'western' countries for ideas. As is discussed within the thesis there are other reasons for the individuals in Kerala to look towards 'the west' for ideas.

This thesis examines an example where individuals in Kerala looked to the west to find solutions for a problem they were facing, that of dementia. I return to this issue in later chapters. These discuss in detail the motivations of these individuals and their perception of the problem of caring for people with dementia. Cohen describes dementia as being perceived in India as a 'western' problem which has recently arrived in India (1998). 'The west' also provides the apparent solution to this problem in the form of the medical model of dementia and allopathic medicine. It seems possible that 'the west' will further provide the solution in the form of service models, as in this thesis.

This chapter has provided a detailed discussion of the situation of people with dementia in each context and the demographic changes that are affecting them. I framed this discussion within the wider cultural background of each context. This chapter has added to my conceptualisation of the 'cultures of care'. The final element to this conceptualisation is the role of social policy and formal services within the culture of care. These elements are discussed in the following chapter.

## **Chapter 5**

### **Day care for people with dementia in the UK and Kerala**

#### **Introduction**

Following on from the discussions in the previous two chapters this chapter completes the description of the 'cultures of care'. The chapter outlines the development of day care for people with dementia and discusses the relevance of social policy in this development in Kerala and the UK. I discuss how social policy has influenced the day care centres studied within this thesis. In the UK there is a long history of social policy and formal care for older people but there is little social policy specifically for people with dementia. People with dementia usually access generic services for older people as there are few specialised services. In comparison, in Kerala there is little history of social care for older people or people with dementia. As described in chapter 4 the main source of care for older people in India is the family. In the past few years the idea of social policy for older people has been developed in India. During the International Year of Older Persons in 1999 the Government of India produced a policy document for older people. There is a suggestion that this document was produced in response to pressure from the United Nations (HelpAge



International 2002). This document is analysed within this chapter and its relevance within this research is discussed. At the time of the research the only specialised social services for people with dementia in India were those of the ARDSI.

The chapter concludes with a comparative policy analysis of the two contexts. The comparison highlights the huge difference in the policy background to day care in the two contexts. Social policy in the UK has been important in shaping the development of day care in the UK. There is a long history of social policy and the UK is often seen as the leader in the field of day care for older people (Nies et al. 1992). In India the influence of Indian social policy on the development of day care has been negligible. This difference points to the reason that the UK was used as the source of ideas and information for the processes of policy transfer and policy translation within this thesis. The policy analysis elucidates the influence of culture on policy and services within the two contexts. I argue that culture remains a strong influence on social policy both through the actions of policy makers and through social organisation. These influence how policy and services are developed. Culture permeates and influences family structure and social policy and hence influences the development of day care for people with dementia in the two contexts.

It is worth repeating here the reasons for conducting the comparison between the UK and Kerala. The UK is confirmed within the analysis as the main source of information and ideas for the development of day care in Kerala. The comparison is made between a country and a state to aid the comparison. India is a huge country with a wide diversity of culture and tradition and it would not make sense to compare the UK with India. Kerala is a state with a population of approximately 30 million and so is a more appropriate size to compare with the UK. I argue that the cultural

diversity across the UK is similar to that across Kerala. Within the research the actual day centres studied in the UK are in Scotland. Within the comparison in this thesis Scotland is taken as a representative part of the UK. I argue that the differences between Scotland and the rest of the UK are not significant in relation to the differences between the UK and Kerala. However, the detail of social policy in Scotland is different in some aspects to that in the rest of the UK. These differences are mentioned within this chapter where relevant.

The perception of people with dementia within social policy in the UK is constantly changing. Historically people with dementia who were considered 'mentally disordered' were placed in large institutions where conditions were extremely poor (Kitwood 1997:11). At the beginning of the Twentieth century a change took place in the perception of insanity. The discovery that syphilis was a medical disease led to its medicalisation and that of other similar conditions (Kitwood 1997). It was not until the 1980s that Alzheimer's disease underwent a similar medicalisation, sometimes referred to as 'alzheimerisation' (Kitwood 1997:22). This framed dementia within the medical model, described in chapter 3. This traditional view of dementia as a disease and the medical model of dementia are slowly changing as more emphasis is put on the social aspects of dementia as discussed in chapter 3. Within services the emphasis is moving towards community care for people with dementia and support for their carers (Tinker 1997). In the *National Service Framework for Older People* specialised services and community based services for people with dementia are recommended (Department of Health 2001:91). The emphasis on community care and the growth of the mixed economy has led to the closure of long term geriatric wards and to dementia care services being provided within social service departments (Innes 2002:483; Chamberlayne and King 2000). This means that care for people

with dementia, a condition once seen purely from a medical perspective, is now largely paid for within social services (Innes 2002:489).

## **Policy for people with dementia in the UK**

Dementia has historically not been highlighted within policy debates and there is little government policy focusing on dementia (Sassi and McDaid 1999). Dementia is more recently highlighted within the *National Service Framework for Older People* and the importance of providing services for them is emphasised (Department of Health 2001). People with dementia generally access generic services for older people although there are some specialised 'dementia' services (Audit Commission 2000). Where specialised services do exist they are usually of a high standard (Brown 1997). People with dementia access more generic social services for older people than other groups of older people and have a high impact on the cost of public services (Cm 4192-I 1999; Philp et al. 1995). The *National Service Framework for Older People* estimated the annual cost of caring for people with Alzheimer's disease in England in 1993 as over one billion pounds (Department of Health 2001:90).

There is a wide range of services for people with dementia which can be accessed by individuals living at home. These include: home care, out patient clinics, memory clinics, specialist therapy, home or residential respite and day treatment or day care (Audit Commission 2000:38). The main source of specialised services for people with dementia are NGOs and charities. There has been a rapid development in social services provided by voluntary organisations that provide innovative projects for people with dementia (Kitwood 1997). One example is Alzheimer Scotland - Action on Dementia (AS-AD). Their policy aims include

'to provide and to secure the provision of high quality services for people with dementia, to be the national and local voice of and for people with dementia and their carers in Scotland and to improve public policies for the benefit of people with dementia and their carers' (Alzheimer Scotland - Action on Dementia 2001:1).

Global organisations such as ADI also provide guidance and advice both for individuals and groups who are involved with caring for people with dementia. Specialist day care for people with dementia is the focus of this thesis. The development of this type of day centre is described below within the policy context.

## **Day care for people with dementia in the UK**

Day care is an important aspect of community care for people with dementia (Tester 2001). Day care services are popular with people with dementia and their carers (Tinker et al. 1999; Levin et al. 1994). Studies show that some people with dementia benefit from attendance at day services with improvements noted in mood and social behaviour (Levin et al. 1994; Curran 1996; Zarit et al. 1999). A widely used definition of day services is:

'a day service offers communal care, with paid or voluntary care givers present, in a setting outside the user's own home. Individuals come or are brought to use the services, which are available for at least four hours during the day, and return home on the same day' (Tester 1989:37).

This definition covers day care for both health and social needs, both day centres and day hospitals. Day centres and day hospitals are fundamentally different in a number of ways but much overlap in their function and in the characteristics of users is noted in research (e.g. Bacon and Lambkin 1997). This research focuses on specialist day care centres with a social emphasis run by voluntary organisations.

Day services have a range of purposes including helping people remain independent in the community, social care and company, rehabilitation and treatment, assessment and monitoring and providing support for carers (Tester 1989:40-41). Specialist day care run by voluntary organisations usually has a more social focus and focuses on providing social care and company, supporting carers and helping people remain independent in the community (Nies et al. 1992:254; Bacon and Lambkin 1997). In general day centres aim to provide social care in the form of activities, company and some basic personal care. Day centres are staffed by a mixture of paid and volunteer staff, some of whom may be trained social care workers (Tester 1989). People with dementia who attend day care in Scotland receive a range of services from day care staff, more so than other client groups (Scottish Executive 2001). These services include domestic and practical help, social development, leisure and personal care.

There are many reasons for referral to day centres. The most common include providing individual support, reducing isolation and providing company, respite for informal carers and stimulation (Collier and Baldwin 1999:588). Clients of specialist dementia day centres in Edinburgh were found to be referred to the centres by a wide range of professionals and services including community psychiatric nurses, social workers and day hospitals (Davidson 1997:51). This survey found that 29% of day care clients live alone in community housing, 54% with a carer, 10% in sheltered housing and the rest in a variety of supported and residential accommodation (Davidson 1997:54). These figures are different from those for people with dementia in general (see Spicker and Gordon 1997) and would suggest that people with dementia within residential settings do not attend day care. Two surveys found that the majority of people who attended day services enjoyed the experience (Farrow

1992; Moriarty and Webb 2000). The majority of carers found it very helpful for a number of reasons, including respite for themselves and company for the person attending (Farrow 1992).

Many people with dementia access day care services. In one study 67% were found to regularly attend day services (Levin et al. 1994) and another found 58% attended day care (Moriarty and Webb 2000:58). People with dementia attend both generic day services for older people and specialised services (Moriarty and Webb 2000). An advantage found in specialised day services is that staff are more knowledgeable and better trained with more positive attitudes towards people with dementia (Davison et al. 1994). Studies show that some people with dementia benefit from attendance at day services with improvements noted in mood and social behaviour (Levin et al. 1994; Curran 1996; Zarit et al. 1999). One study found that day services were particularly beneficial to women and people living alone (Curran 1996). Activities undertaken at day centres are important for people with dementia; they can promote self-confidence and can help to maintain cognitive skills (Archibald 1992).

### The policy context of day care for people with dementia in the UK

Day care is an integral part of community care for people with dementia (Tester 2001). The idea of community care has been around for decades but little real progress was made towards community care provision until the 1990s (Means and Smith 1998). Emphasis on community care for people with dementia has developed alongside the emergence of social models of dementia over the past ten to twenty years. An ethos of caring at home for people with dementia with a focus on their

social needs has developed over the twentieth century (Innes 2002:487; Tinker 1997; Kitwood 1997).

The origins of day care can be found in the 1950s in the development of day hospitals (Tinker 1997; Tester 1989). Day care services developed from day hospitals to provide social interaction and basic levels of care for people who no longer required medical attention (Tester 1989). Day services in the voluntary sector developed from organisations such as the Women's Voluntary Service, which was active during the World War II. Following the war their work continued but focused on groups with particular needs such as older people (Nies et al. 1992). Day care was further promoted through the National Assistance (Amendment) Act 1962, which allowed local authorities to provide meals and recreation for older people either in residential homes or through day care, clubs or workshops (Tinker 1997:139). Following this act and through the 1970s day centres with a more social focus in both statutory and voluntary sectors developed (Tester 1989; Nies et al. 1992).

The white paper *Caring for People* set out aims for the further development of community care in 1989 (Cm 849 1989). The stated aim was for 'people who are affected by problems of old age, mental illness...to be able to live as independently as possible in their own homes or in 'homely' settings in the community' (Cm 849 1989). The government gave a strong message that they were committed to the principles of community care. *Caring for people* set out six main objectives one of which was 'to promote the development of domiciliary, day and respite care to enable people to live in their own homes wherever feasible and sensible' (Cm 849 1989). This suggests that day care services would comprise a fundamental element of community care.

The National Health Service and Community Care Act 1990 implemented many of the recommendations of *Caring for people* over a three year period (Tinker 1997). This act gave local authorities the lead responsibility for the planning and co-ordination of community care services in their area (Scottish Parliament 2001). Local authorities were encouraged to make more use of services run by the private and voluntary sector (Cm 849 1989). New funding structures were introduced to reduce the bias towards residential care (Tinker 1997:142). These changes should encourage provision of day care services run by voluntary and private organisations. The culture of services for older people has not, however, changed dramatically with financial pressure on local authorities restricting the development of new and innovative services (Harding 1999). There is evidence of high levels of unmet need for older people (Philp et al. 1995). Older people currently would wish to remain in a home of their own but this often depends on what services are available in their area (Tinker et al. 1999). Services for older people remain at a low level reflecting their position in society and pervading ageist attitudes (Harding 1999). Literature on policy implementation stresses the common gap found between the stated goals of legislature and the actual service provision on the ground (Means and Smith 1998:43).

There was little coordination and organisation in the development of day services and little clarity in the policy guiding it (Levin et al. 1994). Little evidence was found of formal philosophy, aims or objectives at any level of service planning or provision (Department of Health and Social Services Inspectorate 1992). The UK is, however, often seen as the leader in day services as they developed earlier than in other European countries (Nies et al. 1992). Day services did not reach those most in need and did not fulfil their potential in the early 1990s (Department of Health and Social Services Inspectorate 1992:1.10). The report of the Royal Commission on



Long Term Care found 260,000 people over 65 receiving day care in the UK (Cm 4192-I 1999). The cost of day care was 3.4% of the total expenditure on long term care services, at 1995-1996 prices (Cm 4192-I 1999). This seems a small percentage for what appears a popular service.

Gradual changes have been noticed since 1990 in the provision of day care with a sharpening of boundaries between different providers and a wider range of types of day service (Tester 2001). The types and number of day services increased between 1980 and 1990 (Bacon and Lambkin 1997). There has been a growth in day centres for specialised groups of older people, for example people with dementia, since the NHS and Community Care Act (Tinker 1997). Bacon and Lambkin classified six types of day centre: voluntary sector, social centres for the active, day care centres, resource centre units, care for mixed user groups and care for the elderly mentally ill (1997:44). In general voluntary groups provide socially based day care for people with dementia, as in this research (Bacon and Lambkin 1997). In Scotland as in the rest of the UK day care is provided mainly by local authorities and voluntary agencies, 72% and 25% respectively (Scottish Executive 1999). Day services for people with dementia were found within mental health services in 9 out of 12 sites in England and Wales (Audit Commission 2000). These centres provided care for people with dementia on separate days from other people with mental illness. This, however, limits the service available to people with dementia and their carers (Audit Commission 2000). Cunningham and Kesterton (1995:54) found that people with dementia were initially included in generic day care services for older people. However, if their behaviour became problematic they would be excluded from these services. This led to segregation with day care for people with dementia supplied on

particular days of the week. Later still specialist full time day care for people with dementia was established (Cunningham and Kesterton 1995).

The fact that the UK is used as the source of information for policy transfer and policy translation might be connected to the large South Asian populations in the UK. So it is of interest to know what day care services people with dementia from these communities use. It is found that generic day centres for older people do not meet the needs of older people from ethnic minority communities (Tester 1996). These groups tend to provide their own day care services. Older people in Glasgow from South Asian communities use and value day care services (Bowes and Dar 2000). It is the only social service for older people that is offered on a culture specific basis for this group in Glasgow (Bowes and Dar 2000). These day centres are run by religious or community based groups. The choice for day care is partly due to the history of the services and the groups running them and partly due to funding restrictions (Bowes and Dar 2000). There is little knowledge of dementia among these groups although it seems possible that people with dementia may use these day care services. The main purpose of the day centre for users is social contact with peers and other people (Bowes and Dar 2000). A study in Edinburgh found that a much greater proportion of older people from minority ethnic communities attend day care than from majority populations (Bowes and Macdonald 2000). A study in Leeds found that day care was particularly valued by older people from ethnic minorities (Tinker et al. 1999:42).

Tester (2001:19) concludes that day care continues to be 'almost invisible' in policy documents related to care for older people. There has, however, been some increase in day care since the early 1990s particularly for older people with mental health problems (Tester 2001). Policy changes have increased the emphasis on

community care and a mixed economy of care leading to the development of more specialised day care centres run by voluntary organisations. Day care services are popular with informal carers and the people with dementia themselves. They provide a useful range of services which enable people with dementia to receive the care they need while living in their own homes. Currently provision of day care is not at a level to meet the need of people with dementia in the UK. The provision of day care for people with dementia is inconsistent across different areas of the UK. Policy changes have supported the expansion of day care services but major changes in service provision are only taking place slowly. The development of day care in the UK is long standing but lacking in clarity and organisation. Despite this the UK is seen as the leader in day care within Europe. This thesis suggests that individuals in Kerala also see the UK as a leader in this field.

### **The 'culture of care' in the UK**

Looking back over the previous three chapters it is possible to develop a discussion of the 'culture of care' for people with dementia in the UK. This 'culture of care' results from the interplay between formal policy and services, the role of informal carers and the conceptualisation of dementia. In general care for people with dementia in the UK is provided by both formal and informal means. Services provided by public, private and voluntary health and care organisations supplement care provided by family and community carers. Chamberlayne and King (2000:126) describe the 'culture of care' in the UK as 'a triad of public, private, and social dimensions, in which caring is located within individualised strategies.' The promotion of a mixed economy of care means that private care and voluntary care is being used more and more as public provision is reduced. The promotion of community care has

led to a changing culture within care services with more emphasis on the user and their carer (Means and Smith 1998; Chamberlayne and King 2000). The day centres in this thesis are promoted by the mixed economy of care, through the promotion of voluntary provision and the ideology of community care.

Within the ideology of community care there have been changes in the conceptualisation of dementia leading to what is sometimes described as a 'new culture of dementia care' (Kitwood and Benson (Eds.) 1995:1). There is an ongoing shift from the medical conceptualisation of dementia towards the social as described in chapter 3. Ideas such as user and carer empowerment and normalisation have led to new approaches to care for people with dementia (Means and Smith 1998; Emerson 1992; Tyne 1992). The social component of care services is more emphasised. In the *National Service Framework for Older People* the role of day care for people with dementia is described as 'providing a range of stimulating group and one to one activities' (Department of Health 2001:7.51). This is reflected in the development of specialist services for people with dementia which mirror developments seen in services for other groups such as people with learning disabilities (Woods 1995). Kitwood describes the old culture as based around the medical model and focusing on the deficits of people with dementia and problems of management (1995). The 'new culture' focuses on the individual within a social framework (Kitwood 1995:8-10). The cultural change is evident in the use of new activities and therapies within dementia care services (Woods 1995; Fox 1995). Fox found evidence of cultural change within specialist day care centres for people with dementia in the UK (1995). These changes suggest there has been a cultural shift in how people with dementia are cared for in the UK especially within specialised services. These different elements of formal and informal care characterise the

'culture of care' in the UK which frames the day care centres and influences the enactment of day care by the staff.

## **Development of policy and services in Kerala, India**

There are no specific policies for people with dementia and very few services for them in Kerala. As with older people, people with dementia are usually cared for at home by family members. One Indian NGO has been established to raise awareness of dementia and to provide services for people with dementia and their families. The ARDSI was established in 1992 and provides a range of services across India (Roy et al. 1996). This organisation was established in Kerala and runs various services within the state including day care and domiciliary care (Roy et al. 1996). It is this organisation and its day care services in Kerala that are the focus of this thesis.

The Government of India published its first comprehensive policy document for older people *The National Policy on Older Persons* in 1999 (Government of India 1999). The development and publication in 1991 of the UN's Principles for Older Persons and the declaration of 1999 as the International Year of Older Persons spurred some developing countries into developing policy for older people and India was one of these (HelpAge International 2002:76). *The National Policy on Older Persons* outlines a large number of reforms to existing policy as well as new policy to be implemented (Government of India 1999). The mandate is made that 'the state shall within the limits of its economic capacity and development make effective provision for securing the right to public assistance in cases of old age' (Government of India 1999:3).

The development of day care for people with dementia in Kerala took place in 1996, several years prior to the publication of this policy (Roy et al. 1996). It seems possible that formal policy in India may later influence the continuing development of day care but as discussed below the scope of the policy document is wide and India is a vast country making the policy very difficult to implement. A short discussion on the policy document follows as it is interesting to compare its central aims with those in the UK to illustrate the role of culture in shaping social policy. The discussion also suggests that policy transfer may have taken place during the development of the policy document in India.

One central theme within the policy document is to offer social support that enables older people to remain living with their family in their own home (Government of India 1999). The document stresses the role of the family in looking after older people (Government of India 1999). There is an emphasis on promoting a mixed economy of care within India but this appears to be due to the lack of funds available from the government rather than to promote a more competitive culture of services. The government proposes many changes affecting the well being of older people but then calls upon agencies other than itself to provide these.

A further series of changes are proposed within the policy to existing legislation and policy within central government in India. Women's rights are to be strengthened and legislation is to be introduced to protect older people who are subject to violence and abuse. Age-related discrimination is to be removed from employment and education along with an increased age of retirement. Carers of older people are to receive benefit similar to maternity benefit when taking time off work to care for older people. Legal aid is to be made free to older people and a better, faster system is

proposed (Desai 1998). Ageism in work, paying carers and protecting older people from violence are all recent themes familiar to discussions on the situation of older people in the UK. This seems to indicate that when compiling this policy document in India ideas and information were used from different countries.

The parts of the policy document relating to services reflect the culture of India. Services for older people are to include 'day care, multi-service citizens centres, out reach services...home visits' (Government of India 1999:62). Funds are to be diverted from institutional services to family and community settings. Non-institutional care is to be promoted through voluntary organisations to replace family care where women work or the family is small (Government of India 1999:60). A tax relief is to be offered to encourage cohabitation of children with their parents (Government of India 1999:82). The media is to be used to promote intergenerational bonds and dispel negative images of older people (Government of India 1999:88). Curricula at all stages of education are to be designed to promote strong intergenerational bonds. Schools are encouraged to interact with older people within the community drawing on their experience and knowledge (Government of India 1999:57). Some of these proposals are reminiscent of UK policy documents discussed above. These proposals, however, may be due more to the culture of India rather than any process of information transfer. Older people are traditionally cared for within the family in India and therefore resistance to institutional care is unsurprising. The promotion of the family as a central part of social organisation reflects both the traditional family structure and the fears that this is changing as discussed in chapter 4.

Several development programmes are also recommended. These are to provide information and support to help individuals prepare for and cope with old age,

bereavement and death. Spiritual and religious teaching is recommended to help older people prepare for death (Desai 1998:683). These proposals reflect the strong religious basis of culture in India and relate to the concept of *sanyasa* described in chapter 3.

The importance of NGOs is recognised by the Government of India within the policy document and they are to be supported and promoted. Various financial incentives are proposed to encourage NGOs to support older people (Government of India 1999). There is an emphasis throughout the document on the roles of NGOs. This might be seen to indicate a responsibility being placed on such organisations to lead the way in the establishment of services. Within the developing world NGOs often provide the only non-family support for older people but it is likely that these organisations will not be able to keep up with the growing population of older people (Wilson 2001a; 2000b). This research looks in detail at services for people with dementia run by an NGO.

The range of policies and services within the policy document is vast. No specific targets are set for implementation although mention is made of action plans to aid its implementation. In a country as big as India it is difficult to see that these policies will be implemented even within several years.

Prior to the publication of the policy document in 1999 some formal policy existed to provide pensions for older people (Bhattarai 1989:479). These schemes are for individuals employed within specific industries usually in urban areas (Bhattarai 1989:484). The huge numbers of informal workers in urban and rural areas do not receive these benefits. Some state governments including Kerala do now provide an



old-age pension scheme for some older people such as widows and 'the handicapped' (Bhattarai 1989). The eligibility criteria are different in each state and the pension awarded often very low (Bhattarai 1989). These benefits are often complex and difficult to claim and so may not be accessed by all eligible individuals. Despite the positive aims of the new policy it seems likely that older people in India will remain reliant on family and other means of support rather than formal pension schemes. As discussed in chapter 4 many older people in India continue working for as long as they are able in order to support themselves financially.

The policy document both reflects the local culture of India and the influence of policy documents from developed countries. The emphasis on the role of the family, the teaching of intergenerational respect and the resistance to institutional care all fit with traditional family structure and culture in India. Other aspects of the policy such as anti-ageism appear to be a reflection of recent concerns regarding older people from 'western countries'. It seems likely that the process of policy transfer was influential on the development of parts of the policy document.

Specific policy for older people is currently being developed by the State Government of Kerala based on the central government policy but is not yet available. The history of healthcare in Kerala provides an interesting illustration of the culture of the region. It also sheds light on how the development of services for people with dementia in Kerala may continue. The history of health care in Kerala is lengthy and before the arrival of European medicine traditional Ayurvedic medicine was practised (Raman Kutty 2000). In the late 19<sup>th</sup> century western medicine became established. When the modern state of Kerala was founded in 1956 there were already the foundations for a state health care system. The majority of state government

expenditure in Kerala has traditionally been on education and health (Raman Kutty 2000:103). Up until the mid-1980s there was expansion in the public sector healthcare and many state government hospitals opened. Following the mid-1980s expansion took place in private healthcare institutions and these now outnumber state institutions (Raman Kutty 2000:104). From the mid 1970s to the 1990s there was a period of 'fiscal crisis' in Kerala due to overspending by the state government and an above average deficit compared with the rest of India. The central government of India also reduced funding for state governments at this time. The standard of government run health care has steadily declined due to a lack of funds as the standard of private healthcare has improved.

The growth in private healthcare has also been supported by an increase in disposable income for many people in Kerala. Even amongst the poorest strata of society only 33% utilise government healthcare (Raman Kutty 2000:105). Private hospitals offer better care, better medicines and have more hi-tech methods for diagnosis and treatment (Raman Kutty 2000:106). High levels of education have contributed to the high use of healthcare in Kerala as well as ease of access to hospitals due to the infrastructure of Kerala (Raman Kutty 2000:107). Older people in India generally experience more health problems and the popular choice for treatment is Western allopathic medicine. Ninety percent of older people use this (Irudaya Rajan 2000:29). If this is the case for healthcare perhaps social care will develop in a similar manner. The lack of central and state government funding means that it seems likely that NGOs and private organisations will be important in developing services for people with dementia.

Social policy for older people in the developing and less developed regions of the world, in particular India, is organised, promoted and funded almost exclusively by NGOs. Most services in India for older people are provided by NGOs (Clarke 1998). These include Oxfam and specifically for older people, HelpAge International. It is felt that many organisations currently working in the developing world do not focus on the needs of older people (Yadava et al. 1997; Chilima 2000). The three main local agencies for older people are HelpAge India, Age-care India and Age Aid India (Cohen 1998). HelpAge International became active in India in the 1970s. At that time the main focus was to teach younger people about caring for older people and in fund-raising techniques. They promoted intergenerational understanding and integration (Tout 1989). For people with dementia organisations such as ADI and more local organisations such as the ARDSI provide services and information. Until recently the central government had no involvement in the welfare of older people except through programmes to combat poverty and disease. There were no central government initiatives specifically for older people until the publication of the *National Policy for Older Persons* (Government of India 1999). Currently few or no services are provided for older people or people with dementia and their needs are met by family members (Patel and Prince 2001). In one study health services were found to be lacking and the needs of older people poorly understood (Patel and Prince 2001). Due to the way in which old age is viewed many health problems are not presented to GPs and other health professionals as they are seen as part of the normal ageing process (Patel and Prince 2001). There appears to be a lack of awareness about ageing and its associated morbidity within existing health services.

Overall there is a lack of both policy and services for older people and people with dementia in India. The publication of the recent policy document suggests a shift

towards an interest in the situation and the needs of older people and among them people with dementia. Although the timing of the publication of the policy is probably more related to perceived pressure from the UN during the International Year of Older Persons, it does seem to indicate some interest by government officials. It remains to be seen what actual bearing this document will have on the situation of older people and people with dementia.

### **The 'culture of care' in Kerala**

The culture of care in Kerala is more straightforward to understand than that of the UK. Care of older people and people with dementia is still firmly situated within the family. There are few services and formal policy is still to have a major influence on how people with dementia are cared for. Traditionally the daughter in law cares for her husband's parents when they are older. A belief in family centredness means that older people and people with dementia are cared for within the family. Some older men undertake the final stage of life known as *sanyasa*, described in chapter 3, during which their community cares for them. Many older people, however, live in poverty and continue to work late in life. For these individuals the 'culture of care' may only be relevant when they become frail and unable to work. The concept of dementia is not well understood within Kerala and although people with dementia may be cared for within the family there is a stigma associated with mental health problems. The traditional 'culture of care' is, however, changing with family sizes becoming smaller and a general fear of a loss of traditional family structures and roles. However, these changes are relatively recent and the 'culture of care' still promotes the family as carers of people with dementia.

## **Conclusion**

I have established that the historical situations for policy development in the two countries are very different. The UK has over a hundred years of policy making for older people but still does not provide a comprehensive social policy for people with dementia. The Government of India published its first policy document specifically for older people only in 1999. I conclude that these differences reflect the culture of each context and this in turn reflects the political and historical development of social policy.

I found both similarities and notable differences between the Government of India policy document and recent policy documents produced in Scotland and the UK. The emphasis on a mixed economy of care is a common theme for both countries. The funding and structure of this is, however, quite different in each country. The Indian government may give some support to NGOs, but will not fund them or individuals using their services directly. The emphasis on the mixed economy of care in India may be to do with the lack of money available from the government to fund services.

Both countries give priority to services within the home rather than institutional care. Policy documents from both countries mention day care services as being appropriate for older people. Policies from both countries reflect the unpopularity of institutional care for older people. This is an interesting similarity as this idea has developed over many years in UK policy documents but is present in the first Indian policy document. It would be of interest to know if this is a reflection of the family

structure in India or results from policy transfer from 'western' countries. As discussed I argue that it is related to the local culture in India.

I found obvious differences between policies in the two countries due to the difference in the time over which policy has developed. Social policy for older people developed in the UK from early in the twentieth century but is a fairly recent development in India. The Indian policy document covers a diverse range of policies and services including financial matters, health, employment, education, and social services. In the UK these subjects are more likely to be covered in a number of documents. There are also some interesting differences in language and content. In the Indian document reference is made to death and the need to prepare for death and bereavement, a subject rarely mentioned in UK policy. I conclude that this is a direct reflection of Indian culture as discussed in chapter 3. There is also more emphasis on spirituality and identity with a main concern of the policy being to prevent older people from facing an identity crisis. It would be difficult to find such a view in an UK policy document.

The policy background in the two countries complements the earlier discussions of culture and the situation of people with dementia in the two contexts leading to a discussion of the 'culture of care' in each of the two contexts. I conclude that in the UK the culture of care is formalised within services with an emphasis on community care and social models of care for people with dementia. In comparison in Kerala care is situated within the family and is not formalised as 'work'.

In the preceding chapters, I have established the theoretical framework within which I analyse my data in order to construct an explanation and exploration of the

development of day care for people with dementia in Kerala. The theoretical constructs of policy transfer and policy translation provide this framework. I have established the importance of culture within this framework. I have started to illustrate this through my discussions of culture within the previous chapters. The 'cultures of care' which I have developed provide the contexts between which the policy transfer and policy translation processes have taken place. The following discussions and analysis of the data provide the substance to fill out the framework and link the theoretical constructs with the discussions on culture and specifically the 'cultures of care'.

## **Chapter 6**

### **Methodology**

#### **Introduction**

The fieldwork within the thesis complements the discussion and policy analysis undertaken in the preceding four chapters. The four day centres are embedded in the 'cultures of care' developed within these chapters. The fieldwork enables further analysis of the day centres within their cultural frameworks and builds on the policy analysis.

The main methodological approach of the thesis is ethnographic. The research is undertaken on a small-scale and focuses on the only two day care centres for people with dementia in Kerala, India. This allows a detailed approach and enabled the in-depth analysis desired. This chapter discusses the research framework, outlining the research design and discussing the specific methods. The central research questions are answered through two stages of fieldwork. The first investigates the process of policy transfer and comprises a period of fieldwork in Kerala. The second stage investigates the process of policy translation and



comprises fieldwork in Kerala and the UK. Data are then analysed comparatively. The comparative aspects of the thesis require special consideration.

This chapter goes on to discuss issues of validity and reliability within the thesis. These are again complicated by the comparative and exploratory nature of this research. Issues of access, ethics and consent are of importance as in any research. These issues are compounded by two factors. Firstly, the work is undertaken with people from different cultures and with different languages and secondly, the participation in the research of people with dementia. Another aspect of working in a different culture is the opportunity and necessity to work with an interpreter. This adds depth to the research but also brings its own challenges. Finally this chapter offers a description and explanation of the analysis and writing up of this thesis.

In this thesis the analytical framework for policy transfer guides the research design in terms of what data are seen as important and influences the design of interview schedules. As these interviews took place and other data were collected the research process developed. The concept of policy translation is not set out in such detail and theory regarding this process develops through the analysis of the literature and the data.

## **Ethnography**

The methodological framework for this research is ethnographic. The overall approach can be described as a comparative cross-national ethnography undertaken using the 'safari method' (Hantrais and Mangen 1996:4). This involves a single researcher carrying out the research in all the contexts involved. Using the safari

method to collect data in more than one country on a small scale allows collection of detailed and specific data (Hantrais and Mangen 1996).

Ethnography involves an attempt to place 'events...into a fuller, more meaningful context' (Tedlock 2000:455). Qualitative methods were used which allowed detailed investigation of this specific example of policy development. Qualitative researchers stress the socially constructed nature of reality (Denzin and Lincoln 2000:8). The view of the world as socially constructed is fundamental to the discussion of ageing and dementia and is an important aspect of this thesis (Kitwood 1997; Phillipson 1998). Although the research is exploratory in nature it may be possible for patterns and social forms within the data to be used to develop ideas about social processes at work that may have relevance beyond the data (Coffey and Atkinson 1996). Qualitative research allows for the use of natural data and the generation of hypotheses through the research findings (Silverman 2000). The processes of policy transfer and policy translation have not been investigated in this way before. In this thesis the development of specific theory, particularly on policy translation, is only possible as the data are collected.

The process of ethnography is described as

'the ethnographer participating, overtly or covertly, in people's lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light in the issues that are the focus of the research' (Hammersley and Atkinson 1995:1).

The term ethnography describes both the method of data collection and the written product (Macdonald 2001). Classically the main method of ethnography was described as participant observation. Participant observation itself may involve

various data collection techniques and now many different methods are used to undertake ethnography (Macdonald 2001). An ethnographic approach allows for a full, detailed picture to be drawn of each day centre. Meaning and the perception of the meaning of different behaviours and interactions are important within ethnography (Tedlock 2000). Interviews, observation and secondary data analysis are used to access these. Ethnographers stress the importance of reflexivity and the development and investigation of theory in this thesis requires reflexivity (Hammersley and Atkinson 1995).

The role of the researcher is also important within ethnography (Hammersley and Atkinson 1995; Angrosino and Mays de Pérez 2000; Tedlock 2000). An ethnographer immerses herself in the lives of others within the research situation (Bloor 2001; Gordon et al. 2001). As I conducted fieldwork in two very different contexts my role within each fieldsite changed and developed in each one. The two phases of this research provide different challenges and different approaches. The Kerala fieldwork can be seen as more akin to social anthropology with the aim of 'making the strange familiar'. The UK fieldwork is more classically aligned with British ethnography with the aim of 'making the familiar strange' (Gordon et al. 2001:188; Hammersley and Atkinson 1995). I argue that these differences enhance my data collection. I was able to undertake data collection in Kerala with a fresh perspective, as it was strange to me. When I later undertook work in UK fieldsites I was able to draw on my experience in Kerala to maintain my critical perspective and the quality of the data collection. Ethnographies are often used to provide descriptions and explanations and both are vital within this thesis (Hammersley and Atkinson 1995). The investigation of policy transfer and policy translation both discusses the processes and looks for an explanation of them.

Geertz describes the objective of ethnography as 'thick description' (1973:7). Thick description provides information on both what is done or what is observed and the meaning behind it. The ethnographer needs to make sense of different conceptual structures, which may be superimposed or entwined with others (Geertz 1973:10). Within this thesis the data are collected to enable thick description of the behaviour of the staff, clients, managers and key actors in Kerala and the UK. The concept of dementia, that of a day care worker and other important conceptual structures need to be understood and explored within the data. The different methods discussed below allow development of what Geertz describes as 'thick description' (1973:6).

## **Comparative research**

The thesis is split into comparative and non-comparative parts. The preceding chapters began the comparative analysis between the UK and Kerala. Data for both parts of the research were collected in Kerala. They were, therefore, subject to many of the challenges associated with comparative research, as discussed below. Comparative cross-national social policy is a growing area of research and a general definition is given by Hantrais and Mangan (1996:1):

'A study can be said to be cross-national and comparative if one or more units in two or more societies are compared in respect of the same concepts and concerning the systematic analysis of phenomena, usually with the intention of explaining them and generalising from them'.

The term 'society' is used to describe the contexts between which the comparison is being made. This could refer to country, culture, society or a subset within one of these.

There are many reasons for conducting research across national and cultural boundaries. In the literature there are three main types of comparative research: descriptive, evaluative and explanatory (Bolderson 1988; Hill 1996). Most comparative studies encompass one or more of these types (Hantrais and Mangen 1996). Bolderson (1988) notes that many comparative cross-national studies on social policy are evaluative and are biased towards studies focusing on state sector policies and services. The criticism is also made that social policy comparative work seldom seeks explanations (Bolderson 1988). Tester (1999) echoes this and adds that studies that do exist usually look at large scale examples of convergence and rarely look at the process of policy implementation. Some exceptions have looked for causal factors in the development of policies or specific services, e.g. convergence (Jarrott et al. 1998) and policy transfer (Tester and Freeman 1996). This research is both descriptive and explanatory in nature. It describes and explains the development of day care for people with dementia in Kerala and develops theory regarding this development.

There are many comparative studies between countries within Europe and specific countries within Europe are more often used in comparative research (Berting 1987). The USA is also often used within comparative research with Europe (e.g. Dolowitz et al. 1999; Zarit et al. 1999). These differences may reflect similar interests in research as well as language and cultural similarities between countries. Minimising the differences between countries reduces the complexity of the research and increases its validity (Berting 1987). In this research a comparison is made between a more developed country and a less developed country between which there are few similarities. This type of research appears to be rare. In this thesis this

comparison was chosen as an important link was found between the two contexts, that of policy transfer from the UK to India.

Globalisation is an increasingly important reason to conduct comparative research in the field of social policy. Increasing communication between countries and nations and increasing levels of co-operation, for example, within the European Union, influence policy development. As globalisation progresses it becomes less meaningful to study countries in isolation due to the level of interaction within a global marketplace (Øyen 1990). Comparative research can help to explain the influence of globalisation, to explain the mechanisms of change. Policy transfer could be described as a mechanism for globalisation and so on a small scale this research is looking at an example of globalisation in action.

A more personal reason for conducting comparative research is given by (Lisle 1985):

‘Cross-national comparativists are forced to attempt to adopt a different cultural perspective, to learn to understand the thought processes of another culture and to see it from the natives view point while also reconsidering their own country from the perspective of a skilled observer from the outside.’

Comparative research can be an illuminating way to study one’s own country and an opportunity to discover someone else’s. This was an important personal motivation within this research.

It is important within cross-national research to consider what role the society plays in the research, what function it fulfils. Kohn (1989) subdivides comparative research in the following way: the country, or society, can be seen as the object of

study, the context of the study, the unit of analysis or it can be taken as part of a larger whole. Within this research the society is used as the context of the research and its influence is investigated through the local culture in each place. Øyen (1990) discusses the aims of a good comparativist. Comparativists stress the need to raise questions about the nature of the comparison itself. Non-comparativists see macro social units as 'real' while comparativists consider macro social units to be abstracts, which are fluid and need not be made explicit within research. I aimed to be a good comparativist. My thesis has focused on micro social units within local contexts. The local contexts have been analysed as they influence the micro units under study and have not been considered as fixed entities. As Kohn discussed, the contexts provide the framework for my comparison they are not the focus of my comparison (1989).

Rokkan (1970) emphasised the importance of defining the difference between cross-national, cross-cultural and cross-societal studies. The modern nation-state is a fairly new concept and cultures and societies may cross these boundaries, therefore, careful consideration and definition of the samples under study is required. In this thesis the two contexts under comparison are a state and a country. The choice to make the comparison in this manner was to compare like with like as discussed in chapters 1 and 5.

The approach to comparative research is not always seen as necessarily different from that for other types of research (Hantrais and Mangen 1996). Social research often involves comparison in some form. In cross-national research it is necessary to apply the same principles as in social research but there are added dimensions to consider.

Two specific problems of comparative research are those of definition and equivalence. These difficulties are conceptual as well as language related. Lisle (1985) describes language as a conceptual system that reflects the ideologies and institutions of the country. Tester (1996) discusses the problems of defining and finding an equivalent term for the concept of community care, a term which can describe a wide range of issues in different contexts and countries. A compromise must often be made between specification and meaningful generalisation. Translation of these concepts is a crucial part of comparative research and denial of the differences hides the cultural and historical differences between countries (Wilson 2001b). Bolderson (1988:271) states: 'Instances may be truly comparable and meaningful when they are particular and closely specified but they are then incapable of generalisation without numerous qualifications.' This research was done on a small scale and so it was possible to collect detail and take time to explain and describe the concepts involved in the thesis. The specific conclusions drawn from the thesis may not be useful for wide generalisations. However, general themes and ideas from the research may have relevance in a wider context.

There are different options for undertaking cross-national research and the 'safari' method was chosen for this research (Hantrais and Mangen 1996:4). In safari type research the influence of the researcher's own 'cultural value system, assumptions and thought patterns' is important (Hantrais and Mangen 1996:9). It may affect how data are collected and also what data are collected. The influence of the researcher is discussed as each research method is described and is of concern within the discussion on consent and ethics. To summarise, my overall approach



could be described as a comparative cross-national ethnography undertaken using the safari method.

## **Research methods**

The research was split into two main sections. The first investigated the process and channels of policy transfer to Kerala. The second investigated the functioning of services for people with dementia in Kerala and the UK, that is the process of policy translation. It was planned that a research assistant would be employed in Kerala to help with logistic and organisational needs and to act as an interpreter for the staff interviews. In fact several people within the ARDSI provided background and cultural information and helped with the logistics of the research. An interpreter was employed specifically for the interviews with staff in Kerala. All these individuals could be described as 'cultural consultants' (Jentsch 1998:288). They helped to guide and orient me within the local culture. Two main research techniques were used: semi-structured interviews and observation and these were complemented with documentary evidence. The use of different methods 'adds rigor, breadth, complexity, richness and depth to any inquiry' (Flick 1998:231).

### **Investigating the process of policy transfer**

The exploration of the process of policy transfer process answers the first two research questions as set out in chapter 1. The process of policy transfer was investigated by interviewing several key actors within the ARDSI. The choice of interviewing was to facilitate collection of information from the past. It was also to investigate the motivations of the individuals involved and therefore, explain how and

why the process took place. There is physical evidence of the end product of policy transfer in the form of services. However, this does not elucidate the process of transfer. Some of the important aspects of the transfer were recorded within ARDSI publications and these were used to supplement the information gathered within interviews. The key actors involved in these interviews are described within Appendix B.

A semi-structured schedule was used as this complemented the analytical framework for policy transfer developed for this research. Semi-structured interviews allow for consistency in the type of data collected from each person while giving flexibility for detailed data to be collected on particular opinions, attitudes and experiences (Kvale 1996; Wengraf 2001). Interviews can focus on practical issues as well as more experiential topics to get deeper investigation of the subjective viewpoints of different individuals (Silverman 2000). Each individual interviewed had a different experience of and role in the transfer. I did maintain a basic set of questions but constantly changed and adapted the interview schedules. These interviews were conducted in English as the individuals involved could speak English and I felt that they would not wish to be interviewed through an interpreter. The interviews were tape-recorded and fully transcribed.

The interviews with the key actors of the ARDSI were complemented by interviews with two people involved in local government. This was to further elucidate the formal policy context into which the policy transfer had taken place. The interviews also provided information on the attitudes of individuals within local government with regard to dementia. These interviews focused on the local government's response to people with dementia and older people as well as the

individual's own knowledge and ideas. Both interviews were conducted in English. Appendix C contains all the interview schedules and notes on their development.

During the interviews with key actors in Kerala three key actors were identified in the UK. These individuals can be conceptualised as being at the opposite end of the policy transfer process. I emailed a brief questionnaire to each of them, which asked about their input into the development of day care in Kerala. One key actor did not reply. Data from the other two confirmed that information had been passed from the UK to the ARDSI but did not provide data useful to the overall analysis of the policy transfer process.

### Investigating the process of policy translation

The second part of the research was focused on the process of policy translation and answered the final three research questions as set out in chapter 1. This part of the research investigated the implementation and functioning of the policy in the new context. Case studies of four day centres were developed, two in Kerala and two in the UK. Within the thesis the four day centres are referred to by single terms. These are Cochin and Trivandrum in Kerala and Iona and Jura in Scotland. Cochin and Trivandrum are the names of the cities within which the day centres are located. It is not possible to disguise the location of these day centres as they are the only two in Kerala. Iona and Jura are pseudonyms and do not relate to the location of these centres. Within the thesis the staff in the UK are referred to as day care workers and in Kerala as community geriatric nurses (CGN).

I had initially planned to look at both day care and domiciliary care. However, when I arrived in Kerala I realised that there would be problems with language and access which would make it very difficult to research a domiciliary service in Kerala. The day centre in Cochin was investigated in detail over a period of several months. The second day centre in Trivandrum was observed for one week as due to logistical reasons only a short visit could be arranged. The two day centres in the UK were chosen from those of AS-AD. This organisation is similar to the ARDSI in that it is a dementia specific NGO and affiliated to ADI. This is an important link within the research. The specific centres were chosen due to size and location. They are both of a similar size to the Cochin centre and situated in urban areas with similar populations to Cochin and Trivandrum. They were also chosen as they were in an easy location for me to travel to.

A case study approach was undertaken to investigate each of the day care centres. A case study is 'a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence' (Robson 1993:5). A multi-method approach was undertaken using observation, interviewing and documentary analysis. The research also included 'mucking about' (Lofland and Lofland 1995). This means that any additional information available during the period of fieldwork was recorded and used within the analysis. The structure of a case study can be determined prior to fieldwork or may emerge during the fieldwork (Robson 1993). As this research was exploratory in nature a more emergent structure to the case study was utilised in the first centre to be studied. The following case studies were constructed in similar ways in each location. This was necessary to facilitate comparison.

The case studies comprised a period of observation followed by semi-structured interviews with staff members. Information from documentary sources was collected at the end of the observation period. The observation work was carried out first to allow me to gain a clear picture of what was taking place at the different centres. This also gave me the opportunity to ask questions about what I had observed at interview. I was also able to develop relationships with the staff prior to the interviews.

Issues of access, ethics and consent are discussed later in this chapter. At this point it seems relevant to discuss how I optimised my research within the different fieldsites. It was important that I could spend long periods of time within the day centres without having a major effect on the situations there. It is important to stress that research participants react to the individual ethnographer based on their perceptions and understanding of her (Angrosino and Mays de Pérez 2000). The attributes of the researcher influence her relationship with the research participants and these relationships are dynamic (Angrosino and Mays de Pérez 2000). During the observation period I wanted to reduce my impact, that is I wanted to reduce the 'observer effect' (Adler and Adler 1994:382). I also needed access to the culture of the day centres to understand the interactions I saw there. The researcher needs to establish rapport within the fieldsite while not going 'native' (Angrosino and Mays de Pérez 2000:679). I needed to establish relationships within the day centres without becoming too involved. Fontana and Frey (2000:654) describe this process as 'getting in' to the fieldsite. There were differences in how I did this in the two contexts.

Ethnographers are 'outsiders in insiders clothes' (Tedlock 2000:455).

In Cochin I was welcomed by the staff as someone familiar and they did not appear uncomfortable with me being in the centre. They had a curiosity about my work but mostly about me and would ask questions about my personal life and life in the UK. They knew that I had knowledge of day centres and people with dementia and so were not concerned about me being with the clients. The clients showed a similar curiosity about me and I enjoyed spending time chatting with them. I got further 'into' the day centre culture by dressing in local dress. I did not do this intentionally but for my own comfort. It did, however, help me in several ways to 'get into' the setting. I wore a *salwar kameez* or *churidar*, a tunic with trousers and a scarf, similar to those worn by the younger CGNs and the female management staff. On reflection I can see that by wearing a *salwar kameez* I did three things. Firstly I fitted in with the local culture and looked 'decent' to them. I was not showing my arms or legs and wore bright colours. This particularly helped my interactions with the clients. Secondly I was presenting myself as a young person and so several of the CGNs and staff took a motherly tone when talking and interacting with me. Thirdly I provided a topic for interaction. The CGNs were rarely interested in my 'western' clothes but would make a fuss of any new *salwar kameez* I was wearing. All these aspects helped my acceptance at both the day centres and built trusting relationships between me and the staff and clients.

It became apparent that one of the greatest concerns of the CGNs was that I was undertaking research for the management of the ARDSI. I did my best to explain this was not the case and that I was not going to pass on any information to them. I was able to reinforce this at staff meetings when I would be asked by management to

reflect on my research and advise or criticise what was happening at the day centre. I refused politely to do this on any occasion I was asked and so reinforced my position with the CGNs.

Another barrier with the CGNs and some of the clients was language. I spoke as little *Malayalam* as they did English. This was enough, however, to share jokes and some conversation. Several clients spoke English well. The CGNs would try to help me understand if they felt I should know what had been said in a particular interaction. Sometimes one of the clients who spoke English would act as an in-between during conversations. I was able to follow the gist of most of the conversations at the day care. I did wonder if the fact that I did not speak much *Malayalam* helped me to conduct my research. The 'observer effect' was reduced as the CGNs and clients appeared to be less aware of me as perhaps they felt I did not understand what was being said (Adler and Adler 1994:382). This was not comfortable for me, however useful, and I did make an effort to let the CGNs know that I could follow much of what was being said. In Trivandrum my acceptance at the day centre was quick but not to the same depth as that in Cochin. The two members of staff there were older and so immediately interacted with me in a motherly manner. Neither the staff nor clients spoke English so we got by with a mixture of English and *Malayalam* and with the help of a local resident who spoke English. In different ways all the staff and clients helped me to understand more about what I was observing, often by explaining or pointing things out to me.

In the UK it was easier for me to gain access to the culture of day care myself, without the help of the staff and clients. I have a background of working with people with dementia and this helped greatly. I found the best way 'into' the day centres was

to build rapport with the clients. This seemed to help the staff accept me being around. Both day centres had a variety of trainees and students but I did not fit with these roles and had to carefully explain about my research. It often took a while for the staff to understand what I was doing. The clients were often interested in my research. Having worked in a care environment myself I found some of the behaviours of the staff familiar and this helped my understanding of the setting. Issues of language were not absent in this context. Many of the staff used jargon to describe aspects of their role and behaviours of the clients. I was careful to ask the staff for explanations of these terms. The next part of this chapter goes on to look in detail at the main research methods.

### Observation

I describe this research method as observation rather than participant observation for reasons I discuss below. Observation was carried out to look at what was actually going on at the day care services. It was vital in describing and examining the functioning of the services and for elucidating the roles of the different staff members within the services. The observation focused on the different activities and the interactions taking place within the care setting. In Kerala, the language differences were problematic in the collection of observation data. The observation research overall, therefore, focused more on behaviour than conversation. An interpreter was not used in Kerala as it was felt that it would cause too much disruption to the setting and would not add to the data in a way to balance this effect. Written documents were also investigated and these included care notes, minutes from meetings and organisational publications.



When carrying out the observation I did not have a particular focus for my data collection. The aim was to achieve a clear picture of what went on in each centre in order that this might be compared with data from other centres. I did not know prior to the comparative analysis where the fundamental differences would lie between the two contexts. I was aware that it might be easy to assume the cultural differences I had encountered through living in Kerala might be important as differences in my research. For example, I became aware that gender roles were very different in Kerala than my experience in the UK but when I analysed my data differences in gender roles were not an important difference between the two contexts. My observation work was therefore largely unstructured but rich in detail. I used diagrams and sketches to set out the structural arrangements at the day centres each day and then wrote as much as possible both during and after the periods of observation. Fieldnotes should be written up close to the field and I did this as much as possible (Emerson et al. 2001). There is some debate but fieldnotes usually take place in two stages, firstly in the field they are descriptive and later they include analysis and interpretation (Emerson et al. 2001:352). This was the pattern I felt naturally emerged during my fieldwork. I undertook observation in blocks of up to two hours and organised these blocks to cover all times of the day at day care. Between these blocks of observation I would usually remain at the day centres, sometimes sitting in the staff rooms writing up notes or just spending time with the staff and clients participating in their activities. These periods proved to be important in the research. I could reflect and compare what I had observed and also build my relationships with the research participants. The timings and length of observation are given in Appendix E.

I decided that observation was an appropriate method for this part of the research as it is unobtrusive and allowed me to spend long periods of time at the fieldsites. Observation is often thought of as 'the mainstay of ethnographic enterprise' (Adler and Adler 1994:389). Observation is described as providing rigor to the research when combined with other research methods (Adler and Adler 1994:383). I used my observation data along with interview data to build what I feel is an accurate and detailed picture of each day centre. Adler and Adler (1994:380) suggest that observation notes should include information on participants, interactions, routines, rituals, temporal elements, interpretations and social organisation. My initial fieldnotes included participants, interactions and temporal elements and from these I was able to deduce routines, rituals and social organisation and add my interpretations. Observation should continue until 'theoretical saturation' is reached, in that the 'generic features of...new findings consistently replicate earlier ones' (Adler and Adler 1994:381). I was able to do this in three of the centres but not in Trivandrum due to my limited time there.

I have not called this work participant observation for the reason that I did not feel I was fully participating at each day centre due both to language difficulties in Kerala and the fact that I did not fit an existing role at the day centres. Participant observation, however, covers a broad range of research techniques and I was participating to some degree. Atkinson and Hammersley (1994:249) state that 'it has been argued that in a sense all social research is a form of participant observation, because we cannot study the social world without being part of it.' I was certainly involved in the activity at the different day centres. The importance of the objectivity of the researcher is often stressed within observation work but more recently the relationship between observer and observed is described as a dialogue (Angrosino

and Mays de Pérez 2000:674). It is not possible to achieve complete objectivity in any situation. The role of the researcher is often described in terms of 'membership' within the observed setting (Adler and Adler 1994; Angrosino and Mays de Pérez 2000:675). There are degrees of membership, which affect the role of the researcher and the type of data collected. Active membership is described as the situation whereby an individual researcher takes on a role that advances the group under study (Adler and Adler 1994:379). In my research I did not want to do this. Particularly when I was in Kerala I did not want to add 'western' ideas of my own to the mix. I did have a degree of membership within the settings both in Kerala and in the UK. I did interact with the research participants and took part in some of the activities at the different centres.

### Ethnicity and research

It is important to briefly discuss here the influence of the different ethnicity of the researcher and the research participants in Kerala. Within cross-cultural research there is some discussion on the effect of ethnicity in interview settings. It concludes that interviewers should be of the same ethnicity as the interviewee (Rhodes 1994). This is based on the idea that white people have traditionally exploited black people and therefore the power balance in an interview of this type is unequal. Rhodes (1994) reminds us that ethnicity is negotiated within each encounter and need not result in the negative balance described before. Rhodes (1994) argues that the data collected by a black researcher are not necessarily better than those collected by a white researcher but the two data sets are different. In my research in Kerala I was an 'outsider' (Rhodes 1994:551). I was not part of the local network and I was white while the research participants were *Malayalee* (from Kerala). It might be expected that this would mean that interviewees were less likely to share information with me. I

argue, as would Rhodes (1994) that this actually helped my data collection. As I was an outsider the interviewees did not think I was a risk to their anonymity, as I did not know people within their locality. The CGNs were reassured that I would be taking the interview tapes home to the UK and not giving them to the management of the ARDSI. Another advantage that Rhodes (1994) mentions is that as I was white, my *Malayalee* interviewees may have taken longer to explain things about their culture giving detail as they would not assume that I had knowledge of these things. This did happen in the interviews and my data were richer as a result. In the UK there were not obvious issues around race and ethnicity during my fieldwork. I was, however, a stranger within the day centres and was different because of this. The day care workers took time to explain situations to me, not because I was visibly different to them, but because I was a stranger in their culture of day care.

## Interviews

Semi-structured interviews were carried out with the staff at three of the day centres following the observation work. The staff at Trivandrum were not formally interviewed as no interpreter was available but I did interview Meera who effectively manages the centre. Semi-structured interviews were chosen as they allow flexibility while maintain some structure to the data collected (Kvale 1996; Wengraf 2001). As this thesis involves comparative research there is a need to keep the data structured to facilitate comparison. These interviews were with individuals who had been observed within the first part of the fieldwork and I had developed a relationship with them. These interviews could, therefore, be described as ethnographic interviews (Heyl 2001). With ethnographic interviews the relationship between the interviewer

and the respondent is crucial and can greatly enhance the quality of the interview. I found this to be the case.

The staff in each location included managers, day care staff and drivers. In Kerala, the interviews with managers were conducted in English as they all had a good command of English and I preferred to interview them directly. The managers were also key actors within the ARDSI and their interviews covered both parts of the research. The interviews with the day care staff and driver in Cochin were conducted with an interpreter in the local language, *Malayalam*. These interviews provided the most challenging and interesting aspect of this research and are discussed in more detail below. The staff interviews needed to have enough structure to facilitate the comparative work but enough flexibility to gain as much information as possible. This schedule asked the staff about their jobs and their ideas and knowledge about older people and dementia. The interviews were tape-recorded and transcribed. The interview schedules are given in Appendix C.

I had problems at first in talking to the CGNs in Cochin about interviewing them. I discussed the interviews at staff meetings, as senior members of staff were there to help interpret. These discussions did not go smoothly and the CGNs were suspicious about the interviews. It was only later, when I approached them away from the meeting and with my interpreter that they seemed to understand what I wanted. From then on they were happy to be interviewed. It may have been that the managers wanted to reduce my contact with the CGNs in case they complained to me about their working conditions. The CGNs did in fact do this.

## **Working with an interpreter**

Working with an interpreter was an important part of my methodology and requires further discussion. There are serious considerations attached to working with interpreters within qualitative research and it poses a challenge to the validity of the data collected (Jentsch 1998; Edwards 1998; Temple 1997). The quality of interpretation depends on the ability of the interpreter and his/her relationship with the interviewer (Jentsch 1998; Edwards 1998). Edwards (1998) recommends that the interpreter should be matched to the interviewees and as far as possible to the researcher. For my research I was able to find an interpreter, Nisha, who was the same age and sex as the interviewees with a similar cultural background to them. Nisha was also the same age and sex as me and shared the experience of being a social science PhD student. The matching of an interpreter with the interviewees is not always appropriate as apparent in the discussion of race and ethnicity above. In this situation I felt that the matching between researcher and interpreter and interpreter and interviewee enhanced the situation. Kapborg and Bertero (2002:52) agree that it helps if an interpreter is 'part of the cultural arena' under study. They also recommend that a researcher learn about the country under study before undertaking interviews using an interpreter. I was able to do this as the interviews took place towards the end of my fieldwork period so I was familiar with the local area.

The addition of a third person within an interview situation adds complexity, which must be recognised. Jentsch (1998:279) conceptualises the influence of an interpreter within an interview, terming it the 'interpreter effect.' The position of the interpreter interacts with that of the interviewee and the researcher leading to a complex interplay of roles and power. Despite this Jentsch states that interpreters

play an active and important role within research and are 'a price worthwhile paying' (1998:288). I also found this to be the case.

Kapborg and Bertero (2002) recommend that an interpreter is trained in the field of the researcher and this was the case. I was able to brief Nisha fully on my thesis and my main research questions and aims. She had worked as an interpreter on a qualitative project previously and appeared comfortable with qualitative research and my thesis.

We structured the interview schedule together and Nisha was able to comment on the questions and structure of the schedule and make suggestions based on her cultural perspective, which was more similar to that of the interviewees than mine. For example, she recommended that I avoid direct questions about the relationships between CGNs and clients and instead ask questions round this subject. On completion of the interviews it was clear that this approach had resulted in the desired data being collected. Nisha was also able to rephrase particular questions and use more appropriate terminology. For example, instead of asking about motivations for doing their job, she asked the CGNs what the benefits of their jobs were to them. 'Opportunities for promotion', in English, became 'growth prospects', in *Malayalam*, and 'problems' became 'special circumstances'. Language is crucial in how we interpret the social world; it constructs as well as describes it (Temple 1997). Words that appear equivalent may not be so. Temple (1997) gives the example of 'family', a seemingly simple concept that she found to represent subtly but importantly different things in the UK and Hungary. In my interviews the word 'old' provided a similar example. I asked staff in both countries to define older people and found the term to represent different things to the staff in each context. Nisha was also a source of

more general knowledge. She became my 'cultural consultant' (Jentsch 1998:288) or as Edwards (1998) describes, an additional key informant within my research.

During the interviews themselves there were several things to take into consideration. The specific roles, the physical layout, the interactions during the interviews and the power relationships are all important within interviews and more so when an interpreter is present. In these interviews the roles of the three participants were not always clear. As recommended by Edwards (1998:201) the interviews were conducted with the three participants seated in a triangle, all able to look at each other. I used eye contact and gestures to maintain contact with the interviewee. I used touch or eye contact with Nisha if I felt the interview had gone off track. I felt frustration at times at not having control of the interview. I did not want to interrupt the interviewees but felt at times that the interview had lost direction. Jentsch (1998) also discusses the frustration of losing control of the interview. I was able to discuss this with Nisha after the particular interviews and it happened less often as the interviews progressed. Nisha's role within the interview was crucial. An interpreter can just translate word for word or can take control of the whole interview process but Edwards suggests that they should do something in-between (1998:200). In these interviews I tried to get Nisha to translate as fully as possible but not word for word as that would have made the interviews overlong. As the interviews were taped it was possible to go back to them afterwards for a fuller translation and this was done in detail after each interview.

There is also a power structure within the interview, which I found to be complex and not fixed. We were all females of a similar age and so shared some common ground. Each individual's power is based on her position within the group



and this could be based on her role, use of language and culture (Edwards 1998). It is said that 'in typical interviews there exists a hierarchical relation, with the respondent being in the subordinate position' (Fontana and Frey 2000:658). As a white, visiting researcher it might have been felt that I held the power within the interviews. I did not find this to be the case. From my perspective Nisha held power, as I was reliant on her to undertake the interviews. The interviewees held power, as I was reliant on them to respond to my questions. The interviewees might think I held the power, as I would be interpreting the data collected and producing written work from it. Nisha saw me as having power as I paid for her services and had the final say in what she did but she also realised her own power in controlling the progress of the interviews and my dependence on her. The use of language also affected the power relations, Nisha being the strongest as she spoke both languages and so controlled the passage of information within the interview. The power structures were complex but I feel overall that they did not disadvantage anyone specifically.

In the UK I did not require an interpreter for my interviews with the care staff and drivers. This altered the style of the interviews and changed the balance of power within the interviews. I had gained more control of the interviews and as a consequence the power balance within the interview became more marked. I tried to reduce this imbalance through the relationships I developed with the staff during the observation period. I stressed the importance of their knowledge and opinions within my research.

## **Access and informed consent**

Access issues were of concern prior to the fieldwork but overall they were not problematic. In some ways the ease of access caused concern for the ethical aspects of the research and this is discussed below. Access to the key actors in Kerala was straightforward as in all cases I had met these individuals previously and they were enthusiastic to talk about their experiences. The interviews with local government officials in Kerala were organised through local contacts.

Access to each of the day care centres, both in Kerala and the UK, was straightforward. In Kerala the Chairman of the ARDSI was the main gatekeeper for the Cochin day centre and was enthusiastic for me to undertake research there. Meera, in Trivandrum, was also keen for me to undertake research at the day centre there. It was apparent that in return for this they would like me to comment on the day centres. I explained that my research was confidential and both Roy and Meera understood this. However, they did continue to ask me questions about the day centres, which I continued to deflect.

In the UK access to the day centres was equally straightforward. I contacted the regional managers of AS-AD for the two regions in which I planned to undertake research. These managers both directed me to projects they thought would be suitable for my research. They were clear that it was the decision of the project co-ordinator at each project as to whether I could undertake research there. The project co-ordinators, therefore, became my gatekeepers. The two project co-ordinators were both familiar with the University of Stirling and were both enthusiastic that I undertook the research. As with Kerala I was concerned that the consent procedures may not be

as rigorous as possible as I was reliant on the project co-ordinators for assistance with this process. These access issues are highlighted within the British Sociological Association 'Statement of Ethical Practice' (British Sociological Association 2000).

'In some situations access to a research setting is gained via a gatekeeper. In these situations members should adhere to the principle of obtaining informed consent directly from the research participants to whom access is required, while at the same time taking account of the gatekeepers interest' (British Sociological Association 2000:5vi).

The gatekeepers were enthusiastic for the research to take place but I was wary of how this may have affected the consent process. On further discussion with them I was able to clarify that they took the consent process as seriously as I did. Once I had gained access to the day centres I negotiated consent with the individuals involved.

Ethical issues were important in all parts of the thesis. Ethical considerations differ for each part of the research and are dependent on research method (Mason 1994). Some individuals are closely involved with the research through participation in in-depth interviews. Others, such as the day care clients, are less involved just being observed taking part in their usual routine. It is important, however, that they are all protected during the research process.

A central part of the ethical nature of research is to ensure informed consent is obtained from all research participants. In this research there are several issues surrounding this. The research participants include people from different cultures, speaking different languages, and people with dementia. These groups pose challenges for the consent process. A decision was taken not to look for written consent from the individuals involved but to use a range of methods focusing on the idea of 'ongoing negotiated consent' (Crossan and McColgan 1999:8). The Canadian

Sociological and Anthropological Association (Canadian Sociology and Anthropology Association 1994) ethical guidelines state that 'the signed consent form may be inadequate or inadvisable in certain circumstances, in which case the researcher should employ culturally appropriate methods' (Canadian Sociology and Anthropology Association 1994:3). Ongoing negotiated consent was obtained from the majority of participants although some of the people with dementia involved were not able to give consent directly.

Informed consent comprises three main components. The individual giving consent must be informed about what they are consenting to, they must be competent to give that consent and be able to give consent freely (Crossan and McColgan 1999; Kane 1998; Helchman 1990). The ongoing negotiated consent was obtained through repeated discussions with individuals during the lengthy fieldwork periods and through recorded exchanges on consent for interviews. I used a notebook at all times when I was collecting observation data. If staff or clients requested I would show them my notes and explain their content if they had been present while I was taking the notes. I found the notebook to be useful as it was a talking point, particularly for the clients and often a joke for the staff. It also reduced any ambiguity about what I was doing there. I think the comparative element with India helped for both staff and clients in the UK to engage with my thesis and vice versa for those in Kerala. People in both places were interested in the people in the other. With the CGNs in Kerala I did not speak their language to an adequate level and so relied on other staff to translate what I said at staff meetings. My own rudimentary grasp of the local language did help in ensuring these translations were adequate. At times, however, I was aware that my position had not been accurately represented. At these times I would repeat the process until I was comfortable that I had been accurately represented and that consent had been

given. The CGNs and staff in the UK seemed more concerned about me talking to their managers than about where the information I collected would be published.

People with dementia pose a challenge for obtaining informed consent during research. The issue of competency is the one that is often highlighted (Kane 1998; Helchman 1990; Crossan and McColgan 1999). The question is whether people with dementia are competent to give consent. I would argue like Kane (1998) that in many cases people with dementia are able to give consent. This consent may not be remembered from day to day but can, however, be renegotiated. The clients in India were told about my research by the CGNs and ongoing consent was gained in this manner. Several of the clients at Cochin spoke English and I was able to gain ongoing consent from them. In the Cochin day centres most of the clients were able to communicate well with the CGNs some however had problems with communication. This was the same in the UK. For most of the clients, I was able to speak to them directly and repeatedly about my thesis. For some I was not able to do this. They did not appear to understand what I was saying and were not able to give a clear reply when I asked questions. As this was the case I also contacted the carers of all the clients at the day centres. I chose to contact the carers for two reasons; firstly to ensure that assent was given for all the research participants and to ensure the carers had information about my thesis. This letter gave a short description of my research and where the information might be published. The letter gave the carers the option of contacting me for more information about the research or the project co-ordinators directly if they had concerns about my research. In fact no carers made any objections to my research. Stalker (1998) uses professionals to gain consent for people with learning difficulties rather than carers or relatives. She does this to avoid the paternalistic attitude towards this group of people. In this case I felt that carers

would be a better option as the professionals involved appeared positively biased towards the research. Further in defence of what was perhaps a less formal approach to consent is the fact that the clients are not the focus of this research. Their actions are described within the aspects of day care but are rarely described individually.

Further to consent there is a necessity to maintain confidentiality and anonymity of participants (Lofland and Lofland 1995). Data collected from the interviews with key actors in Kerala are difficult to make anonymous. These issues were discussed at length with these individuals before the interviews took place and all were happy to continue to take part. The names of these people are not altered within the analysis. All other individuals were reassured of their anonymity within the data and any publications and their names have been changed. Appendix B details the key actors and indicates which names have been changed. Some grey documentation was accessed during the research. The structure of forms used and types of information were noted but no specific details on clients were taken from these documents.

### **Reliability and validity**

The reliability of research refers to the possibility of replication of a piece of data collection and the rigour with which the data were collected (Silverman 2000). To ensure reliable data collection it is important to assess the effect of subject and researcher bias within the fieldwork (Robson 1993). In this research there are important biases' to be noted and controlled for from both the researcher and the subjects. I worked hard to collect the data in a rigorous fashion, in the same way in each centre as described above. In this aspect the data collected are reliable. It is

not probable, however, that another researcher could replicate my research in Kerala. I previously worked for the ARDSI as a volunteer. My prior connections probably both helped and hindered my research in a way that would be difficult to replicate. I did not have the same connections in the UK and would expect that another researcher could replicate the data collected there. To ensure reliability consideration must be taken of the effect of the interviewer (Wengraf 2001) and 'observer effect' (Adler and Adler 1994:382). I have discussed at length my impact as an observer and an interviewer. Although overall it is not expected that this research is reliable in that it could be replicated, the rigour with which data were collected ensures that it has an acceptable level of reliability.

The internal validity of the data relates to whether the data addresses the questions that it states it does and whether the chosen research methods are appropriate (Sanger 1996). In the first section, which looks at the process of policy transfer, it must be shown that the policy transfer is the relevant variable. The researcher must investigate what else was happening at that same time and how important the policy transfer was. To do this interviews were conducted outwith the ARDSI that confirmed the relevance of policy transfer. For the final part of the thesis it is necessary to ask whether comparing care services in Kerala and the UK can tell us about the influence of the social and cultural context on the functioning of the services. If the services in each location have a similar basic structure it does not seem unreasonable to assume that the differences are due to local factors.

Validity and reliability are also important within the analysis of the data. There are many methods suggested to ensure the rigour of qualitative analysis. Firstly it is important to ensure that all relevant data have been examined (Huberman and Miles

1994:433). I did this by using NVivo, discussed further below, where I was able to store and manage the data and check that I had coded all the available data and that nothing had been missed. When I continued my analysis by hand I was careful to look at all the relevant data and include that which did not support my theories. With the key actor interviews as with any interview I had to question how 'real' the interview statements were (Silverman 2000). The individuals I interviewed had positions within the organisation and so motivations to protect that position. During my analysis I, therefore, treated their interview responses with this in mind and tried to look beyond what they had said to understand the processes at work. In the case of policy transfer I had concrete evidence and the accounts of other individuals against which I could examine my data which helped to add validity to my account of the policy transfer process. As I had developed theory prior to the research process it was important during the analysis that I did not show 'overconfidence in some data, especially when trying to confirm a key finding' (Huberman and Miles 1994:438).

For the comparative part of the research I built case studies of each of the day centres using a combination of methods. This could aid the validity of my analysis as it may be possible to undertake triangulation of the data. I had interview data and observation data both pertaining to the same situations. I did not, however, see this as an opportunity to undertake triangulation. I could check broad facts about the fieldsites and gain a deeper understanding of them by comparing the data from the interviews with that from the observation. However, more often I looked for differences between the data from the two collection methods. I felt that these differences gave me more information on what I was studying. The discrepancies between what I observed a member of staff doing and their description of what they do gave me information on their understanding and perception of their role. A major



concern with my data was the impact of my presence within the research scenario, especially in Kerala where I was acting within a different culture to my own. I have already discussed how I took steps to reduce this but also included it as an aspect of my analysis.

Finally, the external validity of the research relates to the truth of the conclusions drawn from it and their generalisability and predictive quality (Sanger 1996). This research is exploratory in nature and therefore does not purport to produce conclusions that are directly predictive of any other situation, nor are generalisable. The aim is, however, to produce conclusions which have some relevance beyond the data.

### **Analysis and writing up**

Analysis of a qualitative nature should continue in some form throughout the research (Hammersley and Atkinson 1995; Silverman 2000; Huberman and Miles 1994). I analysed the set of data for each location within itself as I collected the data. I did not, however, attempt the comparative part of the analysis until I had collected data from all four fieldsites. The analysis of the data concerned with the policy transfer was undertaken first to confirm and describe the process of policy transfer. This was started during the fieldwork period in Kerala and I was able to confirm that there were no important data missing. The data from the observation work and interviews with the staff were collated and written up during the fieldwork period and analysed as far as possible. I had time during the fieldwork period in Kerala to reflect on my data and begin the analysis. Hammersley and Atkinson (1995) stress the importance of reflexivity during the research process to improve the analysis of the

data. These early parts of the analysis were recorded within my fieldnotes and helped me focus my data collection. I did not focus my data for the comparative part of the research too much. As discussed above, I needed to keep as much detail and as wide a stance as possible as I did not know which aspects of the data were going to be important within the analysis of the policy translation process. It is important to have detailed descriptions for comparative work as it is from these that the comparative analysis is done (Hammersley and Atkinson 1995).

There are many different approaches to analysing qualitative data dependent on the types of data and the aim of the research (Coffey and Atkinson 1996). Miles and Huberman (1994:10) describe analysis as taking place in three stages: data reduction, data display and conclusion drawing and verification. Data reduction involves selecting and condensing data in anticipation of conceptual frameworks. Data are coded during this stage and grouped into themes and categories. Data display describes how data are presented or displayed to reveal what they mean. The final stage is where the data are interpreted and conclusions are drawn from the data as it is displayed. Each of these stages is described below in relation to this thesis.

The first stage of data reduction was undertaken for each part of the research as the data were collected. To assist with this I used the computer package NVivo Revision 1.2. The data were stored in NVivo where they could be manipulated, reduced, organised and then coded. NVivo provided a flexible tool for coding the data. The different approaches for coding in the two parts of the research are discussed below.

The analysis of the process of policy transfer was the first part to be completed. It was different from the rest of the analysis, as a specific analytical framework had been developed. The analytical framework of policy transfer puts forward a series of questions which when answered provide a clear description and explanation for that example of policy transfer. The majority of this analysis focused on the interview transcriptions from the interviews with the key actors in the ARDSI and the two individuals in local government. In addition to these, characteristics of the day centres and staff were also relevant within the analysis. The interview schedule had been designed with the analytic framework in mind. I was, therefore, able to carry out the research following a fairly simple system. Wengraf (2001:225) describes a process for analysing interview data. The interview material can be analysed to answer specific theory questions and these data are then analysed to answer specific central research questions. This type of approach also allows the emergence of new theory questions (Wengraf 2001). I was able to follow this formula to collect data to answer each part of the analytical framework of policy transfer. I did this through my coding system. This coding system was used to formulate analytical categories which fitted with the analytical framework of policy transfer (Hammersley and Atkinson 1995:208). Coding allows a link to be made between the data and ideas about those data (Coffey and Atkinson 1996). Once I had coded the data according to the categories and concepts within my analytical framework of policy transfer I was able to undertake data display (Miles and Huberman 1994). I used the data to draw a conceptual picture of the policy transfer process from which I was able to draw conclusions about how and why the policy transfer process had taken place. I was able to build a strong case that policy transfer had taken place and a detailed description and explanation of the process.

The analysis of the policy translation process was undertaken in two stages. As the data were collected from each fieldsite they were analysed as they were collated and recorded. The data were reduced and coded to look for patterns in the data such as routines at the day centres and the structure to each day. Data from the observation research and those from the interviews were coded separately as that gave information on different aspects of the functioning of the day centres. The observation data were coded to create categories and concepts that related to the structure and routines at the different day centres and specific activities. The interview data were coded to describe and explore the different aspects of the roles of the day care staff as they understood them. I coded the data from each fieldsite in the same way to aid comparison. I found that I was able to do this up to a point but there were analytical categories and concepts that did not overlap between the two contexts. These additional categories were of interest within the comparative analysis. The data from the two concepts did overlap when structural and temporal categories were compared but the details within these categories were found to differ between fieldsites and between contexts. For example I was able to code for the practice of having tea at each of the four centres but the detail within this category produced interesting and relevant differences. To link with Miles and Huberman's (1994) description of analysis, the data from each fieldsite were reduced and displayed to then facilitate the comparative part of the analysis. A conceptual display of each fieldsite could be compared and conclusions drawn from this part of the analysis. I was building theory about the process of policy translation through this analysis in comparison with the first part of the analysis where I had used the analytical framework for policy transfer. The analysis of the policy transfer and policy translation processes is discussed through chapters 7 to 10. The coding systems for the different interviews are given in Appendix E.

When writing up my analysis I have chosen to refer to particular things in specific ways. I have used 'context' to refer to the two places in which I undertook research: Kerala, India and Scotland, UK. 'Location' refers to each of the fieldsites: Cochin, Trivandrum, Jura and Iona. I refer often to activities in my descriptions of what happens at the day centres. I use 'activity' to refer to formal activities, something that is organised and presented as something which people should take part in and get something from. I talk about the day care staff turning aspects of the day care into activities such as having a cup of tea. What I mean is that these normal pastimes are presented in a manner that suggests they provide more to the participant than just having a drink. A glossary is provided for the Indian terms used and they are spelt according to the standard transliteration used in Kerala. I do not use quotations during much of my analysis and discussion. I do use them within the discussion on policy transfer as these interviews were conducted in English and the quotations add authenticity and support for my discussion. The quotations are presented as spoken and any words removed are replaced by '...'. Where a quotation is used the interview is identified by the name of the respondent in square brackets. These interviewees are listed in Appendix B. I do not use quotations from the interviews with the day care staff. In Kerala these interviews were conducted with an interpreter and I would, therefore, be quoting the words of the interpreter. I think it makes more sense to reflect on the discussions that I had with the interpreter about the data in these interviews and so do not use direct quotations. Extracts from observation notes are used to illustrate specific aspects of day care and are identified with the tag OBS, the name of the relevant day centre and the date they were written on.

## **Conclusion**

This chapter has established the research process and explained how the research questions are answered. I have shown how the design was based around the processes of policy transfer and policy translation. Theory about these processes helped guide the design of the research and influenced the choice of methodology. A range of factors directly affecting the data collection further influenced the research design. The cross-national nature of the research was a major influence and this was due to issues of language and ethnicity as well as practical limitations. Within this chapter I have discussed the issues and challenges of cross-national comparative research and shown how these shape the research design. They were influential on all the data collection in Kerala whether it was to be analysed comparatively or not. The issues associated with working with a vulnerable group, people with dementia, further influenced the research design.

As discussed in this chapter the approach to cross-national research is not necessarily different from other forms of social research. I conclude, however, that cross-national research encourages rigorous research to meet the greater challenges of this type of research. This type of research encourages rigour in planning and design as well as data collection. I found that working in a different culture to my own helped to develop my ability at both observation and interview work. I found that the data collection I undertook in the UK following my work in Kerala was enhanced by the experiences I had in Kerala. The main conclusions regarding my methodology are drawn within the main conclusion to the thesis. This is to allow reflection on their relevance and usefulness in the following analysis. The following four chapters

discuss the analysis of the field data within the theoretical framework developed in preceding chapters.

## **Chapter 7**

### **Policy transfer of day care for people with dementia**

#### **Introduction**

The discussion of the analysis of the field data is undertaken over four chapters. This chapter focuses on the process of policy transfer and the following three comprise three levels of analysis of the process of policy translation. The analysis investigates the process of policy development from the identification of a problem through to the establishment of services. This is an approach rarely taken in policy studies. This chapter analyses the policy transfer process, the process by which information was brought from the UK to Kerala. This analysis uses the analytical framework of policy transfer developed in chapter 2. In order to fully understand the development of day care in Kerala a deeper analysis is required than that provided using the framework. Policy translation provides the theoretical construct by which this analysis is undertaken. This analysis focuses on the differences between day care in the two contexts and takes place over chapters 8 to 10.



This chapter discusses and explains the policy transfer process which led to the development of day care for people with dementia in Kerala. As I argued in chapter 2 the theoretical construct of policy transfer helps to explain what is observed within this research. To recap, policy transfer is described as

'a process in which knowledge about policies, administrative arrangements, institutions etc. in one time and/or place is used in the development of policies, administration arrangements, institutions etc. in another time and/or place' (Dolowitz and Marsh 1996:344).

The development of day care provides a clear example of policy transfer as the idea and model of day care for people with dementia existed outside Kerala prior to its development there. Ideas and information were collected from different places, by different people and in different ways in order to develop the current day care centres. The ARDSI established day care in Kerala and the development of this organisation influenced the development of the day care centres. The development of the ARDSI also involved policy transfer and could be described as the beginning of the policy transfer process. This process continues as the organisation and its services continue to develop.

This chapter is based on a series of interviews with key actors from the ARDSI. Three groups of key actors were interviewed. Those in the first group have all held important roles within the ARDSI and most are still active within it. Roy is the chairman of the ARDSI. He is of great importance within this scenario and this is reflected in the interviews with other key actors and staff who often talk of his central role. Mohan was involved in the early development of the ARDSI. Other key actors from the early days of the ARDSI were not available for interview but the development was traced through documentary sources including conference programmes and a report on the history of the ARDSI. Meera and Thomas are currently involved in

different branches of the ARDSI within Kerala and are developing services within their own regions. They have both been involved for several years. Meera was influential in the development of the Trivandrum day centre. They were both identified by Roy as important figures in the future development of the ARDSI and were chosen because of this.

The second group of key actors consists of current members of staff of the ARDSI. The ARDSI's main project is a group of services and research projects in Cochin that includes the Cochin day centre. Ananthan is a psychiatrist who works part time in Cochin and has been involved in the research and services since their inception. Rajesh was the Senior Project Officer during the research period and was responsible for the services. He had worked for the ARDSI since its inception. Both Ananthan and Rajesh have played a key role in the development of the services of the ARDSI. Usha is the current psychologist at the Cochin services and works both in the day care centre and the memory clinic. She has worked with the organisation for two years. Mary is the current nursing tutor and teaches on the community geriatric nursing course as well as being involved with the day centre in a supervisory role. All of these key actors were influential in the day to day running of the day care centres during the research period.

Two individuals outside of the ARDSI were also interviewed to give information on the policy background in Kerala. These were the Secretary of the Ministry of Social Welfare, State Government of Kerala and the District Social Welfare Officer for Cochin District. Both had knowledge of the local and central government policies and services for older people and people with dementia. Brief descriptions of all the key actors are given in Appendix B.

The data are analysed within an analytical framework of policy transfer developed from the models of Dolowitz (2000) and Evans and Davies (1999). This analytical framework, developed in chapter 2, provides a series of questions that help to clarify and explain the process of policy transfer and give information on the causality of the process. The analytical framework consists of eight questions as identified in chapter 2:

- Who is involved in the transfer?
- What influences the timing of the transfer?
- Why does the transfer take place?
- What is transferred?
- From where is the policy transferred?
- How does the transfer take place?
- What constrains or facilitates the transfer?
- To what degree does the transfer take place?

This chapter begins with a brief discussion on the development of the ARDSI. This is drawn mainly from the interview with Roy and some of the ARDSI staff including Ananthan and Rajesh. This provides important background information on the development of the day care centres. The development of the ARDSI involves policy transfer, which continues through the development of day care. The chapter goes on to analyse the development of the two day care centres in Kerala using the analytical framework. The analysis highlights the restrictions in the explanatory power of the theoretical construct of policy transfer. I argue that the restrictions in the

theoretical construct of policy transfer can be complemented by the theoretical construct of policy translation.

As highlighted during the discussion in chapter 2 and through this chapter it is clear that using this analytical framework of policy transfer does not offer a complete explanation of what happened in the development of day care. As the policy is transferred and implemented it changes. These changes are caused by deliberate adaptations by the actors involved and by the influence of the local culture in the target context as the policy is adopted. The local culture permeates social organisation and individual behaviour and thus affects the policy. Within this thesis these adaptation and adoption processes are referred to as types of policy translation and are discussed in detail within chapters 8, 9 and 10.

### **The development of the ARDSI**

Roy relates that his father was diagnosed with Alzheimer's disease in the early 1990s when he had been unable to find accurate information and adequate support to care for his father in India. It had taken some time to get an accurate diagnosis and follow up treatment and care were almost non-existent. This led Roy to look outside India for information and he made contact with ADI who provided him with information and advice. During this contact it became apparent that there was no organisation in India for people with dementia and Roy took the decision to found the ARDSI himself, encouraged by the staff of ADI. He states that he hoped that the members of ARDSI would be pioneers in their field showing professionals and carers across India how to care for people with dementia. Roy's story is repeated by many of the individuals

interviewed, both the key actors and the staff of the ARDSI. This story is often given as an explanation for the founding of the ARDSI.

Following this decision Roy contacted other Alzheimer's groups, the ones he felt were the best in the world including Alzheimer's Disease Society UK (ADS), AS-AD and The Alzheimer's Association in the USA. These organisations sent books and other literature and corresponded with Roy, some also gave financial support. He mentions AS-AD as having sent a lot of information. Roy did not look to organisations close to India either geographically or culturally but looked to what he perceived as the world leaders in the field. The link with the UK is the closest link for Roy and the other key actors. This appears to be for several reasons. ADI has had its head office in London since the mid 1990s and so contact naturally developed with the UK. Over the years the director of ADS has become a personal friend of Roy and they work closely together on joint projects, including an exchange programme for staff of their two organisations. It also seems probable that the colonial links between India and the UK have also facilitated these connections and guided Roy to think of the UK as a world leader in his initial search for information.

ADI was a primary source...I had established contact with most of the leading Alzheimer's societies around the globe...and a lot of materials coming from Australia and from ADS UK...and from Alzheimer's Association United States...and er these are probably still, er the best run Alzheimer's er, Scottish Alzheimer's, Alzheimer's Scotland because I think that is one of the er, major institutions to provide excellent materials and they were very generous actually sending us materials, each time I asked ...and thinking of er people like er, Professor...and the University of er, Stirling [Roy]

When initially setting up the ARDSI he contacted fellow doctors as well as friends and relatives who had an interest in the field. Roy himself is a paediatric consultant and had many contacts in the medical field. The organisation was founded at a national seminar in 1992 and its main activities at first involved trying to raise awareness across India. Roy encouraged individuals in other areas of Kerala and India to set up smaller organisations as chapters (branches) of the ARDSI. He placed adverts in local newspapers across Kerala to find people who were interested and several chapters developed following meetings with Roy. Meera explains that is how she became involved and developed the Trivandrum chapter.

Roy relates that he was enthusiastic to start services for people with dementia and their carers and applied to HelpAge India for funding to run a project in a rural area, actually his own ancestral village where his father was then living. Roy recalls that he found resistance and disbelief when trying to raise awareness of dementia in India. He felt, therefore, that his first task was to prove that dementia did exist in Kerala.

because, one thing is, there was no data at all, it was very difficult for me to convince anybody let alone politicians and bureaucrats even our own medical community...people would just look up to me and say, oh, do we have Alzheimer's in this country? Because I happen to come across some articles which said there is no Alzheimer' in India...that was even written by some well-known medical people. So it was absolutely important for us to establish the presence of Alzheimer's disease here. [Roy]

The funding from HelpAge India was used to conduct an epidemiological survey of this rural area of Kerala. The money was also used to train staff to care for

people with dementia, CGNs, and to set up services in the area of the survey. The survey was able to identify people in the community with dementia who required support as well as establishing the prevalence of dementia. Mohan explains that the carers in this area requested home care services; they did not want their relatives to be cared for outside the family home. The research was later published in the British Journal of Psychiatry in 1996 (Shaji et al 1996). At this time, 1993, Ananthan and Rajesh were employed to undertake the research and training course. Ten local young women were recruited and undertook a training course. At the same time they undertook the survey work for the epidemiology research and provided home care for people with dementia. Several of these women are CGNs currently working for the ARDSI. This service was funded for three years by HelpAge India and after that time the research was completed and the CGNs trained and the project was stopped. Although the CGNs were working to provide a home care service at this time Roy says that the carers were coping well and so the home care service was also stopped. This information is confirmed in interviews with Ananthan and Rajesh.

It was now 1996 and Roy and Mohan relate that HelpAge India said that they would be interested in funding a project in an urban area and offered funding for another three years. Roy designed the project along with other members of the ARDSI. Rajesh and Ananthan were important among the members of staff who were still working during the research period. This new project was set up in Cochin. It combined a research project conducting an epidemiological survey, home care services and a day care centre. The day care was established in 1996 and is discussed in more detail below. The key actors intended these services to be a model for organisations in other parts of India to emulate. Roy says that this is now happening across India with many chapters thinking about starting day care centres.

The Trivandrum day centre is the first of this kind. The development of the ARDSI illustrates the initial policy transfer that took place when Roy sought information from other countries. This is revisited in the main analysis which follows.

### **The development of day care**

Day care is the focus of this thesis and is analysed in relation to the analytical framework of policy transfer developed in Chapter 2. This chapter is mainly about the development of the centre in Cochin as this was the first day care centre developed and was the main focus of the research. The Trivandrum centre was developed using the Cochin day centre as an example although some alterations were made to what was happening at Cochin. The practical elements and the structure of the two day centres are described in detail in Chapter 8.

To summarise, the analytical framework starts by looking at who undertakes the policy transfer, at what particular time and why. That individual or group then decides what information is needed and decides where to look for it and does this in a particular way. The process of policy transfer can then take place and may be restricted or facilitated by various factors and takes place to a particular degree. Each of the eight questions in the framework is answered in turn below.

#### **Who is involved in the transfer?**

The main 'agent of transfer' is found to be Roy (Evans and Davies 1999:368). Roy is the central figure in the development of day care and initiated the transfer process. The initial policy transfer was apparently influenced by Roy's need to find



information to help care for his father. Later, with the development of day care, it is apparent that Roy's personal motivations to create a particular type of organisation influenced the transfer process. Roy's father was a bishop and held an important position in his local village community. He had founded a school and an orphanage within the village. Roy explains, therefore, that he has a desire and obligation to be involved in charitable works. Roy is also involved with another charity providing care for children with physical and mental disabilities. It appears that Roy's position in his local community and his family frame his personal motivation to be involved in charitable organisations and be a leader within them. Roy fits within Dolowitz's concept of a policy entrepreneur (2000).

There are also networks involved in the transfer process. The role of ADI as an international umbrella organisation for organisations in different countries may have influenced Roy's decisions regarding service design. The ADI and its associates can be seen as an 'epistemic community' (Haas 1992:3). It seems Roy desired to belong to such a community, giving prestige to his own organisation and thus to himself. Roy talks often of becoming the first Afro-Asian member of the ADI and says that he is very proud of this. Through ADI he was able to find out about what was happening in other countries both through conferences and visits to other countries. The important role of NGOs in cross-national policy transfer was highlighted in chapter 2. Roy working with the ADI comprises a policy transfer network as described by Evans and Davies (1999). This policy network is not permanent but strengthens when crucial parts of the policy transfer process take place.

Initially Roy facilitated the policy transfer process. The process is not, however, a discrete event and influenced and facilitated by Roy, other people have

become involved. They have also learnt about and travelled to other countries to gain information about services and policies. Ananthan, Rajesh, Meera and Thomas have all travelled to the UK with the exchange programme with ADS. They have brought new information and ideas back with them. Ananthan and Rajesh both work in the Cochin day centre and have influenced its development and its current functioning. The policy transfer process continues over time with different actors involved at different times.

Meera's involvement in the development of the Trivandrum centre makes her role central within the policy transfer process. Meera relates that, like Roy, she cared for her father who had Alzheimer's disease. She also found little or no information in India and so looked for books from the UK and USA to help her understand what was going on. Her family faced problems in caring for her father and had little support from local doctors. Some time after her father's death Meera relates that she saw an advert in the newspaper inviting people to come to a meeting about Alzheimer's disease. Roy had placed this advert and Meera went along and hence became involved with the ARDSI. Later, Meera's visit to the UK was instrumental in providing ideas for the development of the Trivandrum centre. So the key actors in the policy transfer process are most importantly Roy and later Meera, Ananthan, Rajesh and Thomas. A small number of people, the agents of transfer, link with international epistemic communities to form a policy transfer network which forms when necessary.

### What influences the timing of the transfer?

The recognition of a problem initiates the search for ideas and therefore the timing of the policy transfer process. The timing of this policy transfer process is not

discrete. The timing of the initial policy transfer to develop the ARDSI was influenced by Roy's situation, his father was sick and so he looked for help. This timing coincided with growing global concern over an ageing population and an increase in age-related morbidity so there was a lot of information available to him. The specific timing of the development of day care in Cochin is related to the availability of funding which was obtained from HelpAge India for the urban project in 1996. Roy indicates he decided prior to this that he wished to set up a day care centre and this became possible when the funding was offered. He explains that he had begun to collect information about day care from conferences and visits to other countries. The development of day care is not a one off event. It continues with new ideas and information collected and used to develop the service. The process of policy transfer may continue to take place during the development and functioning of the day care service. Different individuals travel abroad and bring back ideas. New information becomes available over time and this may also be used. This information can be found on the Internet, through personal contacts and at conferences. An example being Rajesh who relates that on his return from a visit to the UK in 1999 he introduced new activities into day care. Meera also used information collected during a visit to the UK to develop the Trivandrum centre. The specific timing of the opening of the Trivandrum centre was influenced by family carers. Meera stated that she had plans to open a day care centre but the impetus for the actual timing came from a family who wanted their mother to attend as soon as possible. It also depended on sufficient funding to set up and run the day care centre.

## Why does the transfer take place?

The question of why policy transfer takes place can be broken down into two specific questions: why this specific information is transferred and why it is necessary to look outside India for the information. The second question can be answered quite simply. It is because the information is not available in India and therefore must be looked for elsewhere. This is the apparent perception of those involved. They did not think the information was available in India or Kerala and looked elsewhere. There may in fact be useful information in India which could have been used to help set up the day centres. The key actors did not seek this information but made the decision to look outside their country to those in 'the west'. They seem to have rejected information from their own culture in favour of that from outside. The reasons behind this may be related to an idea that 'west is best' a recurring theme which is explored through the thesis.

Ananthan and Roy both stress the lack of information on day care within India and say they were forced to look outside. Day care for people with dementia was a new, unique idea in India. Roy used his existing contacts in the UK and elsewhere to seek information from those organisations he felt were the best in the world. Ananthan does not sound altogether comfortable about this and perhaps would have preferred to use a local model. Ananthan explains that day care is available for other groups such as for 'mentally retarded people' [Ananthan] but not for people with dementia.

Why particular information was looked for is complex. The individuals within the ARDSI perceived a need for day care and then went to look for ideas and information in order to set up day centres. Why and how this need was perceived are fundamental questions in understanding this example of policy transfer. As discussed below, there does not appear to be a real or pressing need for day care and so it appears other motivations were involved. From the point of view of the individuals involved power and status may be important. Day care takes place in a building which provides a very clear focus for an organisation and can be shown to visitors. It is concrete proof that they are an active and successful organisation. The desire for day care may also reflect how Roy and later his colleagues collected the information about day care. Much of this was obtained from visiting day centres in the UK and elsewhere. They may have felt it would be good to have a similar place that visitors to Kerala could come and see. The Cochin centre was the first of its kind in India and so added prestige to the organisation and the individuals involved. Several of the key actors, particularly Roy, Rajesh and Meera stress that the two day centres are the first of that kind in the whole of India. Roy had the understanding that day care was seen as a good service for people with dementia in the UK and so states he thought it would be a good service for his organisation and for people with dementia in Kerala.

Dolowitz (2000) describes the why component of policy transfer as a continuum from voluntary transfer to coercive transfer. This example appears to be voluntary with actors in India actively looking for ideas and information elsewhere. It could therefore also be described as an example of lesson-drawing (Rose 1991:7). Roy relates that a key actor in the UK tried to dissuade him from starting day care rather than coercing him in any way.

How the ARDSI perceives the needs of the community and therefore the 'culture of care' affects on how they design their services. How the key actors talk about carers and people with dementia and describe what may happen to them elucidates how they perceive the needs of the community and hence the need for day care. The key actors say that carers expect some cognitive changes with ageing and seek help only when the symptoms and behaviour of the person with dementia become problematic. The first step they take is to contact their doctor looking for a diagnosis and treatment. Carers may try different doctors, specialists and other practitioners such as *Ayurvedic* practitioners. The key actors explain there is a stigma associated with what is perceived as a mental disorder and families may hide people with dementia. Most of the key actors say that carers do not cope well and that they do not seek appropriate help at the appropriate time. They suggest that the 'culture of care' is somehow inadequate in caring for people with dementia.

see, as far as Kerala is concerned...the elderly as I told you, the elderly are having minority social status. And if the person is demented the level of acceptance will be totally less, means total dejection, rejection from society will be expected. The persons will be facing lot of problems. As I told you there won't be any sort of help from the family members. They have lot of works to be given to their kids. Rather than to be given to the Alzheimer's patients. [Rajesh]

Only Thomas relates that families do cope. He has found examples of people with dementia living happily within their family home and being well cared for by their family.

even if they are not knowing that this is Alzheimer's disease but the caring is almost same we can see, that is a very interesting thing, for

the last, er, they are not even just er, know about Alzheimer's disease or anything but they are very nicely managing the disease without trained person we can see a lot of people...yeah, without trained person, they have not even heard about this word, but they are very simply managing for the past ten or fifteen years, I know [Thomas]

The key actors describe differences how people in rural and urban areas cope. In the first study the ARDSI undertook in a rural area Mohan and Roy explain that people wanted to care for their relatives with dementia in the family home and had been coping in that way until the survey took place. In rural areas life is described as simple and based around the family home and there may be support for older people with dementia. The 'culture of care' is traditional and less affected by demographic changes. The Secretary of the Ministry of Social Welfare in the Government of Kerala explains that in villages they just keep the person with dementia at home. Life is simple and they 'won't ask them too many questions' [Secretary for Social Welfare]. Roy states that he felt there would be more need for care for people with dementia in an urban area as more women go out to work leaving older relatives alone in the house during the day. Roy and Mohan relate that HelpAge India had also stressed this as the reason for stopping the funding in the rural area and moving to the urban area. The 'culture of care' in urban areas is changing due to the demographic changes discussed in chapter 4. However, the ARDSI opened a 'Memory Clinic' at a local hospital in 2000 and Usha, who runs the clinic, says that most of the families from urban areas attending the clinic cope at home with information and advice from the staff at the memory clinic. Usha relates that most carers do not wish to take up the offer of a day care place.

There are contradictions in how these carers are described. On one hand Roy says that they may not treat the person with dementia well but on the other hand he says that they do everything to try and get help for their relative. Carers feel obligated or wish to care for their older relatives but coping with dementia is difficult for them perhaps due to stigma regarding mental ill health discussed below. In general the carers are seen as needing help in the form of information, advice and services such as day care. When the key actors talk about the carers of people with dementia they always place the problem within the person with dementia and the pain and suffering within the carer. Rajesh, Mary and Usha describe day care as a service to relieve the suffering of the carers. Meera describes some carers as resistant to the idea of day care while others are enthusiastic to use the service.

The day care centres were set up to meet the perceived need of carers in urban areas. These would be families where both husband and wife work and people with dementia are left alone or left with servants who would not know how to care for them during the day. Most of the key actors indicate that the number of this type of family is increasing due to changes in family structure in Kerala. Everyone interviewed talked about changes taking place in family structures in Kerala. The traditional 'culture of care' in Kerala is changing. Most of the individuals interviewed did, however, live in extended three generational families or if not their parents lived with another sibling. It does seem probable that the need for day care will increase as family structures change but it not clear that this is already the case. The key actors perceive a need for day care that is increasing and so they develop and promote day care as a service for people with dementia. Crisis mongering and international generalisations about the increasing number of older people around the world may also be influential on this example of policy transfer (Marmor 1997). Tester and



Freeman (1996) found that industrial countries facing similar issues with respect to older people have used similar policies.

In fact several of the key actors, including Roy, Ananthan, Mary and Usha, indicate that there is a stigma associated with day care. People in the local community do not want to be seen sending their relative to day care. This is illustrated clearly in the interviews.

'It is a stigma to the relatives and also for the society so er, they are not, um, sending the people to a day care centre, not willing, they are not willing to send a person to a day care centre...because they are thinking it is a social stigma.' [Mary]

'They will be worried and wondering what will my neighbour think of me if I am sending my father to a day care centre' [Roy]

The need for day care as perceived by the members of the ARDSI was not obvious in the local community in Cochin. When the day care was established there were just one or two people attending. Roy talks of a need to sell the idea of day care to the local people who were not interested and did not know about such a service. Ananthan talks of providing tea and biscuits to get people to come and to find out about the organisation. Rajesh on the other hand, perhaps as a more junior member of staff, says that people did want the day care centre. He defends the idea but then admits that actually there were no clients at first and they had to go out and persuade people to come to day care. The attitude seems to be that carers need day care; they just don't know that they need it.

Thomas, who runs a branch of the ARDSI in another part of Kerala, does not believe day care to be a useful service at all. He feels that people in the community would be ashamed to use the service and would be more welcoming of a home care service. This fits with the 'culture of care' where older people are cared for within the family home by family members. In Trivandrum the situation was slightly different with Meera describing more active support from carers to establish the centre. Meera explains that day care is seen as a good option in comparison with residential care. There is a strong resistance to residential care within the 'culture of care' and day care means that the family continues to share the care of the person with dementia. As discussed in chapter 3, the family is central within Indian culture and the idea of residential care does not fit with this cultural norm. Day care in some way fits with the 'culture of care' in Kerala in as far as the majority of care for the person with dementia is still provided at home by the family. Care at day care is however formalised and outwith the home and therefore does not fit with the fact that family members usually undertake the caring roles. The analysis of policy translation investigates these ideas further and assesses how well the concept of day care fits within the culture of Kerala.

To have a day care centre seems very important to Roy and he stresses several times that it is successful and that he has managed to keep the numbers up despite a natural turn over of clients. The centre has been open for six years now and still does not run to its capacity, which is set at 15 clients by Roy and Rajesh. The average number of clients at day care during the research period was 8. This number went up and down between 6 and 10 with more people joining the day care in the later months. At nearly every staff meeting at the Cochin centre during the research period Rajesh stressed the need to get new clients to come to the centre. Usha does, however, stress that there are now a few families who rely absolutely on the day care

service. She says that the need is great but the numbers are small. In Trivandrum the day centre had only been open for a few months during the research period and so the numbers were low. Roy initially had to prove that there were people with dementia in Kerala so now maybe he is proving that they need day care.

Roy relates that he was impatient to set up services as the government could not be expected to do anything due to lack of interest and finance. The State Secretary for Social Welfare in Kerala did not accept that dementia was a problem in Kerala. He explained that he was aware of dementia but was of the opinion that families were coping with it. He says there are other areas of more importance for the State Government to be thinking about and their financial resources are very limited. When Meera informed him that she had found a prevalence of dementia of 5% of those over 60 in Trivandrum he simply told that he did not believe her. He said that he did not believe there would be that many people with dementia in Kerala. The Secretary stressed that the Government of India does provide some funding to run 'old age homes' within Kerala and a number of government run homes have been established. Several key actors relate, however, that people with dementia are excluded from the few 'old age homes' in Kerala due to their symptoms and behaviour. Rajesh paints a very bleak picture for people with dementia who do not have family members to take care of them. He says that they end up in government run asylums for people with mental health problems in which the conditions are very poor. The District Welfare Officer for Cochin was more informed about dementia than the State Secretary but stated that his district did not have any services for people with dementia. He explained that his knowledge about dementia had come mainly from the ARDSI. It seems likely that the government is also affected by stigma relating to people with mental ill health and may, therefore, be less interested in and inclined to

provide for people with dementia. These two interviews do seem to support Roy's claim that no one else will provide care for people with dementia. They are not seen as a priority by those in government and this is reflected in the Government of India Policy for Older Persons discussed in chapter 5.

So the ARDSI perceives a need for day care as carers for people with dementia need help and this is not provided by other agencies. It does not, however, appear there is a strong need for day care specifically and indeed the local community may resist the idea. However, the key actors in the ARDSI, particularly Roy, Rajesh, Meera and to some extent Ananthan continue to emphasise this need. It is possible the need for day care will grow due to the reasons discussed above and the demographic changes discussed in chapter 4 but it is also probable that other motivations are at work. The status and prestige of having a day care centre and the fact that it is a service popular in the UK and elsewhere appears to have influenced this enthusiasm for day care. This may explain the key actors' drive to justify their promotion of day care and their insistence that it is successful.

This discussion starts to highlight the problems associated with the complexity of the policy transfer process. The 'need' for day care is complex and the actual need in many ways contradicts the perceived need. The personal motivations of the key actors meet with their ideas and perceptions of the 'culture of care' in Kerala leading to their promotion of day care for people with dementia in Kerala. The motivations of the key actors are explored further within the discussion of policy translation. The theoretical construct of policy translation provides more clarity on the question of why the transfer took place.

## What is transferred?

Dolowitz (2000) gives six different categories of what might be transferred as discussed in chapter 2. It seems likely that in the present case, many things were transferred including both information and ideas. The individuals involved indicate that they searched for specific information. In the development of the ARDSI Roy looked for a wide range of information about dementia and setting up an Alzheimer's organisation. Meera says she looked for information that would help her and her family understand what was happening to her father. Later Roy began to look at services for people with dementia and collected information about which services are popular and how they are run. He was often told that day care was a popular service for people with dementia in 'western' countries and began to collect information and develop ideas about day care centres.

In order to set up a day care centre specific knowledge is needed. It is necessary to know what happens at day care and what the purpose of day care is. This might include information on types of activities done at day care and a timetable or structure for a day at day care. Information on staff is also needed, for example, how many staff are needed and what training do they need? Also information on the physical structure of day care, ideas about funding and practical information on transport options are needed. These are practical elements but it also necessary to transfer less concrete elements such as the concept of dementia, the concept of caring for people with dementia and within that the role of a day care worker and the purpose of day care. These different elements may be transferred and translated in different ways and are all explored within this thesis.

The individuals involved in the transfer had choice in what they transferred and could pick and choose what they wanted to know and use. This relates to the concepts of lesson-drawing and voluntary policy transfer, discussed in Chapter 2 and above, whereby individuals or groups choose what they wish to transfer (Rose 1991; Dolowitz 2000). Roy and his colleagues have collected information on day care centres and on dementia. It seems that what is transferred based in part on need, here that of Roy and Meera to help their fathers. What was transferred is also related to the cultural position of the individuals involved in the transfers. As highlighted in the literature review culture influences the process of policy transfer through individuals and social organisation. Roy and Rajesh had most input into the day care design along with Ananthan. Ananthan and Rajesh did not have contacts outside India when the day care was first set up and so used the information recommended by Roy. This information was used to design the day to day functioning of the day care centre and to design activities for the clients.

Rajesh visited the UK in 1999 and talked about bringing back ideas about activities, group activities and things such as reminiscence therapy and aromatherapy. Mary also talks about developing activities for day care using books from the UK. She uses Archibald's book 'Activities' (1990). These types of things are fairly concrete, the number of staff, types of activity and the structure to a day. It is not as straightforward to transfer concepts such as 'dementia' and 'day care worker'. As discussed above and in detail below, the process of translation takes place alongside that of transfer and affects the transfer process.

As discussed in chapter 3 dementia is difficult to define. How 'dementia' has been transferred affects what services are developed and how they are designed by

the ARDSI. From the data it seems that the word and concept of dementia have been introduced to India over the past ten years and it is not a familiar concept in the local community in Kerala. The key actors relate that the ARDSI has played a key role in raising awareness and understanding of dementia in Kerala and across India. The individuals of the ARDSI say that the general medical community is still ignorant regarding dementia. This indicates that the concept of dementia has been transferred by the ARDSI, certainly within the group of individuals involved with the ARDSI. How the concept of dementia is translated to the local culture and the local language is fundamental to the transfer and development of services. The discussion here raises questions which are explored in detail within the discussion of policy translation.

From the data it appears that the medical model is dominant in how the key actors and staff of the day centres talk about dementia. The staff of the day centres use the term 'dementia patient' to describe the clients. The staff are nearly all known by medical terms: psychologist, psychiatrist, nursing tutor and CGN. The only exception is Rajesh who is known as the Senior Project Officer. Recent ideas about social models of dementia and ideas such as 'person-centred care' (Kitwood 1993:53) do not seem to be transferred. The individuals appear to pick and choose their view of dementia in the same way as they pick and choose services. When asked to define dementia the key actors use the DSM IV (1996) definition in part, usually saying that it is a degenerative disease of the brain that impairs the social and occupational functioning of the individual. Two examples are given below.

And basically it is a disease that affects the elderly people and er, there are various causes for dementia and er, the basic cause is Alzheimer's

disease. It is the chief degenerative brain disorder that affects memory, emotion and thinking. [Rajesh]

Dementia actually is a group of diseases a group of symptoms and it is actually interfering, it is a mental psychiatric psychoneurotic disease...its actually it is interfering with the daily functioning of the patient, its um, the daily functions of the patient especially the patient is very er, impaired in their intelligence, cognition um, knowledge, [Mary]

Mary's definition is particularly striking in the medical stance it adopts and elaborate terminology used. From the interviews there is evidence of stigma within the local community regarding mental health problems. Some of the key actors describe families locking up or hiding people with dementia. It seems possible that using the biomedical model makes dementia more acceptable within the local community.

When talking about dementia in the local language the key actors all use the term 'dementia' in English and explain it by using illustrative examples of the behaviour of people with dementia. There are several local terms, which are similar to dementia but not directly equivalent, and there seems some confusion and little agreement about their definitions. *Medhashayam* is said by some to mean dementia but Usha and Mary explain more clearly that it is a term for brain disease, meaning 'degeneration of brain' [Usha] or 'absence of intelligence' [Mary]. It seems a fairly general term and Ananthan relates that it may be used within *Ayurvedic* medicine. *Chinnan* is a local, rural word that is only known by some people. It refers to madness in old age, perhaps senility. It is derogatory and reflects the stigma discussed above. There is disagreement among the key actors as to whether it corresponds to



dementia. Usha explains that it describes a state near death when an individual may see and talk to people who are already dead. Many of the other key actors say that it is just an older person with some sort of 'madness'. This would seem to indicate that some concept similar to dementia is not unusual to people in Kerala. Others such as Mohan and some of the CGNs use terms relating to memory loss to talk about dementia, phrases meaning 'memory is gone' and 'low memory power'. All use symptoms to describe dementia to people in the local community, usually focusing on problems with memory, such as forgetting children's names or forgetting that a person has eaten.

There appears to be a lack of interest to understand or explain the local terms. It seems more important to introduce a new idea, a better 'western' idea. The word and concept of dementia are introduced to the local community rather than using local equivalents. This further supports the idea that ideas about dementia have been transferred from outside India. Somewhat paradoxically the key actors and staff do believe that dementia has always been present in India. The initial epidemiological survey was undertaken to prove the existence of dementia. There is, however, little apparent interest on the part of the ARDSI in how that condition was understood or described by local people. The ARDSI now provides information and a definition of dementia for local people. The word dementia is not translated into a local word. This links to the idea of foreignisation, which is discussed in chapter 8 (France 2000:8). More detail is given on the transfer of dementia when the process of translation is discussed in later chapters. The role of a day care worker and the purpose of day care are also explored more fully through the comparative analysis which follows. The policy transfer literature does not give enough detail to elucidate the transfer process

for these elements. The concept of policy translation does have explanatory power and is used to further explain the transfer and translation of 'dementia' later.

So a variety of things have been transferred during the policy transfer process. Specific ideas about the functioning of day centres: staffing, structure and specific activities have been transferred. Along with this information ideas and attitudes about dementia have also been transferred. These have affected the understanding of dementia within the ARDSI and the people they work with as well as how the day centres have been developed, the purpose of day care and the roles of those working within day care.

### From where is the policy transferred?

The simple answer to where policy was transferred from is 'the west', from more developed countries, particularly the UK. Roy relates that he looked for what he perceived as the leaders in the field and went to them for information and ideas. It is as if he assumed that 'the west' would provide the best 'solution' for people with dementia. Roy used his contacts at ADI and the Internet to find out about other Alzheimer's societies around the world. In his words he looked at the best of these, which were in the UK and the USA. Roy developed strong links with the UK during the development of the ARDSI and these remain important in the development of the day care services. The link with the UK is due to a 'subjective definition of proximity' (Rose 1991:3) probably due to colonial links.

Meera had a key role in the development of the Trivandrum day care and had recently taken part in the exchange programme and visited day centres in the UK.

She relates that this influenced how she designed the Trivandrum day care centre. She combined the example of day care in Cochin with the new information from the UK to design her own day care service. The policy transfer took place through two different routes, direct from the UK and via Cochin. Information on staffing, structure and activities were developed from the two sources of information.

### How does the transfer take place?

Freeman (2003c) describes four methods of transfer as discussed in chapter 2. In summary these are through academic journals, through attending conferences, through visiting or being visited and finally through a formal exchange programme. All of these methods of transfer are found within this analysis. Roy, Meera, Ananthan and Rajesh all discuss using literature and books from the UK and USA to develop their knowledge of dementia and understanding of day care. With specific regard to day care the structure of the staffing and the functioning of the day care centre were designed using books from the UK including ADS and ADI publications and also input from AS-AD and the Dementia Services Development Centre, University of Stirling. The Internet is also described as an important source of ideas and information.

Roy, Ananthan, Meera and Rajesh have over the years all attended the ADI conference and brought back ideas and information used in the development of the day care centres in Kerala. This information came both from conference papers and from visits to services wherever the conference was being held. Roy says that he has often visited services in other countries. These ideas and information included specific information about particular activities and more general ideas about working with people with dementia. Later in the development of the day care centres a formal

exchange programme was established with ADS in the UK. Through this several individuals have travelled to the UK and brought information back about dementia and services for people with dementia. These included Meera, Ananthan, Rajesh and Thomas. Meera brought back specific information from a visit to the UK to help design the day care centre in Trivandrum.

because I had the opportunity of visiting a few day care centres in the UK I had seen that...so I knew basically what a day care centre functions, what are the activities and how many people you require then with the experience of the (Cochin day centre), we er, Dr \*\*\*\* and all of us sat together and we discussed how the activities should function at least for every three to four patients we thought we should have er, one carer and then overall supervision, one person [Meera]

Rajesh, Ananthan, Thomas and Meera as well as Roy have all visited services in the UK. Sending members of staff to the UK is seen by Roy as the only way to access good training as there is nowhere in India that they can access training. Roy made the initial contacts through attending conferences and email contacts and initiated the policy transfer process. He now facilitates others to collect information from abroad through the exchange programme with the ADS and attendance at conferences, particularly that of the ADI.

### What constrains or facilitates the transfer?

The characteristics of any example of policy transfer may either facilitate the transfer or restrict it. This depends on a series of factors including policy complexity, feasibility constraints, past relationships and language constraints (Dolowitz 2000:26). The transfer process takes place between individuals and groups in two very different

cultures with two very different 'cultures of care'. These factors influence what is transferred and restrict what can be achieved using policy transfer. The differences in culture are the fundamental influences on this process of policy transfer. Roy has tried to overcome these factors to enable the transfer of day care for people with dementia. The language constraints are reduced as English is a common second language for people in India and is widely used. This facilitates policy transfer from English speaking countries. The historical links between the UK and India also appear to have facilitated this example by guiding Roy's search for ideas.

Policy complexity and feasibility constraints are more likely to restrict the policy transfer. Although day care may appear to be a fairly simple idea it has a number of factors to be considered as discussed above in the question of what was transferred. The following chapters discuss in detail what changes have occurred to the original policy. Roy appears to have tried to reduce the feasibility constraints by transferring other information to facilitate the transfer. Information such as that on other services for people with dementia and information about dementia help the transfer. Roy also established a training course for staff so that he could aid the transfer by using properly trained staff. Koehn and Rosenau (2002) stress the need for resources in the form of properly trained individuals.

The key actors appear to see financial limitations as the main constraint to the policy transfer process. They do not appear to perceive the influence of 'culture' on this process. Roy talks about the structural limitations of the day care centre in Cochin. He was unable to replicate the good example of day care he had seen in the UK as he did not have the financial resources to do that. Roy feels that a purpose built building is the best option. Roy also states that the day centre should have more

trained staff like occupational therapists and there should be more space for the clients who should also be able to go out for a walk. His idea of what day care should be is based on his impression of what he has seen elsewhere. This seems to indicate that his view of day care in the UK and elsewhere is rather rosy. From observation the space in the Cochin day centre is large compared with the day centres in the UK in this thesis and the clients have access to an area where they can walk and sit outside. Also occupational therapists were not observed during this research at day centres in the UK. Rajesh also visited day care centres in the UK and felt that some aspects of the day care could be transferred to Kerala but other aspects could not.

bringing them here in the sense that ideas could be brought but the latest scientific methods...means most modern sophisticated equipments are being used over there...to lift up the persons and er, but er, we are not in a position to purchase all the latest equipments to look after the patients over here. [Rajesh]

The aspects that could not be transferred were again connected to money, the latest scientific innovations, equipment for lifting people and so forth. Roy and Rajesh appear to want to reproduce day care identical to their perception of day care in the UK despite aspects of this being inappropriate to the 'culture of care' and climate in Kerala. These ideas are discussed at length in the following chapters. The financial constraints have led to the key actors adapting aspects of their image of day care. This adaptation process is mentioned in Evans and Davies' (1999) model at the implementation stage but it is not clearly explained. This is a limit to the theoretical construct of policy transfer. Within the literature the implementation process is mentioned but no clear way to investigate and explain what happens is offered. Within this thesis adaptations to the policy are described as planned policy translation

and I argue that they can be explained using theory relating to the concept of policy translation. These ideas are developed and explained fully in the following chapters.

### To what degree does the transfer take place?

Related to the restriction of the policy transfer process is discussion of the degree to which the policy transfer takes place. Was the policy directly copied or did ideas from outside just provide inspiration for the development of day care in Kerala? Dolowitz (2000) describes four levels of policy transfer in a similar way to that of Rose (1991) and Pollitt (2001) when describing lesson-drawing and convergence respectively, as discussed in chapter 2. In this case the policy transfer appears to be regarded by the individuals involved as copying with necessary modifications made due to financial constraints. There is some discussion of other adaptations to the policy due to cultural differences but these appear to be minimal and resisted by some of the key actors. Ananthan talks of adapting ideas from 'the west' to fit their own situation, as does Roy saying that they were intelligent enough to adapt the ideas. From observation there is little evidence of this adaptation to the basic structure of day care. Roy does talk of not using particular activities from the UK such as dancing explaining that it is not normal for older people in Kerala to dance.

Roy appears to resist changing the characteristics of the day care from his perception of those in the UK. As discussed above he looked outside India for the ideas and information. He also resists the apparent reluctance in the local community and tries to sell day care to them. Roy does say that he could make the Cochin day centre culturally appropriate for India but has not done this, he is quite happy the way things are.

'There is room for more culturally appropriate things for patients with Alzheimer's disease in India but I think what we are doing now is definitely making a big change, a big difference in the lives of these people' [Roy].

Roy has transferred information and ideas from 'the west' and appears keen to make this obvious. It appears that he does not want his day care centre to be something familiar to the local community; he wants it to look foreign. When adapting day care for Kerala Roy maintained its foreign appearance as far as possible. This relates to the process of foreignisation (France 2000:8). Meera also adapted ideas both from the Cochin centre and from the ideas she had collected in the UK. She rejected some aspects of the Cochin centre, specifically in her decision to provide lunch for the clients and in her choice of staff to run the day centre. She talks of adapting all the information she had available to design her idea of day care. As discussed above I argue that these adaptations can also be called policy translation and explained within that theoretical construct. The discussion in chapter 2 noted the shortcomings of policy transfer, which have now been illustrated. Although the policy transfer literature describes different degrees of transfer it does not provide an explanation of or mechanism to investigate the implementation process. I, therefore, use the concept of policy translation and the following chapters illustrate its usefulness.

## **Conclusion**

This chapter has completed the analysis of the policy transfer process within the analytical framework developed in chapter 2. I conclude that the process of policy



transfer has been influential in the development of day care for people with dementia in Kerala, India. I further conclude that the analytical framework was useful in elucidating and explaining the data. I have shown that the impetus for this transfer came from the experiences of an individual, Roy. His search for information to help his father led to the establishment of the ARDSI and the development of services within the organisation. Due to factors in his background Roy was motivated to develop an organisation that aims to provide for the needs of many more people than just his own father. I also found that other individuals have become involved in the policy transfer process over time. This describes the formation of a policy transfer network as described by Evans and Davies (1999). The process of policy transfer cannot be seen as a single event or as taking place within a discrete time interval. It continues and develops along with the ARDSI and its services. Through Roy information has been dispersed across India and through his actions other people have been facilitated to look for information themselves.

I found a range of information and ideas had been transferred. Along with information about services for people with dementia comes a language about dementia and ideas and attitudes about it. I conclude that aspects of local culture within Kerala have influenced which ideas and attitudes about dementia are transferred. Overall I found an enthusiasm for ideas from abroad and the opinion that these are better than local ideas. Within the analysis I have shown that the idea that 'west is best' is a recurring theme and a strong influence on both the transfer and translation processes. This is reflected in the main source of ideas and information, which is the UK, and in the specifics of what is transferred.

The reasons why the policy transfer took place are complex. The individuals involved had a range of personal motivations and they also perceived a need for day care. There may be a growing need for day care related to the demographic changes discussed in chapter 4. It is possible that the ARDSI is ahead of its time and day care will become a more popular and acceptable service for families in Kerala. Within the thesis the local community is found to be resistant to the idea of day care. The main reason the policy transfer took place was related to the personal motivations of the key actors rather than any real need for day care. The key actors may, however, be predicting and perhaps producing a future need.

The constraints to the policy transfer process and the degree to which it takes place are discussed in the later part of this chapter. I found from these discussions that 'culture' is a fundamental influence on the policy transfer process. I conclude that the theoretical construct of policy transfer is not sufficiently defined to enable exploration of the influence of culture here. I have started to explore the transfer of concepts such as 'dementia' and 'day care' within this chapter but my discussions have promoted more questions than answers. The following chapters explore the analysis of policy translation and within this analysis it is possible to construct the role of culture within the transfer and translation processes. It is also possible to more clearly explain how concepts such as 'dementia' and 'day care' are transferred and translated.

## **Chapter 8**

### **Policy translation as adaptation and adoption**

#### **Introduction**

The analysis in chapter 7 confirmed that the UK was the main source of information and ideas in the development of day care in Kerala. I argue that it is possible, therefore, to say that through the processes of policy transfer and policy translation day care for people with dementia in the UK has been transformed into day care for people with dementia in Kerala, India. However, no single UK model of day care was used in Kerala rather an image of day care was built up by the key actors. I have chosen day care for people with dementia in the UK run by AS-AD as a close fit to this image of day care. The reasons for this specific choice are elucidated within this chapter. The analysis in this and following chapters confirms and supports this choice.

Policy translation is defined within this thesis as the process by which policy is altered and adapted as it is transferred and then implemented in a new context. The changes made to the policy as it is transferred involve both deliberate adaptations by

the individuals involved and 'natural' changes that occur due to the differences in the new context. I argue that the translation process is inevitable as the policy is transferred and then implemented in the target context. Policy translation takes place alongside the policy transfer process discussed in chapter 7 and then continues on following it. The concept of policy translation adds to that of policy transfer to provide a theoretical explanation for the policy development in Kerala.

This chapter is the first of three which explore the concept of policy translation. Policy translation is apparent in the differences between the policy in the target context and the original or source policy. In this thesis the differences between day care in the UK and day care in Kerala illustrate the translation processes. A comparative analysis between the UK and Kerala is used, therefore, to explore the process of policy translation. Each chapter represents a different level of analysis. Looking back at the question of 'what was transferred' discussed in chapter 2 there were many aspects of day care to be transferred and translated. These included practical aspects such as staffing, physical structure and activities as well as more abstract ideas such as the concept of dementia and ideas about caring for people with dementia. Chapters 8 focuses on the practical elements, Chapter 9 on the behaviour of groups and individuals while chapter 10 explores the translation of more abstract concepts.

These chapters look back to chapters 3-5 where the cultural framework of day care for people with dementia was discussed for the two contexts. The four fieldsites represent each end of the policy transfer and policy translation processes. This chapter and those following provide detailed descriptions of the four fieldsites in this research. These descriptions elucidate the specific cultural framework of the day care

centres in each context. As argued in the literature review the 'culture of care' in each context frames the day centres and influences the processes of policy transfer and translation. Floor plans for the four day centres are given in Appendix A and details of the staff and clients are given in Appendix D.

## **Types of translation**

I found two types of translation had taken place, which I term planned and unplanned policy translation. Planned policy translation relates to deliberate adaptations made by individuals involved in the transfer process. Unplanned policy translation relates to changes made to the policy as it is implemented and enacted in the new context. Another way to think of these concepts is as adaptation and adoption. Planned policy translation involves adapting the model of day care for Kerala. Unplanned policy translation relates to the adoption of the model of day care by the people working in it.

Planned policy translation relates to decisions made by the individuals involved to change specific aspects of the policy during both its development and its functioning. Planned policy translation can be clarified quite easily as it was an active process and those involved reflect upon it in interview. These individuals describe the changes they made to the day care policy and why these changes were made. Planned policy translation affects the functioning and the structure of the day care centres. The reasons for and aims of planned policy translation are due to the motivations of the translators involved and relate back to the question of why policy transfer takes place.

Unplanned policy translation relates to changes in the policy that occur as a result of the behaviour of individuals. This behaviour is related to their motivations and cultural background and to knowledge and attitude. Unplanned policy translation is elucidated by comparing the behaviour and attitudes of the staff members in the two contexts. Unplanned policy translation is interesting as the processes are not immediately obvious and yet are found to be crucial in determining how the services develop in the new environment. Unplanned translation is probably more influential on the actual delivery of the service than planned policy translation. The changes caused by unplanned policy translation are due to the behaviour of the individuals involved in both the implementation and the running of the service.

### **Translators - their aims and motivations**

The policy translation process is complex and involves different groups of actors or translators with different perspectives and motivations. Policy translation affects all levels of the development process and so managers, service planners and care staff are all influential. These individuals influence the policy translation process at different points. The social, cultural and political context in which they are operating affects the process of translation through its influence on individuals and the social organisation they operate within. Managers and services planners have most influence through planned policy translation. They adapt the policy as it is transferred and implemented. The staff involved in the day to day running of the services translate day care in an unplanned manner as they adopt and enact the service. All these individuals are translators of the policy.

Two important aims of translation are those of foreignisation and domestication as discussed in chapter 2 (France 2000:8). Foreignisation in translation results in a passage or policy which appears foreign within the target context. Domestication is a translation process by which the final passage or policy fits well within the target context. These types of translation are both found within the data and are evident in the end product of the translation process. In summary, it appears that foreignisation is the main aim of the key actors involved in this research but a process of domestication takes place as the staff implement the day care service on a day-to-day basis. The key actors try to preserve a day care that appears foreign while the day care staff do their best to make sense of day care within their own cultural context.

In this research the key planned translators for the Cochin centre are Roy, Ananthan and Rajesh and for the Trivandrum centre, Meera. They have different reasons for making adaptations to the policy that is different reasons for planned policy translation. Planned policy translation can relate to logistical limitations such as lack of funds or poor transport systems. Adaptations may also be made to ensure the day care fits within the local culture. Logistical limitations are found to be a fundamental reason for adaptations and these are discussed further within the comparative analysis later in the chapter.

The decision to actively change aspects of the UK model of day care for cultural reasons was seldom apparent. Only one comment was made related to this. Roy mentions that they do not encourage dancing at the day centre as this is not culturally appropriate for older people in Kerala. He mentions this as he has seen dancing as an activity at day centres in the UK. Roy says that the Cochin centre could be more culturally appropriate but he does not see a reason why as it is doing fine as

it is. Meera does not mention culture as an influence on her design for day care although she states that she does wish to hire people to offer non-allopathic therapies for the clients in the future at the centre, such as traditional *Ayurvedic* treatments. The motivation to adapt the model of day care to the local culture does not appear strong within this research.

Meera designed the Trivandrum centre by adapting information both from the UK and from her knowledge of the Cochin centre. She made some adaptations to what she had observed at the Cochin centre. These are due to her own ideas about day care which she developed through reading books, talking to individuals in the UK and USA and her own experiences of caring for her father. She explains that she made the decision to provide lunch for the clients as she felt this was important and desired by the clients and their carers. Meera also decided to hire a different kind of staff. The two women employed in Trivandrum are older than those at Cochin and one is an experienced nurse. Meera felt that their age and experience would make them good care workers. She could perhaps have employed individuals who had completed the CGN course run at Cochin. The processes of policy transfer and policy translation have taken place for the Trivandrum centre. Some of the information used by Meera has already been transferred and translated by the managers and staff at the Cochin centre and some has come direct from outside sources. This illustrates the complexity of the processes at work here. The development of the Trivandrum centre could be described as a second stage policy transfer and translation but also has its own separate policy transfer and translation from the UK directly. Meera along with other members of the Trivandrum chapter designed the day care service there. The main source of information was Cochin in terms of structure and activities. An



individual in an UK NGO was also consulted for advice and ideas. Meera describes adapting this information to design Trivandrum as described in chapter 7.

Overall the aim of the planned translators appears to be foreignisation. The key actors desired to keep the model of day care the same as that in the UK or at least different to anything found in Kerala. Particularly from Roy there is a strong sense that the day centre in Cochin was to be unique and new in India and that it was to resemble those seen in the UK. He set it up using ideas from 'the west' and trained the staff specially to work there. He talks of having to sell the day care to the people in the local community; he had to explain what it was. The day care was not familiar to local people and he did not appear to think it should be as seen in Chapter 7. Meera was also keen to use 'western' ideas but she did also seem interested in what the carers wanted from the day care.

There are aspects of both foreignisation and domestication in the process of planned translation. Meera makes changes to the Cochin model of day care to suit her clients and their carers, so with the aim of domestication. However, these changes are not different from day centres in the UK where meals are provided and many of the staff members are older women with a range of backgrounds. So Meera has taken the bits she liked from the two models of day care, the UK one and the Cochin one. Roy has made changes to his perceived model of UK day care with reluctance. The logistical limitations, which are discussed below, are seen as negatively affecting the resulting day care centre. Roy's aim as a translator appears to be foreignisation. He appears enthusiastic for the resulting translated day care centre in Cochin to appear foreign. He often stresses its uniqueness in India and its importance as a model for the rest of India. He has brought something from 'the west'

and is keen for this to be apparent. His main motivations do not appear to be to provide a day care centre appropriate to the needs of the local community. This is reflected in chapter 7 within the discussion on why policy on day care was transferred and the need for it in the local community. There is little apparent need for day care and this coupled with Roy's desire for it to look foreign suggest there are other reasons to have a day care centre. I touched on this in chapter 7 suggesting that it was connected to prestige and profile. If the day centre blended within the local culture it may not be seen as important and new and perhaps more importantly it would not be seen as 'western'. From my experience in Kerala many people often emphasised the superiority of all things 'western'. The CGNs would ask about my belongings and be surprised if I had bought things in Kerala or expressed a preference for something from Kerala over something from the UK.

The following comparative analysis asks if the differences found between the two contexts are evidence of planned policy translation or of unplanned policy translation. The discussion focuses on the practical and structural elements of day care location, funding, physical layout, transport, staffing and clients as well as the structure of each day at each day care centre. These elements are compared across the two contexts and the differences in them related to the concepts of adaptation, adoption and the different types, aims and outcomes of policy translation.

### **Structure and function**

To recap, the two day centres in Kerala are named Cochin and Trivandrum after their locations and are referred to by these single terms. The day centres provide a socially based day care service specifically for people with dementia. As

mentioned above these day centres were the only day care centres for people with dementia in Kerala at the time of the research. AS-AD, a Scottish NGO, runs both day care centres in the UK. The centres are named Jura and Iona to preserve anonymity for the clients and staff. The decision to use centres run by this organisation was deliberate as discussed in chapter 7.

All the day centres provide socially based care for people with dementia and they all fit with the basic definition of day care (see Tester 1989). They have similar numbers of clients and staff and follow similar patterns of activity through each day. Three centres, Cochin, Jura and Iona, have drivers who take on multiple roles and project co-ordinators who are also responsible for other services run from the same building. These aspects of day care appear to have been transferred without adaptation or translation. There are, however, many differences between the four day centres. More details of the four day centres are given in Appendix D.

The comparative analysis which follows looks in detail at the differences and similarities between the four day centres focusing on physical and structural aspects of day care. This comprises the first level of analysis of the data from the day centres and the first level of analysis of policy translation. The following chapters deepen this analysis looking in detail at specific aspects of day care and at the knowledge and attitudes of the staff. The descriptions of the four day centres allows for layers of analysis to be built up. This first level analysis starts to illustrate the role of culture within day care and asks if the differences in structure and staffing can be explained in terms of cultural differences between the two contexts. The process of policy translation clarifies the influence of culture within the policy transfer and implementation processes. Culture, as discussed in chapter 3, relates to the political,

economic and religious characteristics of a context and the way in which these affect the behaviour of individuals and the formation and functioning of social organisation. The 'cultures of care' developed in chapter 5 provide the framework for the following analysis.

### Location and physical structure

Cochin was set up on the outskirts of the city of Cochin in 1996 as part of a group of ARDSI services there. The city of Cochin is the commercial and industrial centre of Kerala. The day centre is located on the edge of a university campus around twelve kilometres from the city centre. Cochin is located on the first floor of a large rented building and comprises several offices and a large room for the day care. The offices are used for training and research purposes as well as for the day care staff. The corridors and the walls in the large room are covered in various posters and pictures. These include posters about dementia and organisational notice boards. In the main day care room there are also posters of country scenes as well as pictures drawn by the clients. The furniture is all lightweight, consisting of chairs, dining tables and coffee tables and is moved around to accommodate different activities. There are also three beds around the room and a television at one side. The clients use a porch area downstairs in front of the building in the afternoons. The kitchen is used to make tea for the clients and the clients bring their own lunch.

Trivandrum was set up in September 2001 on the outskirts of the city of Trivandrum. It was established by the Trivandrum chapter of the ARDSI and is managed and organised by various members of the chapter, most notably the treasurer, Meera. The city of Trivandrum is the legislative capital of Kerala and the

government offices are there. The day centre is located in a residential suburb of the city around ten kilometres from the city centre. The central hall is used for the day care and this provides a large flexible space. The walls are built only half way with an open metal lattice forming the top half all the way round. The walls are newly painted in a light colour and undecorated. There are various plastic and wicker chairs, small tables, folding beds and a television. These are arranged as necessary during the day. A kitchen is adjacent to the main room connected through a small hatch. The cook from the residential home provides lunch for the clients and staff.

Jura is situated in the city centre of a large Scottish city. It is located on a quiet street adjacent to a car park and a hostel in an area of office buildings. Jura is located on the first floor of a fairly modern brick building. The ground floor consists of a large hall which is used by local amateur dramatic groups. The first floor is then accessed by three flights of stairs or by a lift. It consists of a large office, a large day care room, a small kitchen, toilets, a small hallway and a large conservatory area. The project coordinator and her assistant use the office. The clients spend the majority of their time within the main room only using the kitchen and conservatory areas for specific activities.

The main room is split into two areas, a dining area and a sitting area. The dining area has four small dining tables. The tables are set with tablecloths and plastic flower arrangements. The walls of the dining area have pictures on them that have been coloured in by the clients. The sitting area is carpeted and a number of comfortable chairs are arranged in a circle around several coffee tables. The walls of the room have various framed pictures and the windows have floral curtains. The

whole room is decorated in matching colours and carpeted throughout. The lunches are delivered ready to eat by a local organisation.

Iona is situated in a residential area of a large Scottish town. Iona occupies the ground floor of a large grand house. The day centre utilises two large sitting rooms, one smaller room available for smokers, a large dining area and three toilets. The building is accessed up a long, low ramp. Upstairs there are several offices used by the day care staff, the project co-ordinator and the regional office of AS-AD. The first sitting room has a large fireplace and a large bay window. Various comfortable chairs and a sofa are arranged in a circle around the room along with small coffee tables which are set out when needed and foot stools if clients require them. The second sitting room also has a circle of matching chairs and sofas with several small coffee tables which are set out when needed. The back half of the room has a snooker table and access to a large cupboard where activities are stored. Both rooms are decorated in soft colours with curtains matching the furniture and framed pictures on the walls. The dining room is at the front of the building and has three dining tables with six seats at each. A cook employed at the centre prepares lunch.

The physical layouts and the buildings are very different between the two contexts. In Kerala day care takes place in large halls with sparse decoration and basic furniture. In contrast the day centres in the UK are furnished with comfortable chairs and sofas and decorated in a similar way to a private home. These differences relate to the 'cultures of care' of the two contexts and the different climates. The hot and often humid climate in Kerala means that spacious, uncluttered rooms with simple furniture are cooler and more comfortable. There has been some attempt to decorate the day care room at Cochin with posters. In the UK, however, a more apparent effort

is made to make the day centres 'homely'. This reflects the 'culture of care' for people with dementia in the UK. The UK design could be described as a more developed concept of day care. The day care environment is designed to be like a home rather than a traditional institution supporting ideas such as normalisation and person centred care (Emerson 1992; Kitwood 1997). In Kerala the day care rooms are too big to represent an individual's home and appear institutional and so are presented as clinics or seminar halls. The physical presentation of day care in Kerala does not indicate the same purpose as that in the UK. The 'homely' presentation in the UK suggests social interaction and person centred care which are aims of day care in the UK. In Kerala the purpose of day care is not clearly represented by the physical structure of it.

As discussed, some aspects of the physical structure of the day centres have been adapted to fit the local climate in Kerala. They have been deliberately translated and represent planned policy translation. Other aspects of day care do not appear to have been transferred or perhaps have got altered in translation. The presentation of day care as 'homely' does not take place in Kerala. This difference may represent a planned translation process with the aim of domestication. It may not make sense to the day care workers in Kerala to make the day care homely as the UK concept of day care does not appear to be clearly understood by the clients or staff in Kerala. Further discussion on the concept of day care takes place in chapter 10. The concept of day care is not associated with older people in Kerala and the purpose of day care is not made clear to the clients. Clients are often told they are being taken to work or to a 'clinic' when they are collected in the mornings. It, therefore, makes more sense for the staff to present day care as a clinic or seminar.

From interviews with Roy and Meera it is clear that money is a definite influence on the design and functioning of the day centres. Roy says that the location and building for the Cochin centre were determined mainly by their cost, which had to be kept as low as possible. A decision was also made not to provide lunch for the clients at Cochin due to the cost of this. The Cochin location was also chosen to facilitate access for the CGNs who travel some distance to work each day. The relatively high cost of public transport for the CGNs prohibited them from travelling further. In Trivandrum Meera chose the location as another member of the ARDSI offered it at a low rent. It was, however, an accessible building having been built for older people to use. Both centres in Kerala are situated some way from the city centre and the Cochin day centre is situated on the first floor of the building. Financial limitations have led to planned policy translation which has resulted in the differences in location and type of building observed between the contexts.

### Funding and transport

Cochin was funded until 1999 by HelpAge India. The funding situation since then is unclear and appears unsatisfactory as the management staff often talk about a scarcity of funds. Funds collected from various sources have been used since 1999. The clients also contribute by paying a monthly fee. In Trivandrum the individuals who run the chapter were able to raise funds for the running of the centre. It came from friends and relatives, local businesses and fund raising events. The chapter is currently fundraising to purchase their own vehicle. Trivandrum is run in the main hall of a residential home for older people. The central hall and kitchen are rented by the ARDSI Trivandrum chapter for use during the day. A member of the private trust that owns the home is also a member of the ARDSI and so a reasonable rent was



negotiated. The ARDSI paid for some alterations to the building such as ramps to the toilet areas.

The building in which Jura is situated was bequeathed to AS-AD and is owned outright by the organisation. Funding for Jura comes from the Mental Illness Specific Grant which is provided by the Scottish Executive and the local social work department. The building in which Iona is situated was also bequeathed to the organisation and funding for the running of the centre comes entirely through the local social work department. A unit cost is negotiated on a yearly basis and the social work department pays according to this.

The financial structures of the day centres in the two contexts relate to the history of formal care in the two contexts and, therefore, to the 'cultures of care.' There is a more organised and formal system of funding in the UK compared with Kerala. Finance for day care in Kerala is a hit and miss affair as it is not backed up by a formal structure of any kind.

Transport is another element of day care that is affected by logistics. Travel around Kerala is difficult with busy and badly maintained roads. It is found in Cochin that the bus run to collect the clients is also used to pick up staff and undertake other errands probably to reduce the number of times that bus has to go out each day. The cost of petrol is another related consideration. In Trivandrum the centre did not have its own transport and relied on taxis and auto-rickshaws. There were no funds to purchase a vehicle and hire a driver but the centre was fundraising and since the end of the research period a vehicle has been purchased. In the UK the bus run collecting

clients was rarely used for any other purpose. Money, therefore, affects the location and physical structure of the centres and the transport arrangements for the clients.

Roy states that he is not happy with the compromises at the Cochin centre. He would rather have a more appropriate building nearer the centre of the city. These changes to the policy do not meet with his idea of what a day centre should be like. There is a common attitude in the interviews with key actors that there is more money for care in 'the west'. Indian day centres are described as inferior in terms of their structure. This represents planned policy translation influenced by logistical limitations. The adaptations made to the model of day care are deliberate or planned. However, the motivation of the individuals is to not make these adaptations. The adaptations are made with reluctance. It appears that the underlying motivation of these key actors is that of foreignisation. They wish to maintain the foreign appearance of the day care centre and make necessary adaptations with reluctance.

### Staff and clients

Ten CGNs are employed in the Cochin services. A CGN is someone who has completed a CGN training course run by the ARDSI. This is a one year course that covers aspects of nursing including physiology, anatomy, psychology and nutrition. Although called nurses the individuals are not certified as such. The course could be compared to an SVQ level III with a more medical slant. This course was designed by Roy and his colleagues specifically to train staff for the ARDSI. The CGNs work both in day care and home care on a rota basis. They may also be involved in parts of the research work done by the centre. They all work full time and most are married with young children. The senior project officer, Rajesh, manages the day centre. A

psychologist, Usha, a psychiatrist, Ananthan, and a nursing tutor, Mary, also have some input into the running of the day centre. A driver is employed full time and between the bus runs is involved with handyman duties, running errands and helping in the day centre.

There are two members of care staff in Trivandrum and both are known by members of the Trivandrum chapter and were employed because of these connections. The staff underwent a two day training course provided by staff at Cochin. There is no formal management of the centre but members of the Trivandrum chapter, usually Meera, visit several times a week. The staff are supported by a clinical team at a local hospital. No driver is employed as the clients are collected in a taxi.

Jura is staffed by a day care organiser and one or two day care workers as well as one or two volunteers and students. The driver also works as the handyman at the centre. The day care organiser is a more experienced day care worker but there is little apparent difference between these two roles. The day care organiser takes the responsibility of organising the staff and clients during the day but allows the staff flexibility.

The staff in Iona are the same as at Jura but there are usually more of them. The driver again takes on the role of handyman when required. He also works as a day care worker if the centre is short staffed. The day care organiser co-ordinates the daily running of the day care centre instructing whom to do what and when. She also undertakes administrative work.

The numbers of staff compared with the number of clients is similar in all four centres. This suggests that this information was transferred from the UK to Kerala and this process is reflected in the previous analysis of the policy transfer process. Other aspects of staffing are different. In Kerala there are close links with medical professionals. In Cochin a psychiatrist is employed part time by the ARDSI and a psychologist and a staff nurse provide input to the day centre. In Trivandrum the centre links closely with a medical team at a local hospital. In the UK in contrast links with medical professionals are limited. The project co-ordinator for one of the centres stated that she resists any medical input at the centre as the emphasis is on social interaction and a homely atmosphere. These differences probably reflect a difference in how the purpose of day care is understood in the two contexts, that is how the purpose of day care has been translated from the UK to Kerala.

The decision to have close contact with medical staff at the day centres in Kerala relates to how dementia and care for people with dementia is conceptualised there. It also relates to the practical medical support available in the local communities. There may be little support available in Kerala where there is little general knowledge of dementia among the medical community. The day centre may provide the main contact for medical support. The differences noted above, therefore, are due to adaptations made because of practical differences such as that in the availability of local medical staff but also to more conceptual issues such as how dementia is translated and consequently understood in Kerala. The translation of the purpose of day care and the translation of dementia are central to this thesis and are highlighted through this and the next chapter. Specific discussion on them takes place in chapter 10.

The staff in Kerala are in the main young women who work full time whereas in the UK they tend to be older women working part time. These differences reflect the local 'cultures of care' and the image of care workers or nurses, as they are called in Kerala. In Kerala the daughter in law takes the role of caring for older people within the family. This is reflected in the fact that most of the CGNs are young married women. In the UK the caring role is less defined but usually associated with women. It is also of low status and pay and therefore perhaps why middle-aged women with no formal training often take these types of job. The job in Kerala is also low paid and low status and this is reflected as staff from both contexts have similar educational backgrounds. In the UK there are more volunteers and trainees used to support the day care staff. In Kerala this is not the case. There have been attempts made to get volunteers but during the research period this had not been possible. The concept of volunteer carers is long established in the UK but a much newer idea in Kerala. The idea of having volunteers at the day centres in Kerala has been transferred from the UK but does not appear appropriate as there is no cultural match for these individuals in Kerala. The age and sex of staff has been translated to fit with the culture in Kerala. This may appear to be an example of planned policy translation but I argue that it is probably unplanned as young women in Kerala are probably the only group who would take on such a post. The nature of the staff is dependent, therefore, on the local culture which influences the types of individuals who work as carers.

In Cochin the clients appear to have a range in severity of dementia and it was not clear that all of them do have dementia. The clients come from a range of backgrounds. Several of the men lived in large modern houses with servants while others came from poorer households. The main reason for a client to attend day care appeared to be because their behaviour was difficult to cope with in their house. None

of the clients lived alone. One man attended as he lived with an elderly servant and his son felt that he was depressed. It was also said that another man attended as his family had problems in controlling his alcohol intake during the day. At Trivandrum there were four clients. Two were husband and wife who attended as there was no one at home to take care of them. The other two were widows who live with their sons. Both their daughters-in-law work so there is no one to look after them at home. One of these clients' behaviour was causing concern to her family and they had been locking her in a room of the house when they went to work.

Jura provides care for up to eight clients each day. Most of the clients lived alone and attended the day care as it provided social contact as well as ensuring they received a good meal. Other clients lived with their spouse or children and attended both for the reasons above and to give some respite to their carers. Most of the clients who attended Iona live with family, usually a spouse or child and his/her family. The clients have a range of needs and appear to come to the day centre for a number of reasons. Some live alone and come for social contact and activity, others come because it is difficult for their family to care for them all the time and others come to give their carers respite. Most clients come for a combination of these reasons.

The clients are similar at all four centres although it appeared that some of the clients in Cochin did not have dementia. This is probably related to the way in which dementia is diagnosed and other factors relevant to the acceptance of clients at day care. This is discussed further below. However, there are differences between the contexts in the reasons that the clients attend day care. These are related to the culture and family structures in the two contexts. In Kerala none of the clients lived alone as would be expected with the Indian emphasis on family care of older people.

In the UK many lived alone or with a spouse, few lived with other family members. Clients in Kerala attend if their behaviour is problematic to other household members or in the unusual situation that there is no one else at home to care for them during the day. In the UK it was more common for a client to live alone and attend day care for social interaction. These differences do not appear to be due to planned policy translation. They probably relate to unplanned policy translation with the result of domestication. As with staffing the types of clients who attend day care result from the referral and assessment processes. The type of client in each context results from the different needs of individuals and families and their motivations to utilise day care. As discussed in chapter 7 there was little apparent enthusiasm for day care within the local communities in Kerala while in the UK there are waiting lists at both centres. In Kerala the staff undertake surveys to try and identify clients for day care and run awareness programmes in the local media to advertise their services.

### Daily routines

The daily routine at Cochin is fairly well set and rarely changes; it is based on a timetable displayed in the main room. The day begins with the clients being assisted to sit in a large circle of chairs facing each other when they arrive at around 10 am. The clients are encouraged to stand up and join in with prayers which most do. After prayers the clients are encouraged to stand again and the CGNs direct them to do some exercises. Following the exercises the clients all sit in the circle of chairs and the CGNs bring the newspapers. These are read aloud and discussed with the clients. One CGN makes the tea during this time and serves it to the clients after the newspaper reading is finished. This morning routine rarely alters. After tea there is a period during which the clients and CGNs do a variety of things. They may play

games in smaller groups or sit and chat. Often an activity on the blackboard is done after tea involving most of the clients. The TV is put on later in the morning. Lunch takes place around 12.30 and is followed by a period of rest during which the TV remains on and most clients and staff sit in front of it either watching or sleeping. Other clients may lie sleeping on the beds provided and the CGNs may go into the staff room for their lunch. At 2pm the clients are assisted downstairs to sit in the front porch. The afternoons are usually spent listening to a CGN read from a magazine or singing and chatting. Around 3pm tea is served again and the clients leave on the bus at 3.15 pm.

The days at Trivandrum followed a fairly set pattern during the relatively short observation period. There is a timetable on the wall of the centre which was copied from Cochin and this was followed to some extent. During the research period a new TV arrived and the clients and staff spent a fair amount of time watching the TV. The clients are helped into the building when they arrive and sit in a semi-circle of chairs near the door. The day starts with prayers as in Cochin. Following the prayers the clients sit down again and either the newspaper is read or the staff encourage the clients to sing. All the staff and clients join in with the singing. At around 11am the tea is served and the staff assist the clients with their tea. Between tea and lunch a variety of activities may take place. The clients may be encouraged to do some exercises or do a game on the blackboard. One of the residents from the home may join the clients for a chat and the clients and staff may also play carom, a local board game. Lunch is served around 12.30 and the staff assist the clients with this. After lunch the clients may take a rest or may sit and watch the TV. This quiet period lasts until around 2pm. In the afternoon the television usually stays on and the staff and clients may continue watching it. They may also play carom again or other games



such as Snakes and Ladders. There may also be periods of singing again. Tea is served again at 3 pm and the staff and clients sit chatting until the taxi comes to collect them at 3.30 pm. Three of the clients go off with one member of staff while the remaining client stays until 4.30 when the taxi returns to collect her.

There is a fairly set routine at Jura, which is followed daily. The staff meet at around 8.45 before setting out on the bus run. Two staff go on the bus and the others prepare the morning tea and toast. On arrival at the centre the clients sit in a large circle of chairs and have tea and toast and chat to one another and the staff. Once they have finished tea the clients join in with some physical games such as throwing a ball or hoops over a target. After tea the group splits into smaller groups who undertake a variety of activities which usually include housework tasks. Once these things have been done the clients do other activities such as knitting, colouring and reading. The clients remain in smaller groups until just before lunch when they move into the big circle again. Once in the big circle the clients join in with more physical games until lunchtime. Lunch is served at around 12.30. Following lunch the clients sit in the big circle and have tea and biscuits. In the afternoon the clients do a variety of things, again usually in smaller groups. These might include board games and housework or they may all sit together to watch a video. Later in the afternoon the clients go back into the big circle where they chat together and have a final cup of tea. The clients are assisted downstairs and onto the bus at around 3.15 pm.

At Iona there is a set routine for the day. The staff meet at 8.45 am for a daily meeting during which they plan the day ahead. The clients come in on two bus runs with different morning routines. Those on the first run arrive by around 10.30 am and sit together in one sitting room where they have tea and biscuits and chat to the staff.

After tea the clients are encouraged to take part in some exercises and then possibly a quiz, more chat or reading the newspaper. The second bus arrives around 11.30 and the clients sit in the second sitting room where they have tea and a chat. This usually lasts until lunchtime when the clients from both rooms are assisted into the dining room. Lunch lasts about one hour. After lunch the clients are split into two groups again, often men and women. A variety of activities are done in the afternoons including crosswords, bowls, singing, quizzes, and games such as dominoes or bingo. At around 2.45 the staff assist those going on the first bus to get ready. These clients are assisted onto the bus and the remaining clients move into the front sitting room. The first group goes off and the second sit and have tea and biscuits in the front sitting room usually chatting with the staff. There may be a game played after the tea is finished, usually dominoes, but often the staff and clients just chat. The second bus leaves around 4 pm.

By examining the summaries of what takes place each day at the centres it can be seen that there are several different aspects to day care which are found to be similar in both contexts. There are four main parts to each day: time spent on transport, time doing activities, time spent in essential tasks such as eating and assisting the clients to the toilet and time in-between transferring between the other three. An additional period is also observed in the UK. Before the first bus run in the morning the staff gather together for a short meeting. In Kerala there are also periods of rest which are not seen in the UK. The four main aspects of day care are similar in both contexts but the proportions of time spent on each aspect are different between the two contexts. In the UK more time is spent doing activities than in Kerala and at Iona particularly a lot of time is spent transferring between different parts of the day. In Kerala more time each day is spent in an unstructured way with the staff and clients

passing time together. During these periods the staff respond to the clients rather than being more proactive in engaging them in activities. The differences between the daily routines in each context relate to unplanned translation processes. These differences occur as the staff and clients enact day care. The comparison of the daily routines confirms that in appearance the four day centres are as different from one in the same context as from one in the other context. This appears to confirm the process of policy transfer. Analysis of the differences in the proportion of time each day spent on different aspects of day care and the detail of these aspects reveal more subtle differences between the two contexts and illuminate the policy translation process. Specific aspects of day care are explored in the context of policy translation within the following chapter.

## **Conclusion**

This chapter developed the concept of policy translation beyond that in chapter 2. This chapter forms the first level of analysis of policy translation. The discussion of the comparative analysis looked at the differences in practical and structural aspects of day care. Many of the differences noted are found to be due to planned policy translation. They are due to deliberate adaptations made by the key actors in Kerala. The main reasons for these differences were shown to be financial and practical limitations. Adaptations such as the size and layout of the room were made to better suit the climate of Kerala. I have shown that the key actors made the changes to the model of day care with some reluctance. These adaptations or planned policy translations result in a service that maintains much of the 'western' appearance of the model from which it is drawn. This is particularly notable in Cochin. I conclude that

the motivation and aim of the translators who undertake planned policy translation is foreignisation.

As different aspects of day care were explored it became apparent that, in addition to deliberate adaptations, other changes were taking place as the policy was transferred from the UK and then implemented in Kerala. The discussion above highlighted differences in the staff and clients and these differences were found to reflect the local culture in each context. These differences do not appear to be due to planned policy translation but result from the behaviour of groups and individuals. I conclude that these differences are due to unplanned policy translation and influenced by culture. I argue that the translation of concepts such as 'dementia', 'care' and 'day care' affects the implementation and day to day functioning of day care in Kerala. The differences highlighted above suggest that the transfer and translation of the concept of dementia are fundamental within the development of day care for people with dementia. They affect the understanding of care for people with dementia, the purpose of day care and the role of a day care worker. These concepts are not straightforward to define and are culturally bound. I argue, therefore, that their translation from the UK to Kerala is also culturally bound.

The exploration of unplanned policy translation requires a deeper analysis. The following chapter looks at specific aspects of day care in turn to investigate the process of unplanned policy translation. The discussion focuses on the behaviour of the different individuals involved. Unplanned policy translation occurs during the adoption and day to day enactment of policy. The staff who work at the day centres undertake translations as they enact their role within day care. Managers such as Roy, Meera and Rajesh also cause unplanned translations as they pass information

on to the staff at day care. Rajesh and Meera have more direct effect on the day centres as they occasionally participate in the activities at day care. However, I conclude that the main influence of the key actors on the day-to-day functioning of day care is through the CGNs. The cultural perspectives of the CGNs affect the way in which they use the knowledge about day care and dementia which they are given. This in turn affects their behaviour at day care and, therefore, how day care is enacted.

## **Chapter 9**

### **The detail of policy translation**

#### **Introduction**

This chapter continues the comparative analysis and explores in detail specific aspects of day care. It examines the behaviour and interactions of individuals and groups and compares the two contexts. While the practical changes discussed in the previous chapter resulted from the process of planned policy translation with the aim of foreignisation, this chapter illustrates unplanned policy translation taking place through the processes of adoption and enactment. The behaviour of the day care staff illustrates these. The differences between the two contexts illustrate examples of unplanned policy translation. Most of these examples show the CGNs to undertake a process of domestication when translating specific aspects of day care (France 2000:8). Domestication describes a translation process which results in a product that is different from the original and which fits with the new, target context.

Some examples fit well with the theory of policy translation. Others are less clear and may represent a 'failure' in translation or a translation process with no clear

aim. It seems probable that not everything that is transferred is noticeably altered as it is translated and this chapter explores an example of this. It also discusses an aspect of day care that appears to have been translated but the translation process has resulted in an inappropriate outcome for the situation. The differences highlighted within this chapter reflect differences between the two contexts in the conceptualisation of dementia, ideas about caring for people with dementia and the role of the day care worker. Chapter 10 draws together the analysis in chapter 7, 8 and 9 to explore the translation of these concepts.

### **Having a cup of tea**

Having a cup of tea provides an interesting illustration of the process of policy translation with the aim of domestication. Teatime is an important aspect of day care in both contexts. 'Having a cup of tea' is as important and common in Kerala as it is in the UK. At day care teatimes give structure to the day and provide for the physical and to some extent the social needs of the clients.

At the day centres in Kerala tea is served twice a day. Teatimes feel functional; drink, eat, finish and then do something else. They do not appear to be social times. The CGNs pass round the tea and offer any assistance to the clients but do not join them for tea. The staff also pass round biscuits or a snack usually placing them into the clients' hands. The timing of teatime does provide a definite structure to the day and is important in that respect. Lunchtime has the same functional feel. Although the arrangements are different in the two centres there are similarities in how the staff behave. They take a service role, helping to serve the tea and checking the clients have everything they need. The staff do not take their own tea or lunch at the

same time as the clients and always check the clients have everything first. Young women would normally take a similar role within their own houses. The following extract from observation notes gives an example of teatimes at Cochin. Tea is served in stainless steel beakers which are difficult to hold when the tea is hot. The tea is cooled after it is served. This is quite normal and in a café you would be given an extra beaker in which to cool your tea. In all the extracts from observation notes the names of the CGNs start with S and L, the male clients with R and V and the female clients with M.

Lata comes to the window with two cups of tea; she calls to Lakshmi and then to me asking me about coming to the engagement party tomorrow. Lakshmi and I go over to the window and chat for a couple of minutes, the clients remain quiet and still. Lakshmi starts to hand round the tea wordlessly. Lakshmi goes back and forth to the window collecting the cups of tea, Vinu goes over to her and she tells him to sit down and passes him some tea. Lata comes in with the rest of the tea and Lakshmi goes to get the biscuits. Lakshmi hands them out two at a time placing them in the clients' hands' saying 'here sir' to each resident. Lata sits up on a desk cooling a cup of tea. Rohit calls to Lakshmi and she sits close to him talking softly for a moment. Lata brings me a cup of coffee [special treat]. The men sit silently sipping their tea and dipping biscuits. Lata and Lakshmi stand to one side chatting for a minute holding hands. Lakshmi puts away the biscuits and wanders about tidying. Lata stands in front of Varun cooling his tea. Lakshmi is humming softly as she goes around collecting cups. [OBS 22-27 Oct 2001 COCHIN]

In the UK teatime is a social time when much conversation takes place. The staff at both centres facilitate conversation and may ask simple questions, to which they know the answer, to encourage the clients to talk. Teatimes are definitely social



times with the staff active in ensuring that. The process of serving tea is prolonged and ritualised. Tea is served from teapots and in cups and saucers. The staff member pouring the tea asks each client in turn what they take in their tea before passing it to them. On occasion the clients are assisted to help themselves to milk and sugar. The clients appear to enjoy these periods and most join in with the chat. Some of the staff mention in interview that all aspects of day care can be defined as an activity and give teatimes as an example. The staff approach teatimes with this attitude and ensure that the clients are engaged in social activity. Teatime is also practical with the morning teatime being important as food is served as some clients may have missed breakfast or taken it very early.

There are important differences between the two contexts in the way that teatimes are organised. In Kerala the staff take a service role, helping the clients with the organisation of the tea and serving it to them. The staff do not join the clients for tea. The staff in Trivandrum do take tea but walk around while they drink it usually checking on the clients. It is the opposite in the UK where teatimes are a joint occasion for staff and clients. These differences may appear to reflect an inadequacy in the translation of this part of day care. In fact I would argue the opposite. The staff behave in a way appropriate to their own culture. Young women would take a service role in their own homes in Kerala and may not eat with the men of the household. Therefore teatimes have been adopted as an important structural part of day care in Kerala but they have been translated by the staff to fit their own culture and are acted out in this manner. The CGNs have translated the idea of having a cup of tea at day care into a process that appears to make sense to them and to the clients. The CGNs have undertaken an unplanned process of domestication as they 'having a cup of tea'. It does not appear that the CGNs actively undertake this translation but that it takes

place passively as the process is enacted. This example highlights the conceptualisation of care for people with dementia in the two contexts and the role of the day care worker. In the UK the presentation of teatime as an activity reflects the formal 'culture of care' and the staff members' understanding of caring for people with dementia.

## **Reading the paper**

Newspapers and magazines are used in activities with the clients in all the centres. In Cochin most of the clients sit in a large circle in the mornings while one CGN reads from the paper. Starting by giving the day's date, she then reads stories she thinks are interesting usually starting with the lead article. On occasion a male client may be asked to read aloud and the CGNs suggest which stories to read. Most of the other clients appear to listen although some may read another paper or chat to one another. Clients and CGNs ask questions about the news stories and there are often short discussions as the reading goes on. This is illustrated in the example below.

The clients sit in the circle of chairs with me, Lakshmi and Lata. Lata starts to read from today's paper, she sits close to Vinu and leans towards him as she talks making sure he is following. Lata also looks over at the other clients as she is reading, Mary sits forward as if she is listening intently. Lakshmi and Raja have a short quiet conversation about something in yesterday's paper, which Lakshmi has...Lata talks over to Raja and Rohit also joins in the conversation...Meena is talking and muttering to herself and no one is responding...Lata goes back to reading the paper. Malini is disturbed and gets up, starting to wander around the room...Lakshmi follows her and brings her back leading her by the arm talking softly to her...Lata has continued reading from the

paper, drawing Raja and then Varun into conversation about things in the paper. Lata then asks Rajeev about a story about Anthrax, which she has read out, Rajeev replies talking for a minute or so. Lata then asks Rohit a question, which he answers, Mary asks Lata a question and Lata talks at length. It all appears to be related to the news [OBS 29Nov-02Dec 2001 COCHIN]

In Trivandrum the newspaper is taken round in the morning to each client in turn. The client is asked if they want to read the paper and then shown articles that may be interesting. As the client reads, there may be discussion with other staff and clients about the news. Sometimes the staff ask the client to read a story out loud so others can listen or a staff member reads an article to the whole group. The other clients may listen or may be chatting or singing. The newspaper is presented in a flexible and focused manner. The reading of newspapers is central to Kerala culture as there is almost 100% literacy and the local newspaper is the most widely read local language paper in India (Prakash 1999). Older men commonly meet to read the newspaper together in the mornings. This makes this an ideal activity for day care and explains why it is apparently enjoyed and the clients willingly participate.

Newspapers and magazines are also used in the UK. Newspapers and magazines in Jura are used mainly with one particular client who does not appear to enjoy many of the other activities. Occasionally other clients may look at the paper or a magazine. In Iona two newspapers are provided daily which are used in activities and read by the staff at their breaks. When the newspapers are used for an activity this involves a member of staff reading articles from the paper and then discussing the news with the clients. The clients are prompted with questions and encouraged to take part in the discussion. Particular female members of staff try to find what they

think are nice stories and try to avoid distressing stories. These newspaper discussions appear to reflect a reluctance to expose the clients to anything that might upset them. At Iona the tendency was to use stories from current newspapers to prompt discussion of the past, often with the theme that things were much better then. In Jura although newspapers were not used directly the staff and clients often discussed current events, particularly sporting events and local news. Reading the newspaper does provide a social activity which is enjoyed by many of the clients.

There are important differences between contexts here that relate to the 'culture of care' in each context. In Kerala the newspaper discussions were based on the current news and the clients participated in this. The discussions also included confirmation of the day and date. In Jura the date is displayed on the white board in the dining area and this may be mentioned or confirmed to clients if they ask but in Iona no mention is made of the date. In Kerala the reading of newspapers is integral to daily life and makes a popular activity for the day centre. It is approached in an honest manner. The paper is read and discussed as it appears. In the UK this is not the case. Newspapers are presented in a manner to avoid distressing the clients or in an effort to stimulate conversation about the past. The clients are protected from what is really happening. The newspaper reading is altered to become an activity. This is similar to the conversation at teatimes which is constructed by the staff to facilitate the client's participation. The staff appear to have the attitude that the clients are different in some way to them and should be protected from distress and talked to in a different manner. This is not the case in Kerala where the approach is more natural but may be confusing or distressing for the clients. The staff in Kerala have translated the activity of reading newspapers in a manner that makes sense to them. They have domesticated this aspect of day care so that it fits with the culture of Kerala. It does

not seem to occur to the CGNs that they should alter or filter what is in the newspaper. The clients are treated as adults and a 'normal' atmosphere prevails. As with having a cup of tea this translation process is unplanned and takes place through the behaviour of the CGNs. This example again highlights the differences in the construction of 'care' in the two contexts. In Kerala less effort is made to construct every aspect of day care as an 'activity' which is appropriate for people with dementia. Within the 'culture of care' in Kerala care is focused within the family and, therefore, not conceptualised as 'work'. The staff and clients read the newspapers together to learn about the news. In the UK the staff use newspapers to promote social activity among the clients as part of their role as day care workers.

## **Rest**

At all the day centres there are periods of time in-between more formal aspects of day care such as mealtimes, teatimes, activities and time on transport. I have called these periods of rest but they are not labelled as such in the UK. In Kerala there are several periods of rest and these can comprise a large proportion of the day. This is probably due to the high temperatures in Kerala and a need to rest during the day. During the rest times formal activities do not take place but the TV or radio may be turned on. During these periods the clients may be walking around, watching TV, sleeping, reading the newspaper or chatting to each other or a CGN. The CGNs may be taking their lunch, reading the newspaper, sitting chatting to each other, watching the TV, washing lunch dishes, chatting to clients or tidying up. During these times the interactions between clients and staff are largely response interactions. The CGNs respond to the clients, to something they have said or done such as going out of the room. If a client asks about going home the CGNs offer an explanation and

reassurance. If a client wants to go to the toilet the CGN tells them where to go or takes them if necessary. If a client goes out of the room a CGN may call to them to come back or go and get them and lead them back. A lot of these interactions are about control of the clients, keeping them in one area. The CGNs watch and sometimes count the clients as they move about. The examples below illustrate these periods of rest.

Varghese and Varun are watching TV and chatting, Raja is in the corridor pacing, Meena and Rasheed are sleeping, Rohit is sitting at table with me, Malini is wandering around the room at speed, Limy is with her pulling at her arm. Minnie is sitting on her cot. Shalini sits apart at another table reading the paper. Lata and Lakshmi are in the office. Shalini comes over and tells Rohit to talk to me, telling him I speak English, she then goes over to Malini and guides her back to a chair, Shalini pulls another chair up and sits beside Malini. Limy goes into the office where her and Lata have their lunch. Shalini remains at table with me; she is reading the paper. Lakshmi stands in the doorway talking to Raja and blocking the way when Malini tries to leave the room. The TV has no picture on it just lines but no-one seems to have noticed, Varghese and Varun are still sitting in front of it but are talking to each other [OBS 15-20 Oct 2001 COCHIN]

Rajeev, Raja are joined by Varun in front of the TV, which now has a picture. *(the picture often went off)* Vinu is washing his hands, Rasheed reading the paper, Mary still fiddling with her dishes, Meena sleeping, Varghese is smoking, Rohit is eating, Malini is wandering. Limy and Lata are talking at one side of the room and Shalini is in the office having lunch. [OBS 15-20 Oct 2001 COCHIN]

Periods of rest are not encouraged in the UK. There may be quieter times during the day when the clients and staff chat between activities but these periods are

short and clients are discouraged from sleeping. The differences in the rest periods between contexts are probably in part due to the differences in climate but also to cultural differences. It is more common to rest during the day in a hot country. They may also be due to the CGNs understanding of their role and of the purpose of day care. There seems to be a perception that the CGNs are there as guardians for the clients during the day with less emphasis on engaging the clients in activity. This can result, however, in a relaxed atmosphere where the clients are left to do what they want to within the space of the day centre. Many of the female clients at Cochin do not take part in more formal activities and often spend their days in one specific part of the day care room. The female clients may chat with staff, sleep or watch what is going on in the room. They are given the freedom to do this in a familiar space. In the UK it appears that the staff take very seriously their role in keeping the clients active throughout the day and plan activities accordingly. Clients are encouraged to take part in whatever activity is taking place. The staff control the position of clients within the day care rooms and what they are doing at any one time. The clients are split into groups according to how many staff are present rather than according to what they want to do. In Jura there is more flexibility but at Iona the clients remain in groups of six with one activity for the group.

These differences seem to relate to the staff members understanding of their role at day care. The staff in the UK have a more formal approach and understanding of their role as day care workers. The staff are more self-conscious of their behaviour. They are busy fulfilling their role throughout the day at day care. In Kerala the staff spend much of the day passing time with the clients and responding to their needs rather than actively encouraging the clients to take part in activities. The clients have more freedom to choose what to do but there are fewer things for them to do. Again

the staff in Kerala appear to be translating day care in an unplanned way with the aim of domestication. This relaxed, informal, responsive approach to day care appears to fit with the 'culture of care' in Kerala.

### **At the blackboard**

Word-based activities are often carried out in Kerala using a black board. In the Cochin centre the clients sit in rows facing the blackboard where one CGN stands. She writes the date up and then calls to one of the clients to come up to the board. There is then discussion on what they should write, usually a list of some kind: fruits, local districts or temples. The idea is that the other clients call out examples and the individual writes them on the board. What often happens is that the client goes ahead and writes the list while the others sit quietly and the CGNs instruct the client as to what to write and encourage and correct him. Most of the clients sit and watch the activity or go to sleep; others may be walking around the room. The clients do not show a lot of enthusiasm for this activity. However, it is done nearly everyday after morning tea for a period of around half an hour. At the Trivandrum centre there is also a black board. This is used for a one to one activity where staff and clients write things on the board and chat about them. They might write their name or draw a picture. At Trivandrum the activity is seldom undertaken and only lasts a few minutes. The example given below is from Cochin.

Six clients are seated in a row in front of the blackboard with Limy standing in front of it, Shalini and Raja sit behind the others. Limy walks up and down in front asking the clients what the date is, she tells them and writes it up on the board. Limy is throwing the chalk up and down in her hand and looks like a schoolteacher...Limy writes up on



the board 'districts of Kerala' in Malayalam. She hands the chalk to Varghese who stands up at the board. He starts to write the names of the districts, Varun suggests that he should start with Trivandrum as it is the capital, but he has started with Kochi. Limy is also calling out all the names.

The driver waves his hand in the air and lists all the districts. Raja lowers his head into his hands...the driver gets up and gets a cloth and wipes the board clean, he takes the chalk from Varghese and writes 1. 2. Etc. up to the right number of states. He gives the chalk back to Varghese instructing him to list the states from north to south. Raja gets up and wanders off. Lata is still chatting with Rohit...Varghese apparently makes a mistake and Limy gets up and wipes one word off the blackboard. The driver stands up again and gives Varghese more instructions. The driver goes up to the board and draws a map of Kerala pointing to where each of the districts is. The driver then leaves the room, Varghese and Limy stand at the blackboard together and Varghese finishes writing up the list [OBS 15-20 Oct 2001 COCHIN]

In the UK word-based games are often undertaken at Iona. These usually comprise quizzes and crosswords. The quizzes are often taken from books of activities written specifically for people with dementia, which are also used in Kerala and may be the model for the blackboard activity. The crossword used is a giant wipe clean crossword that is stuck up on the wall in a place where all the clients can see it. A member of staff then fills it in as the clients call out the answers to given clues. The staff facilitate these activities, giving extra clues to help the clients get the correct answers. These activities can go on for long periods of time. Specific clients tend to take part more often with other clients perhaps sleeping or looking about the room. This may be because some clients are very quick to answer and others do not get a chance or that they cannot hear or see properly to take part. These types of activity

are fairly common in Iona and appear to be enjoyed by many of the clients. They provide a social activity that challenges the clients to think and take part.

The differences in these activities are reflected both in the behaviour of the staff and in the participation of the clients. In Kerala the clients participate as instructed while the clients in the UK appear to enjoy these activities and take part with enthusiasm. The blackboard activity appears to be an inadequate translation of an activity used in the UK. There is no obvious equivalent in the CGNs' knowledge and so they pick the closest fit. The CGNs appear to have translated this activity with the aim of domestication to resemble something familiar to them. The activity resembles the behaviour of pupils and teachers at school. The use of a blackboard and the arrangement of the clients in rows of chairs facing the blackboard reflect this. The CGNs behaviour also often reflects that of a teacher, some pace up and down in front of the clients while giving them instructions.

This activity appears to be an attempt to copy an UK style activity, perhaps by Rajesh, the Senior Project Officer, on his return from the UK. However, the translation process has resulted in an activity which does not interest the clients and which they do not seem to understand. The clients do follow the instructions given by the CGNs and do take part but with little enthusiasm. The CGNs aimed to domesticate this word-based activity but the process has been unsuccessful resulting in an activity that does not fit in the target culture of Kerala and does not appear appropriate for the clients. This reflects a process of domestication which appears to have gone wrong. The translation process has taken place but the changes caused by the translation process have altered the activity into something which does not fit within day care in Kerala.

## **Exercises**

Exercises are done as an activity at all the centres. In Cochin, Trivandrum and Iona these are general exercises done by the clients in a group led by a member of staff. In Jura the clients get exercise through participation in various ball and hoop throwing games. In Cochin and Trivandrum the clients are encouraged to stand up and the staff demonstrate what they should do. The staff count out loud and direct the clients and some join in standing up, others remain sitting. The clients need a lot of encouragement to join in and do so only reluctantly often giggling and looking uncomfortable or annoyed. This example is taken from Trivandrum. The staff are actually having to move the clients' arms up and down. Minnie tries to divert them by lifting her arms for a hug. During the last part of the exercise both staff and clients are giggling at what they are doing.

After a minute or so Lily calls to the clients, telling them it is time for exercises and tells them to stand up. Maya stands up, she is clapping, and walks over to the cook and they chat. Leela follows Maya telling her to come back, they are laughing. Lily leads Madhuri and Manisha by their hands to the back of the room. Leela leads Maya alongside them and directs the clients to stand in a row, which they do. Lily sorts Maya's shawl over her shoulder.

Leela and Lily start to demonstrate the exercises, Maya comes over to Leela lifting her arms as if to embrace Leela. Leela takes her hands and starts to move her arms up and down counting 1, 2, 3, 4. Lily is with Manisha, standing behind her and lifting her arms up and down, also counting in time with Leela. Madhuri is watching and also moving her arms up and down. Leela goes over to Madhuri and gives her

careful instructions for the exercises, Maya watches them. Lily and Leela both go to help Madhuri, both instructing Madhuri and demonstrating some arm exercises, still counting out loud. Maya sits down and watches them. Manisha is continuing with the exercises on her own. I go over to them and chat with Maya. Lily takes Manisha's hand, Leela takes Madhuri's and I take Maya's, we walk in pairs following each other and walk round the room chatting and giggling. This goes on for several minutes then we all stop together. [OBS 04-10 Feb 2002 TRIVANDRUM]

In the UK all the clients join in with the exercises sitting down which means everyone can take part in the same manner. This makes exercises inclusive although many could do the exercises standing up. In Jura the clients appear to enjoy the physical games they do and most take part with enthusiasm. In Iona the clients take part in the exercises in a similar way to Cochin and Trivandrum. A member of staff shouts out instructions and the clients reluctantly lift their legs and arms as instructed.

Iona, Cochin and Trivandrum all seem similar. Jura appears to be the only day centre where exercises have been interpreted in a manner to fit with the clients' perception of exercise. Certainly in Kerala the resulting activity does not fit with the local culture and does not make sense to either clients or staff. In Iona the staff appear to find the exercises suitable and continue with them despite the clients' apparent reluctance. In Kerala exercises are often done quickly. These exercises seem to represent an example where translation has not resulted in the activity being noticeably altered. There is no equivalent in Kerala and so the staff do not have an alternative form or translated form for exercises and so enact them in the manner in which they are done in the UK. The staff in Kerala have done little to translate this activity and get round this by undertaking it at speed so that neither they nor the

clients suffer too much! A more culturally appropriate alternative could perhaps have been found which the clients would feel comfortable taking part in.

## **Touch**

Another area of interest within the analysis was the physical interactions observed. In Kerala there are a lot of physical interactions between clients and staff and within these groups. There are no discernible taboos about touch as there were examples of touch between both sexes in both groups. Male clients would hold hands with each other and male staff members would touch female clients and so on. Four main purposes to touch were found: control by staff, helping by staff or clients, aggression by clients and 'gentle' touching by staff and clients.

Helping interactions usually involve a CGN touching a client on the hand or arm and assisting them to stand up, walk or get on and off the transport. Sometimes the CGNs put their arm around the client's back to give support or a firmer touch is used to help a client to stand up if they fall. On occasion clients hold hands or go arm in arm to give support to each other when walking. Control interactions usually involve a CGN using physical contact to control the behaviour of a client. These interactions may limit where the clients go or prevent or promote specific behaviours. The CGNs hold a client by the hand or put their arm around their shoulders to keep them in a particular area such as the day care room. This type of interaction is often very brief with the client led away from a doorway or gate and then left. On rare occasions clients are held with force and prevented from moving. Physical contact is also used to prevent behaviours such as undressing or aggression with the CGNs physically intervening. Behaviours such as eating, drinking or taking part in activities may be

controlled through physical interactions. Touch in these incidences is by the member of staff and is usually on the arms, hands or back of the client.

Malini walks near Raja and starts to rush at him moaning loudly and raising her arm. Raja reacts aggressively shouting and raising his hand. Malini hits him on the arm and he retaliates by striking out but missing. Soniya puts both her arms around Malini pinning her arms to her side and keeps a hold of her. Soniya walks backward pulling Malini with her. Shalini stands between Raja and Malini talking to Raja, telling him to calm down and scolding him for trying to hit Malini. Raja argues back for a minute. Soniya releases Malini and takes her hand. Raja strides off talking to himself. Sushmita, Shalini and Soniya all talk to Raja for a minute or so.

[OBS 21-28 Nov 2001 COCHIN]

This example of control also illustrates physical aggression by two clients. Physical aggression was observed with several clients and was directed both at staff and other clients. Both male and female clients displayed physical aggression and most incidences were associated with the client being prevented from going somewhere. Other incidences had no clear origin while some involved clients responding to teasing by staff members. Physical aggression was only observed at the Cochin centre and included slaps, thumps and pinches to the face of both staff and clients as well as slaps to staff member's arms. Staff responded to physical aggression usually by restraining the client or moving out of range if they were the targets of the aggression. These interactions were all brief. There appeared to be little anticipation of these behaviours by the staff. The example below describes a particularly extreme example of the CGNs controlling a client. This example also illustrates the natural reactions of the staff to the behaviour of the client. The staff do

not attempt to calm Mary down but in fact almost fight with her and then towards the end when they have secured the gate they leave her alone.

Unnoticed, Mary has walked over to the gate and has managed to open it and has just squeezed through the gap when Limy and Shalini notice. Limy grabs Mary's arm and physically pulls her back through the gate, Mary is holding on to the gate with her other hand and it swings open as Limy pulls her. Shalini pulls Mary's hand off the gate and closes it. Limy lets Mary go and Mary walks off in the direction of the side of the building. Limy and Shalini approach Mary who raises her hand, she is carrying a plastic bag with her tiffin box in it, Mary threatens to throw the bag at Limy. Limy jumps out of the way and the bag lands under a tree. Limy is shrieking at Mary to stop and sit down, Limy goes over and takes her arm bringing her over to a chair where Mary sits down. Mary reaches out and knocks over the chair next to her on which Limy had been sitting. Mary then gets up and goes into porch. Mary is over by the gate again and through it in a moment. Limy and Shalini rush over and take one of Mary's arms each and physically pull her back through the gate. Mary is shouting and pushing them away, she grabs the book from Limy and throws it onto the ground. Limy and Shalini release her and Mary sits down for a moment before going back to the gate. Shalini has secured the gate with some chain. Mary goes back and sits next to Limy.

[OBS 29Nov – 05 Dec 2001 COCHIN]

'Gentle' interactions describe incidences where touch is used gently: to reassure, to praise, to gain attention, to tease or to display affection. Gentle touch takes place between all groups and seems dependent on personality rather than any rules about social behaviour. Young men, such as the driver or the cook in Trivandrum, touch female clients on their face and neck with affection when talking to them. Male clients hold hands with female staff and may rub their back while chatting.

A CGN may sit holding hands with a female client as she is talking to another CGN. These interactions can be both brief and long lasting. Two individuals may hold hands for the duration of a conversation. The example below has two incidences of gentle interaction. The second is between a young man and a female client and occurs without any embarrassment despite it involving the young man dressing the client.

Lata is sitting again and Malini stands behind her, Lata reaches up and takes Malini's hands shaking them gently and rubbing her arms. Malini stands there for a couple of minutes before wandering off. Meena appears in the porch, she has taken off her half sari and folded it neatly and is carrying it over her shoulder. She is wearing her sari top and a white *mundu*. The driver walks up to her and grabs the half sari off her shoulder, Meena protests and the driver laughs. He unfolds the sari and shakes it out, he then throws it over her shoulder and in two quick motions wraps it round Meena and tucks it in as it should be. He then straightens the piece over her shoulder with a flourish. Meena hardly appears to respond to this performance and continues to quietly grumble, she wanders off. [OBS 15-20 Oct 2001 COCHIN]

The physical interactions at both centres in the UK were analysed in the same manner as those in Kerala. There were no incidences where a client was physically aggressive but a number of problematic physical interactions involving a male client, Neil, occurred. Neil touched female members of staff on their legs and bottoms and tried to touch their breasts. When such interactions took place most of the staff would tell Neil firmly to stop and then move away from him. The staff responded to Neil in a similar way to the staff described in Archibald's work on residential care (2002). The staff developed strategies to cope with his behaviour but in doing this Neil became 'labelled' and this may have further prompted his behaviour (Archibald 2002). Another client Grace spent a lot of time walking around the centre and often staff would



remove obstacles from Grace's path to allow her to continue to walk, such as opening doors. If Grace was prevented from moving around the staff felt she might become aggressive. The staff showed anticipation of this behaviour and took steps to avoid it.

Many clients in the UK have good physical ability and do not appear to require all the physical assistance that the staff give them. Interactions involving control and assistance in the UK are found to be difficult to analyse independently. There were numerous examples of physical interactions that involved a member of staff apparently helping a client. These included holding the client's arm to help them off the bus, putting an arm across the client's back to guide them into the dining room and placing their hands under a client's arms to help them up out of a chair. These interactions took place at all times of the day in both centres and involved both male and female staff and male and female clients. There were no apparent rules about who could touch and help whom, the only exception being Neil who was usually assisted by a male member of staff. There were few examples of physical interaction being obviously used to control a client.

The small number of control interactions in comparison with Kerala may also be due to differences in the client's abilities and behaviour. Perhaps it is that the clients in the UK have less problematic behaviour and thus require less control or perhaps it is that the day care centres in the UK provide care that reduces these behaviours. It is probably a combination of the two but staff interactions definitely effect the overall functioning of the day care.

It is clear that the staff controlled what took place at day care. The clients moved from sitting rooms to dining rooms when instructed and took part in activities as

they were organised for them. Apart from Grace none of the clients spent time outwith the main rooms of the day care centres or outwith the main groups of activities. This appears to be a result of two processes. On one hand the staff provide interesting activities for the clients and so they remain within these boundaries out of choice. On the other hand, by constantly offering clients things to do and encouraging them to take part in activities the staff maintain control of the clients. This is illustrated in group exercise games in Jura. These are easy to control and are used if there are staff shortages. In Iona some clients may not participate in an activity but remain in the same area as those who are participating. These clients are often prompted to take part in the activity when it seems clear they are not interested. This appears to be to maintain control of these clients.

Finally gentle interactions are again difficult to distinguish from helping and control interactions. An arm around a client's shoulder may help and guide them into the dining room while also offering reassurance and giving affection. There were some interactions that were obviously gentle and affectionate. At Jura there were several clients who lived alone and the female staff would hug and kiss them on the cheek before leaving them at home. One male member of staff in Iona would laugh and joke with female clients and may give them a kiss on the cheek as part of the interaction. This type of gentle physical interaction appeared to depend on the client and the staff only interacted in this way with a few specific clients. The clients themselves rarely touched each other although occasionally female clients might hold hands if walking together. One female client in Iona was the exception. She would often hold hands with other female clients and she would hug staff and on one occasion kissed a male client on the cheek. In Jura the staff often gave the clients manicures and hand massage and this involved gentle interaction for both. Very little

touch took place anywhere but hands, arms and upper back, just an occasional kiss to the cheek. Overall the physical interactions were very similar and did not divide easily into gentle, control and helping interactions.

The main difference between Kerala and the UK was in the ambiguity of the physical interactions in the UK. It was seldom clear what the real purpose of the interactions were. Some involved strategies by the staff to prevent other behaviours. Others were used to control the clients' movements. These control behaviours were subtle and hidden from the clients and often appeared to be affectionate, which they might also have been. There were many more physical interactions in Kerala outwith transfer times. For example CGNs and clients often hold hands as they chat. In the UK most physical interactions took place during transfer times to guide the clients around the centres. This would suggest the main purpose of touch was to control the clients' movements although the interactions would often be presented as helpful or affectionate.

These differences reflect cultural differences between the two contexts. From my experience in Kerala touch was much more common. Friends both male and female hold hands while talking. The staff often sort each other's clothes or hair and would straighten and rearrange my clothes when I was at day care. People generally live closer together in Kerala. Public transport is crowded and six or seven people squeeze on a bench designed for three on a train. This accounts for the higher number of interactions seen in Kerala. The clarity in purpose of physical interactions in Kerala again reflects the CGNs translation of their role. The ambiguity of physical interactions in the UK suggests they are performed as part of the role of a day care worker: to control, help and reassure. In Kerala the physical interactions reflect what

is taking place at any one time and again promote a natural environment. It appears that through their behaviours the CGNs are once again undertaking unplanned policy translation with the aim of domestication.

The above examples provide the detail to support the theoretical construction of policy translation and its explanatory power within comparative analysis of this kind. These examples of policy translation all fit with the local culture of Kerala and therefore illustrate unplanned policy translation with the aim of domestication. Having a cup of tea, reading the paper, rest and physical interactions all reflect the local culture. Staff and clients appear relaxed and engaged in day care during these periods and interactions. Day care during these times makes sense for the staff and clients in Kerala. Although some of the physical interactions in Kerala appear extreme and perhaps distressing for the clients and staff these interactions do not seem to bother either group in a way that might be expected. The clients get angry and agitated but do not seem surprised or upset when arguing with the staff. They are arguing or angry for a reason and would be confused if the staff did not respond appropriately. Some aspects of day care are not translated or their appropriateness becomes lost in the process such as the above examples of exercises and the blackboard game.

## **Conclusion**

This chapter comprises the second level of analysis of policy translation. It explores the behavioural component of translation. The Kerala day care staff are responsible for how day care is actually delivered to the clients and their behaviour shapes this. They translate into action the information and ideas given by their

managers regarding the functioning of day care. As the examples above illustrate, these translation processes are usually unplanned. The staff do not actively adapt aspects of day care. They simply enact them in a manner that makes sense to them. They have the aim of domestication. The CGNs are trying to make day care fit within their culture. I conclude that these translations often result in a day care service that makes sense to both staff and clients.

However, I found that some elements, such as the blackboard game, do not easily translate to something fitting with the culture of Kerala. In this example the staff alter the activity to fit with something they do understand, school. This does not fit with the clients who attend day care who do not appear to enjoy this activity. In comparison, teatimes are performed in such a way as to sit comfortably in the new context. The clients have their tea or lunch in a manner familiar and comfortable to them. The CGNs take on the service role that would be expected in their homes. Other aspects such as the exercises, described above, are examples of a situation where the transfer and translation processes have not resulted in a noticeable difference between the two contexts. The enactment of the exercises is similar in both contexts. The discussion of touch brings in more general issues regarding the transfer and translation of day care for people with dementia and in particular the role of the CGN or day care worker.

As with chapter 8, this chapter highlights the importance of the conceptualisation of dementia. This affects how the purpose of day care is understood and how the staff understand their roles at day care. An important difference was established within this chapter between the behaviour of the staff in the two contexts. The staff in the UK appear more self-aware or self-conscious in their

behaviour at day care. In Kerala the staff members' behaviour appears natural and responsive to what is actually taking place. I conclude that this difference reflects a difference in their understanding of their roles at day care and their conceptualisation of 'care'.

Chapter 10 draws together ideas from chapter 8 and 9 to look at the translation processes in a more general sense. It discusses the translation of concepts. The discussion within the chapter takes up the main points raised in these chapters. The translation processes are influenced by the 'culture of care' in each context through the behaviour of individuals and groups in each day centre. Thus the influence of culture is central to the translation processes and more so for unplanned policy translations. Chapters 8 and 9 suggest that the fundamental elements which have been translated are the concept of dementia, the concept of day care and the role of the CGN or day care worker. The translation of these is discussed and analysed in detail in the following chapter.

## **Chapter 10**

### **Translating day care for people with dementia**

#### **Introduction**

As concluded in the previous chapter there are three fundamental concepts that have been translated from the UK. These concepts shape how day care is enacted in Kerala. They are the conceptualisation of dementia, the role of a day care worker and the purpose of day care. This chapter draws together the data and analysis to investigate each of these concepts. The discussion leads to the development of a clear theoretical construct of policy translation and assesses its influence and importance in the development of day care for people with dementia in Kerala. The chapter starts by comparing the atmospheres at each of the four day centres. This gives an overview of how day care takes place in each location. The comparative analysis of the different atmospheres supports earlier conclusions about the process of policy translation and provides an introduction to the following analysis.

The conceptualisation of dementia by the day care staff affects how they 'care' for the clients and how they understand their own role. This understanding of

dementia can be linked to the models of dementia discussed in chapter 3. The conceptualisation of dementia also influences the purpose of day care as it is understood and enacted by the day care staff. This chapter provides the final level of analysis of policy translation and draws together the conclusions from preceding chapters to assess and develop the theoretical construct of policy translation.

## **Atmosphere and mood**

The overall atmosphere at Cochin is quiet and relaxed. Significant parts of the day are unstructured with the clients and staff passing time together chatting in groups, watching TV or moving around the room. The clients and staff interact in a relaxed way and the clients seldom become agitated. The clients move around the large day care room as they want, calling out to staff if they need help. The staff respond to any requests from the clients for help. The staff do prevent the clients from moving out of the main room. These interactions may result in raised voices and arguments in which both clients and staff take part. There is an air of normality at the centre and the staff do not often appear to consciously modify their interactions with the clients. This is a difference noted from the behaviour of staff in the UK.

The overall atmosphere at Trivandrum, like Cochin, is quiet and relaxed. The low number of people at the centre means that interactions are unhurried and relationships appear affectionate. A lot of time is spent chatting and passing time together watching TV or perhaps a squirrel in the garden. The cook and one of the residents from the old age home also pass time in the day centre chatting to and often joking with the day care clients. The clients display few signs of agitation. The one



client left towards the end of the day may become anxious to get home. There is a lot of laughter and again, like Cochin, the interactions appear natural and unaffected.

The overall atmosphere at Jura is cheerful and busy. The centre is often noisy as the staff maintain an almost constant conversation with the clients, asking lots of questions and encouraging the clients to chat to each other. The clients are usually cheerful and greet each other and the staff with affection. The clients display ownership towards the centre and a concern and interest in the others at the centre, particularly visitors and new clients. The staff appear to be fulfilling a role at the centre. They behave in a particular way with the clients. In interviews they talk about 'how to' interact with people with dementia. The staff were observed to frequently ask clients the same question from day to day despite obviously knowing the answer. Overall the atmosphere is relaxed. A relatively high number of staff means activities are flexible and rarely hurried.

The overall atmosphere at Iona is busy and organised. It is the biggest of the four day centres and this was reflected in the atmosphere there. It had the most organised routine to each day which was carefully planned each morning. The staff pre-planned what the clients would do and which clients would spend time together. This resulted in a slightly institutional feel with staff spending time discussing who should be where and when. The relatively high number of clients meant that a lot of time was spent transferring and organising the clients from room to room within the day centre. The staff also spent more time organising their own breaks and doing administrative work than in the other centres. During activities the staff would be busy encouraging the clients to take part and chatting with them to keep them engaged with

the activity. Like Jura, the staff behaved in a manner they thought appropriate with the clients.

The differences in the atmosphere at the four centres reflect the behaviour and mood of both clients and staff. In the UK the staff maintain control of the clients and their behaviour at day care. The staff do this through their interactions with the clients and through anticipation of the clients' needs and behaviour. The role of a day care worker is to meet the clients' needs and prevent them becoming agitated or upset. In Kerala the staff take a more passive, responsive role with the clients. They respond to a client's behaviour and apparent need rather than anticipating it. This alters the interactions between the clients and staff and the atmosphere of the day centres. In many ways the atmosphere in the Kerala day centres is calmer as the staff are not busy all the time ensuring the clients are busy. It also means, however, that at other times the atmosphere can become tense as staff and clients argue if, for example, a client becomes determined to leave the centre.

These differences reflect differences in the staff members' understanding of their roles and the staff members' attitudes and knowledge. The staff in the UK appear to have a more formal and apparent 'role' at day care while the staff in Kerala undertake a more responsive and less proactive or formalised 'role' within day care. The staff in the UK respond in particular ways to the clients. They maintain control of what the clients are doing by encouraging activities and promoting participation by all the clients. The UK staff talk to the clients in particular ways for example repeatedly asking them the same questions which the staff probably already know the answer to. The staff actively work to prevent the clients becoming agitated or bored. In comparison in Kerala the staff only actively promote activities first thing in the morning

and spend most of the day responding to the clients. The Kerala staff control the clients by arguing with them and physically preventing them from leaving the day care centre by bolting the doors. The staff talk to the clients in a natural and unpractised manner. These differences reflect differences in their understanding of dementia and care for people with dementia, their understanding of their roles and the purpose of day care. The following analysis looks in detail at these.

### **Translating dementia**

The concept of dementia is fundamental within this scenario. How the different individuals understand the concept of dementia affects their behaviour within the day care, especially when interacting with the clients. Information about dementia in Kerala has come from a variety of sources, both written and from individuals' experiences. There is a wealth of written information on dementia from books, journals and the Internet to which many of the individuals in Kerala have access. At Cochin there are many books on dementia from the UK and USA to which all staff had access. However, the CGNs were not able to read English and were dependent on the management staff to translate this information. The translation of 'dementia' takes place on a broader stage than that of day care and the role of a day care worker. More sources of information are available to more people.

When translating the concept of dementia the translators had choice about what information they translated and how they did this. The translation of dementia is not done in an unbiased manner. The perspective of the translator affects how this translation takes place. The specific word dementia was not translated. All the individuals within this research use it in its English form. As discussed in chapter 7

there are possible equivalent terms in *Malayalam* but they are not used. This suggests an aim of foreignisation by the translators. I think it is also related to the medicalisation of dementia and the biomedical model of dementia as discussed in chapter 3.

The key translators appear to have focused on the medical model of dementia rather than looking at more recent ideas about social models. Although Roy talks about the ARDSI being a carers' society there is still a strong influence apparent from the medical community. At a recent ARDSI conference titled 'Caring for the Caregiver' nearly every speaker was a doctor. Thomas, Rajesh and others interviewed say that this focus on the medical reflects the local culture. They explain that in Kerala there is a high regard for medical professionals and little regard for social professionals. The use of the biomedical model of dementia is reflected in the language used by the key actors and the staff of the ARDSI. The key actors and the staff at day care use particular English terms associated with the medical model of dementia. The most common and important being 'dementia patients' or just 'patients' to describe the clients. Some of the terms around the concept of dementia are also given in English particularly 'brain, brain cells, and symptoms.'

By using English words dementia may be seen as a more formal concept, a more medical concept. The use of the word 'patient' to describe the day care clients supports the idea that dementia is a disease and that people with dementia require some medical help or professional support. Using these terms may help to decrease the stigma associated with dementia and mental health problems in the local community in Kerala. The apparent resistance to social models of dementia may be to reduce the stigma surrounding dementia. A social model of dementia may actually

accentuate this stigma not just for the person with dementia but for their family too. By placing dementia within a social context might be to place blame for it on the family. As discussed in chapter 7, Cohen (1998) emphasises the need in India to stress the medical nature of dementia.

When asked directly the CGNs do not seem to have a clear concept of dementia. They do understand it has an effect on a person's memory and their ability to function on a day to day basis. Beyond that there is a great variation in how much each CGN understands about dementia and many appear confused about what it is. When asked to define dementia the CGNs give a range of answers. Some appeared to have learnt an English definition of dementia and they quoted this in English when the question was asked. When probed these CGNs would talk about dementia in a similar way to the other CGNs. This discussion focused on memory loss or in their terms: 'a decrease in memory power.' The CGNs talked about brain cells dying off and causing deficits in memory. The CGNs give a diverse and seldom overlapping range of causes of dementia including old age, meningitis, Alzheimer's disease, Pick's disease, Huntingdon's disease, head injury, alcoholism and stroke. This appears to reflect training or information about dementia from which only parts have been remembered.

When asking how they talk to other people about dementia it is possible to get a much clearer idea of how the CGNs conceptualise it. The CGNs describe dementia to people in the community as a disease that leads to brain cells dying and consequent changes in behaviour. Many of these are related to memory but others to simple daily activities such as preparing food and also to physical abilities such as continence and walking. This is a working definition with an important stress that

dementia is a disease. The CGNs also stress that people with dementia should not be blamed for their behaviour. Several of the CGNs talk about carers who felt the person with dementia was deliberately doing things to annoy them, such as telling their neighbours that they have not been fed.

When compared with how the staff in the UK conceptualise dementia there were similarities. The staff in both contexts appear confused about the exact definition of dementia. Both groups have had training on dementia and appear to have retained some of the facts from this training. Both groups of staff have similar working definitions of dementia which appear to be useful to them. The staff use these definitions when talking to carers and individuals in their local communities. The similarities between the two contexts may be related to how the idea of dementia is translated. There is a lot of information on dementia available from books and websites. This reduces the number of translation processes and therefore the influence of different translators as dementia is translated.

How the CGNs conceptualise dementia is further illustrated by examining how they discuss the day care clients. There is some confusion on the part of the CGNs as to which clients have dementia. However, there is a clear idea that the majority of clients do have dementia and the confusion may lie in what the different types of dementia may be. I am, therefore, going to relate what the CGNs say about the clients to how they understand dementia.

When talking about the clients the CGNs discuss a range of behaviours which are displayed by the clients and which relate to their conditions. The most common aspect discussed is memory loss, that the clients forget simple and important things.

There are two things that seem to be important to the CGNs: that the clients forget who their children are and that they forget they have eaten and demand more food. These two indicators are important in the affect they have on carers particularly the client's children and specifically their daughters in law. The daughter in law is expected to care for the older people in the family. It would reflect badly on her if her parents in law could not remember her name or if it was thought that she was not feeding them properly. The CGNs are nearly all daughters in law themselves and so this may reflect fears about their own lives. It may also reflect whom they are most likely to talk to among the carers of people with dementia, which would be the daughters in law. This illustrates how an individual's culture affects how they translate and conceptualise dementia. In comparison in the UK the main concerns of the staff are that people with dementia forget where they are or forget they have put a pan on the stove. These reflect the family structure and 'culture of care' for people with dementia in the UK. People with dementia in the UK are more likely to live alone and therefore issues of safety come to the fore.

Overall, looking back at chapters 8 and 9, it is possible to relate the differences seen between the two contexts in terms of the different models of dementia. The behaviour of the staff in the UK seems to indicate that they are using a social model of dementia. The staff appear aware that what they do affects the behaviour and mood of the clients. They realise the importance of social interaction. The staff alter their behaviour to help the clients take part in activities, conversation and to prevent the clients becoming agitated or upset. This results in an inclusive environment for the clients in which they are able to take an active part. It also means that the clients rarely become agitated or upset in any way. They also rarely appear bored.

In Kerala the staff approach the clients in a different way. There is less evidence to suggest that they alter their behaviour when interacting with the clients. They appear to approach the clients as they would any other older person. They appear affectionate and use terms of endearment when talking to the clients suggesting they see the clients in the same way as their own older relatives. Whether this means the Kerala staff are using the medical model of dementia is not clear. The language used by the staff in Kerala suggests the use of a medical model. They talk of the clients as patients and call themselves nurses. They do not, however, treat the clients as if they are unwell. The one thing they do stress is that the clients are blameless for their behaviour, that it is the result of a disease. The differences between the two contexts reflect a different understanding of dementia.

The above discussion supports a two stage process of policy translation. The key actors are instrumental in bringing the information about dementia to Kerala. They appear to undertake voluntary policy transfer as they pick and choose the model of dementia, which fits with their culture. There is little evidence that ideas about the social nature of dementia are transferred and translated. Their aim as translators seems to be that of foreignisation as they resist the local terminology and understanding of dementia in order to introduce a 'western' medical model and terminology. They do this, however, in a manner which fits with the local culture to some degree. The focus on the medical model may be to reduce the effect of the stigma about mental health problems in the local community.

The CGNs then conceptualise dementia in their own way introducing a second step to the translation process. The CGNs also adopt the western terminology for dementia and understand some important ideas from the medical model such as the



loss of memory and the fact that the clients are not to blame for their behaviour. The CGNs do not, however, appear to treat the clients as if they are unwell and they do not appear to 'nurse' them. The CGNs' conceptualisation of dementia affects their ability within their role and their understanding of day care.

### **Translating the purpose of day care**

Day care as a concept constitutes a range of practical components including staff structure, transport arrangements, the number and type of clients, the physical layout and the use of time each day. Each of these components is translated within this scenario. Some of these aspects such as transport and the physical structure of the building were discussed earlier within the discussion of planned policy translation. Other components such as the type and number of staff and clients were discussed in chapter 8 as were the use of time each day and the physical layout of the day care centres. To fully understand the translation process it is necessary to also look at the purpose of day care as conceptualised by the managers and staff and the understanding and reality of the role of day care worker or CGN.

The accepted purpose of day care in the UK is discussed in chapter 4. In summary, the purpose of day care is to provide for the social needs of the clients and to provide respite for carers. The way in which the CGNs and day care workers perceive the purpose of day care affects their behaviour within day care and consequently what the day care actually provides for the clients and carers. In Kerala the CGNs describe the purpose of day care as taking care of the clients and some CGNs also mention that it is for the carers, to give the carers relief. The CGNs also discuss research as a purpose of day care. The continuation of the day care in

Cochin is dependent on research funding. The CGNs seem to suggest that the day care centre is not simply there because there is a need for it external factors of funding and research are also important. The need and importance of day care is, however, illustrated in success stories told by the CGNs. Some clients are described as having improved in particular ways following attendance at day care. One man improved physically, one lady was incontinent less frequently and another became less aggressive and restless. The CGNs, like Roy, emphasise the need for day care despite evidence to the contrary.

Overall the CGNs discuss the purpose of day care in simple terms. I suggest that the simplicity of their answers reflects a lack of depth to their understanding of the purpose of day care. The interview and observation data suggest that for the clients the day care provides a sitting service during the daytime which gives respite to the carers. For many of the clients the atmosphere and activities at day care provide them with social interaction and activity that makes the day care a pleasant experience and fulfils their social needs. For other clients, particularly those who 'wander', the day care becomes a place they are kept in during the day. The understanding the CGNs have of purpose of day care limits the potential of day care for the clients.

In comparison the staff in the UK describe different aspects to the purpose of day care. The staff summarise that the day centre offers care and activity for the clients where they are safe. Several mention that coming to the day centre can also ensure a client maintains her independence for longer. The day centre is described as enriching the lives of the clients. Most staff mention a second purpose of respite for the carers. The staff in the UK clearly elucidate what they understand the purpose

of day care to be. In the UK the stress is on company for the clients. Many of the clients live alone and so company and also food is important. In Kerala none of the clients live alone, most live with family members and one lives with a servant. They do not, therefore, have the same need for social interaction. The purpose of day care in the two countries is different both due to the actions of the staff and the situations of the clients. The different cultures mean that the needs of the clients are different and this may explain the differences observed in the purpose of day care in the contexts. It is also possible that the translation of the purpose of day care, as undertaken by the CGNs, is incomplete. They do not appear to have a full understanding of the purpose of day care. Another argument may be that during the translation process they have domesticated the purpose of day care to fit with the local culture. I argue that the data suggest the former, as it is apparent at times in Cochin that the needs of the clients are not being met. This argument is continued below.

### **Translating the role of a day care worker**

The conceptualisation of the role of day care worker is evidenced in the language the day care workers use, what they say about their role, and in what they are observed to do at day care. By looking at each of these in turn it is possible to further elucidate the translation processes which have been undertaken between the UK and Kerala.

#### **Language**

In Kerala the CGNs use a lot of English words connected to their role. Dementia, as discussed above, is always referred to as 'dementia'. The CGNs also

refer to 'day care' in English although there is a local equivalent that translates as 'day time home'. Several words relating to their job are given in English such as 'caring, survey, field and caregivers'. Many of the day care activities are given English names 'ball-passing, seminars, exercise, newspaper, playing cards and Snakes and Ladders' despite there being local equivalents. In some cases the use of English may reflect the lack of a local equivalent but in others this is not the case. The apparent lack of translation for these words may be because the English word is more commonly used and understood. The English words may also give a more accurate description. The use of English terms may also add legitimacy and importance to their role. This may also reflect a process of foreignisation by which the CGNs maintain the 'western' appearance of the day care through the use of English words. This suggests that to some extent the CGNs share Roy's aim. They also gain status from working in a unique and 'western' style organisation.

It is interesting to compare the language used by the staff in the UK, specifically the jargon used. Some staff use jargon more than others and this possibly reflects a difference in the level of training they have received as well as their position and personality. The project co-ordinators and day care organisers at Iona were more likely to use jargon about their roles. Jargon includes words and phrases such as 'care package', 'challenging behaviour', 'mental stimulation' and 'distraction techniques.' There was a resistance by many of the staff to use particular terms such as old or older and an attitude that they are not politically correct terms. There seems to be a similarity in the way the staff in both contexts use language within their roles. In Kerala it is English and in the UK it is jargon that is used similarly within their normal language. Care working is not a highly respected profession in either context and so

the staff perhaps try to enhance their role by using specific terminology to add legitimacy and emphasise their expertise.

### Talking and Doing

The CGNs seem to find it difficult to summarise their duties and responsibilities when asked to describe them. Several talk through the day care timetable and list everything that they do in a day. Others just say very briefly that their responsibility is to take care of the clients. A couple of them are more sophisticated explaining that they do whatever the clients need them to do. Two also mention that they have a responsibility to the carers of the clients to keep them safe. A common opinion is that the most important aspect of the job is to keep the clients safe when they are at day care. The simplistic way in which the CGNs talk about their responsibilities may reflect a lack of depth to their understanding of what they are doing but may also indicate they do not view the job as complicated.

Three main components of the role are observed. Firstly guarding the clients, secondly personal care for the clients and thirdly helping the clients to take part in activities. The guardian aspects involve watching the clients and checking they do not go out of the given area for day care and using gentle physical contact to contain clients. The control aspect is emphasised by the CGNs as they state that keeping the clients safe is very important in their role. Personal care includes assisting clients to and from the toilet and helping with eating and drinking and with washing and dressing. The CGNs do not talk about these aspects of the job very often. It seems they find them a routine part of their role in taking care of the clients. At meal times the CGNs take a service role but this is not reflected in the manner in which they

discuss their role. The CGNs are observed to do this but do not discuss it as an aspect of their role. The CGNs describe their role in simple terms but are observed to do much more than they describe. The CGNs do not appear to conceptualise the different aspects of their role separately but incorporate them into 'caring for the clients.' I suggest that they do not think of many of the things that they do as work and therefore do not talk of them as such. This fits with the 'culture of care' in Kerala.

In the UK the staff also describe their role in simple terms but expand and emphasise different aspects of it. The staff emphasise their role in helping the clients during activities and the effect of activities for the clients. At Jura there is an emphasis on activities which help the clients to regain skills and which enable them to feel that they participate in the day care and are valued. In Iona there is an emphasis on 'mentally and physically stimulating' the clients through activities and interaction. The role of a day care worker is to facilitate these aims. This added complexity to the role is also reflected in how the staff conceptualise the clients.

The CGNs do not usually generalise about clients and often name specific clients when describing events. The CGNs do not see the clients as a homogeneous group; they see them as quite distinct individuals. The only way the clients may be grouped is by a particular behaviour, usually wandering behaviour. The CGNs describe the clients as different because they have dementia but rarely appear to alter their behaviour when interacting with the clients. The staff in the UK do generalise about the clients and talk about them in fairly general terms. They also state that people should behave differently when interacting with people with dementia. These differences imply that the staff in the UK conceptualise the clients as 'people with dementia' whereas in Kerala they are more often seen as individuals. Both groups of

staff, however, talk about having affection for the clients. In Kerala this is not seen as problematic but in the UK it is. The staff in the UK talk about maintaining a professional relationship with the clients. Some staff become more attached to the clients than they think they should. The CGNs do not appear to have translated the concept of a day care client to match that found in the UK. Again these differences reflect the different 'cultures of care.'

The CGNs refer to a degree of professionalism and expertise and talk about undergoing lengthy training to become a CGN. There is challenge to the role which they say they are able to meet because they have been trained to do it. Another indication of the CGNs expertise may be found in how they talk about teaching others about dementia. From experience in the community the CGNs talk about people having misguided ideas about what dementia is. The CGNs educate these people and tell them what they should be doing as they see themselves as experts. This perceived expertise slightly contradicts the above discussion as the CGNs do not seem to behave as experts at day care. The staff in the UK also perceive themselves as being expert in caring for people with dementia. They discuss strategies they use to interact with difficult clients and this is reflected in what was observed. In Kerala expertise may be of more value in the community. There is not much knowledge of dementia in the local community and so the CGNs are in a position to educate people about dementia.

The differences between the two contexts probably reflect an incomplete translation of the concept of day care by the CGNs in Kerala. The CGNs understand that they should keep the clients safe while at day care and understand that they should be given things they like to do. The CGNs do not appear to feel that their role

is to occupy and stimulate the clients during the day but mainly to keep them safe. The CGNs do not conceptualise other parts of day care such as teatimes, lunchtimes and time on the bus as activities. The CGNs also do not appear to conceptualise their interactions with clients as 'work'. In the UK the whole day at day care is controlled by the staff and conceptualised as 'day care', each aspect presented as an 'activity'. The focus on the family and extended family network of India and Kerala means that most people live with individuals of different ages. This cultural norm may explain why the CGNs interact naturally with the clients. The differences may also be due to the longer history of formal care for older people in the UK. The staff in the UK are used to the idea of social care. In Kerala medical care is well understood but ideas of social care are just developing.

Overall three main differences were found between the two contexts. These can be summarised as the use of strategies, anticipation and normalisation. In the UK the staff often use strategies to cope with difficult clients. They plan their interactions with clients and these strategies are known and used by all staff. For example, at one centre the staff organise the dining room and staff interaction at lunch times to try and minimise one client's disruptive behaviour. This type of strategy was not observed in Kerala. The staff there would respond to the behaviour of clients. If a client tries to leave the centre they prevent him from doing so by locking doors or holding on to his hand. The staff did not appear to anticipate these behaviours and did not plan strategies.

The staff in the UK anticipate the client's behaviour. Clients may be helped to the toilet before they ask and staff encourage clients to stay interested in different activities during the day. This displays anticipation of the clients' becoming bored and



restless and wanting to leave. On a couple of occasions when there was a period without activities clients did ask to leave. This suggests that the activities were usually successful in keeping the clients occupied. In Kerala clients were often observed becoming restless and making attempts to leave the centre. The staff did not appear to anticipate this behaviour. The clients were not kept busy for long periods in the day and as a result appeared to become bored and at times very difficult for the CGNs to manage.

Finally normalisation, as discussed in chapter 5, is quite a complex idea and the differences between the two contexts are not straightforward. In the UK there are apparent attempts to actively 'normalise' the situation at day care by increasing the clients' abilities to participate. Activities are altered so that all the clients can take part in them and specially designed activities are often used; such as giant dominoes and special quizzes. Teatimes, mealtimes and time spent on transport are presented as 'activities' by the staff. As described above, staff ask questions to which they know the answers to maintain and encourage conversation with the clients. This behaviour by the staff helps the clients to participate in day care. However, somewhat paradoxically it reduces the 'normality' of day care. Something as simple as having a cup of tea is altered by the staff to become an activity. In contrast in Kerala there are some activities designed just for day care but not many. During periods of rest and transfers there are many seemingly natural interactions between clients and staff. There is not a constant programme of organised activities and the clients and staff are given an opportunity to interact together in a more natural way. I would argue that by not fully understanding and translating the concept of day care the CGNs in Kerala promote a normal environment in which the clients are able to behave naturally. In

contrast with anticipation and use of strategies the staff in the UK promote an inclusive but specialised environment for the clients.

The CGNs do talk about behaving differently with people with dementia and the need to treat them differently but this is not seen in observation. I think that the CGNs are given a picture of what it means to be a day care worker but when they undertake the role a translation process takes place. When the CGNs act out the role they do so in a manner that makes sense to them. They do not alter aspects of day care, such as having a cup of tea, as it does not make sense to them to do this. This final process of translation, the act of being a CGN or day care worker has the aim of domestication. The CGNs enact day care in a manner that makes sense to them as illustrated in chapter 9 where specific aspects of day care were analysed comparatively.

## **Conclusion**

This chapter comprises the final level of analysis of policy translation, the conceptual level. I conclude that the differences in the mood and atmosphere at the day centres illustrate the differences in how fundamental concepts are understood. The differences in the mood and behaviour of the staff and clients reflects the conceptualisation of dementia, day care and the role of a day care worker or CGN. As found in chapter 9, the staff in the UK show more self-awareness of their behaviour and their role at day care. In Kerala the CGNs' behaviour is more natural.

I conclude that the process of translation of the concept of dementia is different from those of day care and the role of day care workers. As discussed there were

many books and other sources of information directly available in Kerala. In contrast the model of day care was based on information gained from visits to other services by the key actors and their conversations with individuals in the UK. The key actors controlled what was transferred and how the concepts of day care and dementia were translated as they passed this information to the CGNs. I have established that they focused on the medical model of dementia. It seems somewhat paradoxical that in many respects the key actors are found to look for up to date information on services for people with dementia but their conceptualisation of dementia is within the medical model. I conclude that this reflects the key actors' motivations to reduce the stigma associated with dementia within the community in Kerala. I further conclude that the conceptualisation of dementia by the CGNs reflects an incomplete understanding of the medical model of dementia. The CGNs know some important ideas about the medical model of dementia which they understand within their own cultural framework.

I conclude that the CGNs' understanding of 'day care' is also incomplete but does reflect an aim of domestication within the translation processes that have taken place. They appear to understand the purpose of day care as keeping the clients safe during the daytime to give their carers some respite. This reflects the local 'culture of care' in Kerala. Older people remain at home cared for by family members. It seems unlikely that they would be encouraged to take part in card games and quizzes but would in fact be involved in the ordinary household activities. In a similar way the CGNs domesticate the purpose of day care to fit with their culture. They spend time with the clients in a natural manner.

I conclude that these ideas are also reflected in the translation of the role of a day care worker. How the different staff conceptualise their role is reflected in the time

they spend undertaking the different aspects at day care. I have shown that in the UK much time is spent doing 'activities' but this is not seen in Kerala. I argue that this again reflects a process of domestication by the CGNs. They translate day care into something which they understand and which fits within their cultural framework. Their understanding also reflects their conceptualisation of dementia. In the UK the staff work within a social model of dementia. They believe that social interactions are important when working with people with dementia and so invest time and thought into these interactions. The CGNs do not have the same understanding and so continue to communicate with the clients in a natural and unselfconscious manner.

I conclude that the translations of the three fundamental concepts of dementia, day care and the role of a day care worker by the CGNs take place in a similar manner. The CGNs pursue an aim of domestication as they translate these concepts. They try to make sense of these concepts within their own cultural framework, within their own 'culture of care'.

## **Chapter 11**

### **Conclusion – the development of day care for people with dementia in Kerala**

#### **Introduction**

The central aim of the thesis was to develop theory on how social policy from one context is transferred and then utilised in the development of social policy and services in a new context. This has been achieved through the development of theory on the processes of policy transfer and policy translation. This thesis provides a case study with enough detail to fully explain this example of policy transfer and policy translation and also provide a framework for analysis which could be used elsewhere. This final chapter brings together the arguments and conclusions from the thesis. This chapter is split into four sections. The effectiveness of the research design is discussed drawing on reflections from the whole thesis. The research conclusions follow and are split between the two concepts of policy transfer and policy translation. Finally I place the thesis within a wider context to explore issues for further research.

The thesis is unusual for several reasons. Firstly, it is uncommon for policy studies to investigate the policy process from the initial identification of a problem through the policy development process and on to discuss implementation and enactment of policy. Secondly, it is unusual to undertake a comparative analysis between a more developed and a less developed context. In this thesis the comparison proved interesting due to the connection made through the policy transfer process. Thirdly, specifically thinking about studies of policy transfer, this research is unusual as it involves a less developed country within which there was little or no policy prior to the transfer process. This meant that the policy transfer process could be clearly elucidated as it did not become enmeshed within a process of ongoing policy development within Kerala. The involvement of a less developed country also meant that cultural influences became central to understanding the processes involved. I conclude that this thesis provides a framework for research on how social policy from one context is transferred and utilised in a second. Importantly it highlights the role of culture within the transfer and translation processes.

## **Issues of method**

The ethnographic approach enabled a detailed exploration of policy implementation through the different stages of this process. The semi-structured interviews with the key actors in Kerala provided enough detail to fully explain the process of policy transfer within the analytical framework developed here. I have shown that the semi-structured interviews with staff members and the observation were effective in developing case studies of the four day centres. The systematic data collection methods aided the comparative analysis within the thesis. The approach has suggested some ways of addressing cross-national comparative research. The

'safari' method was found to be an effective approach for research of this scope. I undertook data collection in both contexts and this greatly enhanced my data and subsequent analysis. My experience of data collection in Kerala taught me important lessons which enhanced my data collection in the UK. Working in a different culture highlights the importance of the impact of the researcher within data collection and issues of power and ethnicity within research. I conclude that the approach taken here could be used in other comparative ethnographic research.

### **The process of policy transfer**

I have established that the theoretical construct of policy transfer is fundamental in explaining the movement of ideas and information between the UK and Kerala, which led to the development of day care for people with dementia in Kerala. The process of policy transfer is evident from interview data and from the structure and functioning of the day care services in Kerala. I conclude, therefore, that policy transfer took place within the development of day care for people with dementia in Kerala. Theory on policy transfer helped to explain what was observed within the data. The models of Dolowitz (2000) and Evans and Davies (1999) provide a theoretical basis from which the policy transfer process can be explained.

I conclude that the analytical framework of policy transfer developed within this research provides a useful tool for describing and explaining the process of policy transfer. The eight questions in the framework provide a method by which the data are analysed and explained. Within the thesis I have used this framework to further develop theory about policy transfer. The existing literature on policy transfer provided the background to this framework and through this research the concept of policy

transfer is more clearly defined. I conclude that the analytical framework used in this thesis does provide a framework within which policy transfer can be fully explained.

The following discussion explores the specific conclusions drawn from the use of the analytical framework of policy transfer. This example fits with Evans and Davies' definition of policy transfer as an 'action orientated intentional activity' (1999:367). I conclude that in this thesis the process of policy transfer was voluntary. The transfer took place because the key actors involved were motivated to search for information in other countries. Their personal motivations coupled with their perceived need for information led to the process of policy transfer. In the existing literature on policy transfer there is the suggestion that policy transfer is often a coercive process either driven by external pressure or by an internal desire to compete with similar countries. Much research on policy transfer has taken place between more developed countries. Transfer between EU countries or between the UK and the USA or Australia may appear to be voluntary but is often due to political or economic pressures. The example within this thesis is different. The key actors were within a less developed country and were under little apparent pressure to develop the policy and services described here. There was little evidence of coercion but the key actors did feel a motivation for their services to be like services in 'the west'. It seems probable that policy transfer between less developed and more developed countries will be different in nature to that between countries with a similar level of development.

Roy had a freedom whereby he could pick and choose the policy ideas and services that he thought would be best or that he himself wanted to transfer. This is due to the fact that the context into which the transfer took place was 'empty'. That is to say there was no equivalent policy or services in Kerala prior to the transfer



**process.** This meant that the policy could be transferred and placed within the new context with the adaptations and changes described within the thesis. Much of the complexity of policy transfer studies (e.g. Jacobs and Barnett 2001) results from the existing policy complexity in the target context. In this case the policy complexity was missing. Instead I conclude that the complexity in the transfer process was due to the cultural differences between the contexts. I have shown the influence of culture was strong both on the transfer process and the subsequent implementation process. Culture influenced the direction of the policy transfer search and the type of policy, services and practice that was transferred. I conclude, therefore, that this example of policy transfer was in some ways easier to explain due to the lack of policy within the target context. However, the differences in culture between the two contexts added a subtle complexity to the process. This type of research highlights the importance of culture within studies of policy transfer.

I found that a relatively small number of people were involved in the policy transfer process in Kerala. One individual, Roy, initially drove the policy transfer process. He then encouraged others to seek information and to visit other countries to gain ideas and information. Roy acted as both the 'agent of transfer' and the 'client of transfer' (Evans and Davies 1999:367). I found that 'dementia' was not widely regarded as a problem in Kerala. It had only come to the attention of a small number of people who had become aware of it through their own personal experiences such as Roy and Meera in this thesis. If awareness of dementia had been higher across India I expect more individuals would have been involved.

In the thesis I have shown that policy transfer is not a discrete process but continues over time and involves different people at different times. In this thesis the

development of the ARDSI involved policy transfer. This continued over time and led to the development of the day care centres in Kerala. The question of timing is raised within existing policy transfer literature but often to suggest that transfer takes place at one point in time. It is found here that particular events triggered the process of policy transfer. The illness of Roy's father initiated Roy's participation in the policy transfer process. The transfer process continues from that point over time. The day centres are continually being updated as more ideas and information become available. I conclude that policy transfer is rarely a discrete event but instead a process that continues and develops over time. Freeman (2003c) describes policy learning as an ongoing process whereby individual policy makers continually learn from each other. People do not learn in discrete intervals about specific subjects but instead absorb information and develop their knowledge over time (Freeman 2003c).

I also established that policy transfer continues within one context as ideas spread. In this thesis the initial policy transfer took place from the UK to Kerala. I found that the information was then transferred around Kerala and across India. Roy initiated a 'policy bagatelle' (Freeman 2003b:2). I would describe Roy as a policy entrepreneur (Dolowitz 2000). He brought the policy ideas and information to Kerala and was then able to disseminate this information around Kerala and India where previously it had not been available. In fact much of the information would have been available to anyone with Internet access. However, people did not apparently look for the information. Roy's real role appears to be in raising awareness of 'dementia'. Cohen (1998) talks of Alzheimer's being seen as a western disease, which has been brought to India and which is new to India. In fact from the data within this thesis and from previous research (e.g. Shaji et al 1996) it seems clear that dementia did exist in Kerala prior to the policy transfer. The difference is that it was not conceptualised as

such. I conclude that the concept of dementia within a western, medical cultural framework has been transferred to Kerala. This conceptualisation of dementia is then perpetuated within Kerala and India as Roy and his colleagues spread their ideas to other parts of the country.

I found that the concept of policy transfer was able to explain some of the observed differences between the day centres in the two contexts. Within the discussion of the degree of policy transfer I established how the key actors adapted what they transferred. However, I argue that the concept of policy transfer is not sufficient to explain the process of development and implementation observed. The concept is limited in its ability to explain the process of policy implementation and the changes and adaptations observed within this process. The limits to the theoretical construct of policy transfer became apparent during the planning of the research and were confirmed during the data analysis. I conclude that the development of day care in Kerala was more complex than the analytical model of policy transfer could describe or explain. The literature around the concept of policy transfer tends to be mechanistic. It ignores the subtlety of the processes involved and the influence of culture through the actions of individuals and groups involved. I argue that many of the differences found between the day centres in the two contexts are related to these cultural differences. I further argue that the theoretical construct of policy translation can be used to build up the discussion of the development of day care for people with dementia in Kerala. It explains aspects of both the transfer and implementation processes and introduces 'culture' into the analysis. I conclude that the theoretical construction of policy transfer and the analytical framework developed within this thesis are useful and have explanatory power. They help to explain the data observed and add important detail to the explanation. I further conclude, however, that there

are limits to the theoretical construct of policy transfer particularly with regard to explaining the policy implementation process.

### **The process of policy translation**

I argue that literary translation provides a useful analogy for the development of the concept of policy translation. I have shown that ideas relevant to the translation of a piece of text from one language to another can be adapted to explain the translation of policy from one culture to another. The concepts of domestication and foreignisation were developed from theory on literary translation and I have shown that these were useful within the analysis. I argue that these concepts deepen the understanding of the development of day care in Kerala beyond the explanation given by the concept of policy transfer.

I found that policy translation is a useful concept to describe and explain the process of day care development observed in Kerala. The process of transfer and the following process of implementation after the policy that is being transferred. I have established that these alterations are the result of translation processes. Each stage in the transfer and implementation processes involves communication. It is within these communication processes that translation takes place. Culture influences the communication processes through the behaviour of groups and individuals. I conclude that the process of policy translation is fundamental in determining what is actually delivered as day care to the users of the service and that culture is an important influence on the policy translation process.

I found that different individuals act as policy translators at different stages in the transfer and implementation processes. In this research there were two main stages of policy translation. Firstly the key actors translated information from the UK as they transferred it to Kerala. Secondly, this information was communicated by the key actors to the managers and staff of the day centres. I argue that the result of this second stage of translation is evident in the behaviour of these individuals as they enact day care. The staff translate what they have been told into their own knowledge about dementia and day care. They do this from their own cultural perspective. This knowledge then influences their behaviour at day care. I have established how the individuals involved in these two stages of translation act as translators. All translators act within their own cultural framework and, therefore, culture influences the policy translation processes. I conclude that the 'cultures of care' in each context frame the day care centres and influence the process of policy translation.

I found that different groups of translators and different individual translators have different aims. These different aims affect the appearance, effectiveness and appropriateness of the resulting service. Two different aims of translators are described as foreignisation and domestication. In this research I established that in general the key actors had the aim of foreignisation. They wished the information they translated to retain something of the culture from which it had come. The key actors showed deference to and respect for 'the west' and tried to preserve the 'western' appearance of day care. Many of the changes made by the key actors were deliberate adaptations to the policy, that is they were examples of planned policy translation. The main reason for these adaptations was limited financial resources and they were undertaken with reluctance. The key actors appeared motivated to develop services, which fitted with their image of services in 'the west'. The idea that

'west is best' is also apparent in the translation of 'dementia.' The western, medical model of dementia is barely translated as it is transferred. The solutions to 'dementia' are also transferred in the form of allopathic medicine and, as in this thesis, western style services. I found that the view that 'west is best' led to the key actors taking little account of the 'culture of care' in Kerala.

As demographic changes alter the 'culture of care' in Kerala it is possible that it is becoming more akin to the 'culture of care' in the UK. Small families, fewer informal carers and, for some, financial resources to pay for care are all characteristics more akin to the 'culture of care' in the UK. If the key actors in Kerala believe this to be the case this provides one explanation of their actions. They perceive a need for 'western' ideas to cope with their 'western' problems. I found, however, little current need for day care in Kerala and therefore conclude that as well as a perceived or predicted need for day care the key actors were motivated by personal issues. I conclude that the prestige of having a unique 'western' style day care was as important for the key actors as any perceived need for day care in the local community hence the aim of foreignisation.

In contrast I found that the staff had the aim of domestication when acting as translators. It is the staff who deliver the day care service to the clients and carers. It is the staff, therefore, who influence what the day care actually is. The CGNs enact the transferred and translated policy. The CGNs translated many aspects of the day care into something which they and the clients understood. I argue that they are trying to make day care fit within their culture. I established that the staff in Kerala do not often actively adapt aspects of day care. They simply enact them in a manner that makes sense to them. They undertake unplanned policy translation. The CGNs'

**translation of many of the aspects of day care results in a day care service that on the whole makes sense to both staff and clients.**

**Central to the thesis is how the CGNs translate and subsequently understand important concepts. These concepts are 'dementia', 'day care' and the 'role' of a day care worker. I have established that the CGNs adopt a medical model of dementia in the language they use to talk about dementia. The use of medical language is important to reduce the stigma associated with mental health problems in the local community. The medical model is not apparent, however, in how they interact with the people with dementia at day care. Their translation of the concept of day care and their role at day care has taken place with the aim of domestication. I argue that this makes their conceptualisation of dementia more complex than simply transferring the medical model of dementia from the UK. How the CGNs interact with the clients and fulfil their role at day care suggest that they do not conceptualise dementia as a medical condition. Their understanding of dementia results in a relaxed and 'normal' atmosphere at the day centres in Kerala and the clients are treated as individuals rather than as 'people with dementia.'**

**Specific examples within the analysis have highlighted the complexity of the processes involved and the variety of ways in which transfer and translation can take place. The example of the blackboard game illustrates how the translation process can result in unexpected and inappropriate outcomes. The analysis illustrates the strength of the concept of policy translation. It is able to aid the understanding of complex situations.**

I argue that policy translation is not just about language. I have established that language is an important aspect of the translation process but I argue that it is about more than language. Behaviour and understanding are also translated. I conclude that policy translation has greatly enhanced the understanding of the development of day care for people with dementia in Kerala. It complements the analysis of policy transfer but moves on from this to give a deeper understanding of what took place. As with policy transfer I conclude that my theoretical construction of policy translation has explanatory power and could be used in different research situations.

### **Issues for further research**

This thesis is framed within globalisation. Policy transfer and policy translation are relevant within the process of globalisation. They can be used to understand and explore changes which are taking place across the world. This thesis offers a method of investigating how social globalisation takes place. To further investigate and understand the processes of globalisation this thesis could be used as a template to investigate similar service developments around the world. Globalisation is becoming increasingly influential on how social policy develops. The use of the theoretical constructs of policy transfer and policy translation could offer useful routes for exploring and explaining the changes collectively referred to as globalisation.

An issue raised within the thesis was that of policy transfer and translation between developmentally similar or dissimilar countries. I propose that transfer and translation will be different in nature when they take place between a less developed and a more developed country than when between two more developed countries.



**These** differences may relate to global power structures and be influenced by economic and social globalisation. Research on this would further develop the theoretical constructs of policy transfer and policy translation.

The changes brought about by policy transfer and related processes may lead to policy in different countries becoming more similar. This process is described as policy convergence (Bennett 1991; Pollitt 2001). Policy transfer may be described as a mechanism of convergence. It would be of interest to explore whether the example within this thesis is part of a wider pattern of change. To establish this it would be necessary to undertake similar research in a range of locations. The framework of globalisation suggests the development of policy and services here may well represent a convergent solution.

Another route to develop this thesis further is to revisit Kerala and look again at the services there. By assessing the success of day care in Kerala in meeting local need it would be possible to further the analysis of policy transfer and policy translation. By assessing the success of day care it is possible to assess the success of the policy transfer and policy translation processes. Within the framework of globalisation policy makers around the world are looking to other countries for ideas and information. This research would provide useful information for policy makers on whether policy transfer and policy translation are good routes for developing new policy.

A final issue for research is to concentrate on the concept of dementia and look at how it is translated into different cultures. This could be described as a study of 'cultural' globalisation. The two types of model of dementia discussed within this

thesis already provide two approaches to dementia. They result in different approaches to providing care and services for people with dementia. Then, within this thesis, a third conceptualisation of dementia is found. How these models are adopted in different cultures and how they combine with local ideas about ageing and dementia leads to very different conceptualisations of dementia. The cultural assimilation of 'dementia' into different contexts may reflect whether or not cultures are becoming more similar.

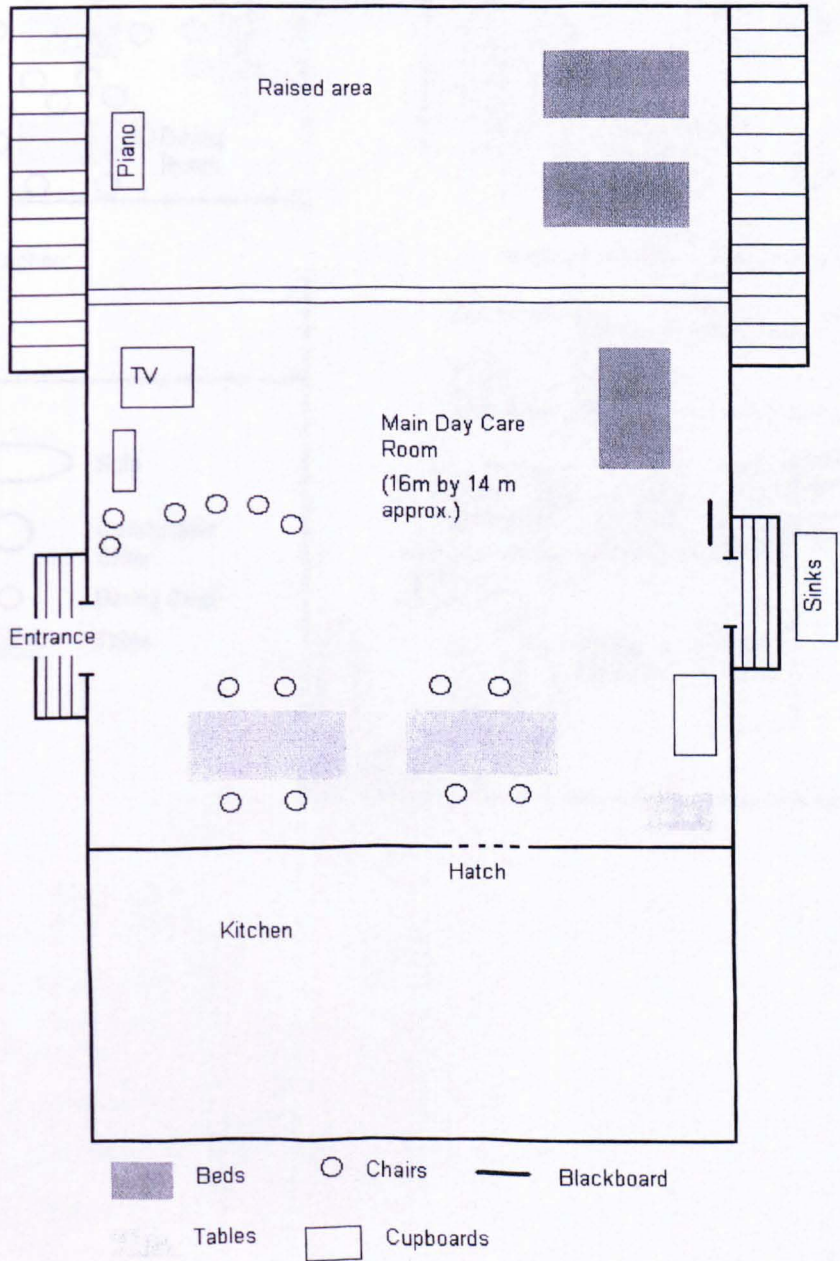
## **To conclude**

The thesis describes a process by which new services are developed in a less developed country. An important aspect of these services is that they are 'western' in appearance. Globalisation is often described as a process by which things are becoming more similar across the world. These services could, therefore, be described as a result of globalisation. I conclude that policy transfer and policy translation can, therefore, be described as mechanisms by which globalisation takes place. Within this thesis I conclude, however, that through the process of policy translation with the aim of domestication individuals in the target context slow or disrupt the process of globalisation. Things may not be getting as similar as they seem.

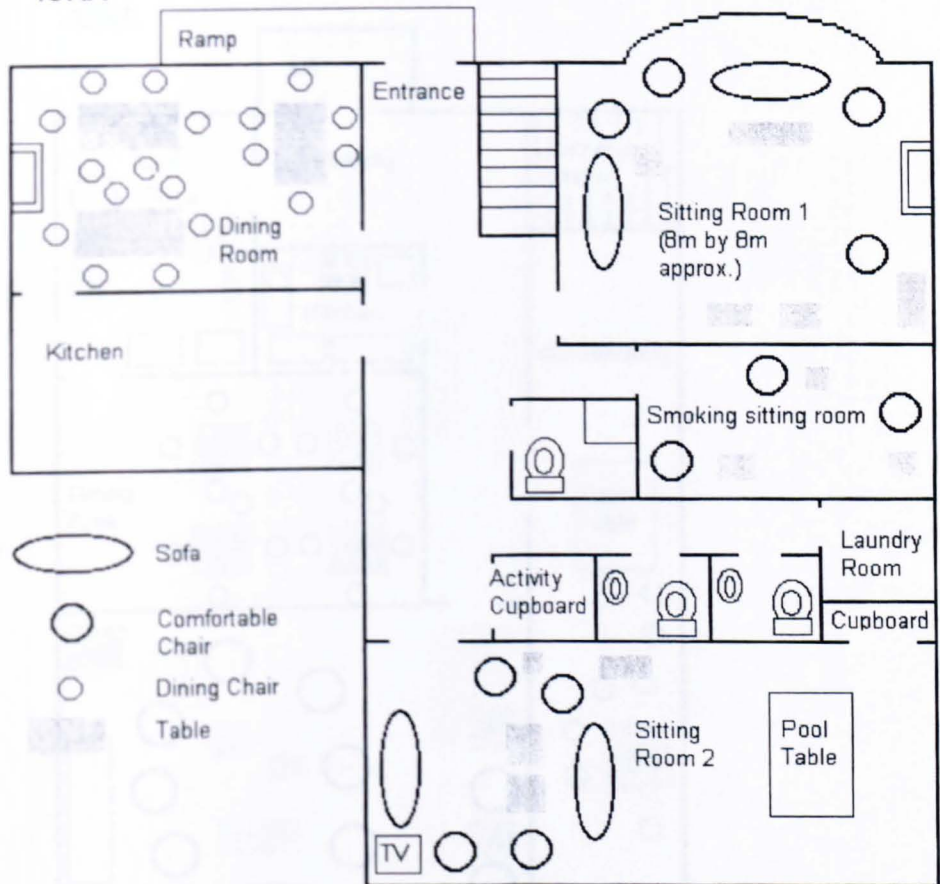
## **Appendix A - Floor plans of the four day centres**

# TRIVANDRUM

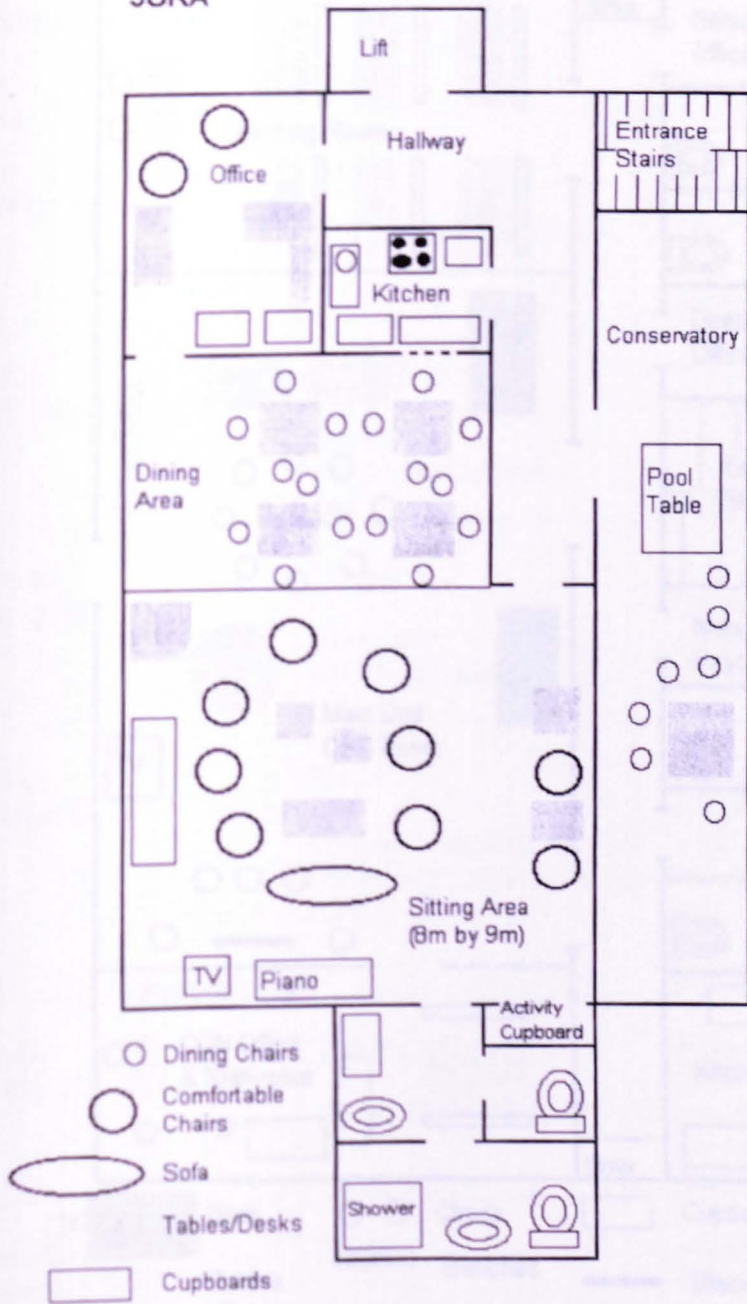
Toilets below raised area, accessed by stairs at sides of building



IONA



JURA





## Appendix B - Key actors and staff in Kerala

Name (changed or not)	Location and Post Title	Description
Roy (unchanged)	Kerala Chairman of the ARDSI	<i>Roy has been the chairman of the ARDSI since it was established in 1992. He plays an active role in the ongoing development of services.</i>
Meera (unchanged)	Trivandrum Secretary Trivandrum chapter	<i>Meera was involved in the establishment of the day care centre in Trivandrum and is effectively the manager of the centre.</i>
Thomas (changed)	Kerala Secretary ARDSI Chapter	<i>Thomas is involved with the development of services for another chapter of the ARDSI. He was named by Roy as a key actor in the future of the ARDSI.</i>
Mohan (changed)	Kerala Former member of the Governing Board of the ARDSI	<i>Mohan was involved in the establishment of the ARDSI in 1992. He helped to write the constitution for the organisation and with the initial planning of services. His involvement stopped around 1996.</i>
Rajesh (changed)	Cochin Senior Project Officer	<i>Rajesh has worked for the ARDSI since 1992 and has been involved in the development of services. During this research he managed the Cochin day centre.</i>
Ananthan (changed)	Cochin Psychiatrist (part-time)	<i>Ananthan has worked for the ARDSI since 1992 and has been involved with research and the development of services. He works part time at the Cochin day centre offering advice to the staff there.</i>



<p><b>Usha (changed)</b></p>	<p>Cochin  Psychologist</p>	<p><i>Usha has worked for the ARDSI since 1999 and works mainly in the 'Memory Clinic' of the ARDSI. She provides advice and support for the staff at the day centre on a part time basis.</i></p>
<p><b>Mary (changed)</b></p>	<p>Cochin  Tutor on Community Geriatric Nursing course</p>	<p><i>Mary worked for the ARDSI from 1997. During this research she worked part time in the day centre offering support and advice to the CGNs.</i></p>
<p><b>District Social Welfare Officer</b></p>	<p>Cochin</p>	<p><i>The District Social Welfare Officer is a local government post covering the Ernakulam district, which includes the area where the Cochin day centre is situated. The DSWO is involved in planning and commissioning social services within this area.</i></p>
<p><b>Secretary Department of Social Welfare, State Government of Kerala</b></p>	<p>Kerala</p>	<p><i>The Secretary works with the Minister for Social Welfare, State Government of Kerala.</i></p>

## **Appendix C - Interview schedules**

- **Key Actor, Kerala - Interview Schedule**
- **Community geriatric Nurses in Kerala – Interview Schedule**
- **Day Care Staff in the UK - Interview Schedule**

### **Key Actor, Kerala**

This interview schedule was tailored for each interview as each key actor had a different role; notes are made on the schedule to illustrate these adaptations.

#### **Section1. – Older People in Kerala**

How would you define or describe an older person?  
(characteristics, age, life stage, male vs. female)

Do older men and women fulfil certain roles within life in Kerala?  
(family/social/religion)

Where do older people around here generally live?  
(family, with spouse, alone)

What are the main reasons for this?  
(tradition/culture/practical)

Where do the older people in your family live?

What are the reasons for this?

Does your local culture/tradition/religion offer guidelines regarding care for older people?

What problems do older people in Kerala face?

What local or central government policy is there for older people? (health, social, welfare)

What services and/or facilities are there for older people?

#### **Section 2.**

What do you understand by the term dementia?

Who does it affect?

What causes dementia?

Would you say you were knowledgeable about dementia?

Where did your knowledge come from?

What are the consequences of dementia for carers and family?

What are the consequences of dementia for people with dementia in Kerala?

Will people with dementia be included in services for older people?

*(I had planned to ask about services and policy but it became clear that this was covered in the previous section)*

What is the general understanding of dementia in Kerala?

Is there an equivalent term for dementia in Malayalam?

How do you talk about dementia to someone in the community who may not be familiar with the word 'dementia'?

Are people familiar with the symptoms of dementia?

*(The interview then splits into two main groups:*

- 1. Key actors still working for the ARDSI within the Cochin day centre*
- 2. Key actors involved in the work, either now or previously, of the ARDSI but not paid staff.)*

### **Section 3.**

#### **Group 1.**

*(Ananthan, Rajesh, Mary and Usha. Meera was also included in Group 1 with the questions directed to the development and functioning of the Trivandrum day centre)*

Could you give me some background information about you and how you came to work for the ARDSI?

Job title and description, any changes since working for the ARDSI?

What is your involvement in day care?

Who is your boss?

What are the most important aspects of your job?

What are your motivations for doing this job?

Tell me about the development of the Cochin day centre?

What are its objectives and purpose?

Why was it set up?

How was it set up?  
(information/ideas)

Why day care?

Who was involved?  
(other organisation/individuals)

Where did the ideas and information come from to develop the day centre?

Tell me what happens in day care?  
(activities/timetable/identification of clients/referrals)

How do the local community and the local press respond to the day care?

How are the services in Cochin linked with other organisation?

Do you personally have links with other individuals or organisations inside or outside Kerala?

#### *Section 4*

When was the ARDSI established?

Tell me what you know about the establishment of the ARDSI.

Where there specific events that influenced it's development?

What other organisations and individuals were key in its establishment?  
Are these local or international?

What was the motivation to develop the ARDSI?

What is the aim of the ARDSI?

How were you involved in the development?

#### **Group 2.**

*(This group consists of three individuals (Roy, Thomas and Mohan) all with different roles within the ARDSI and their schedules were designed accordingly. Roy is the Chairman of the ARDSI and actively involved in the establishment of the ARDSI and its development. His interview was lengthy and fairly unstructured as I was looking for as much information as possible about the beginnings of the ARDSI and the subsequent development of day care. Mathew works within one chapter of the ARDSI and was asked more general questions about the ARDSI and the development of the chapter he was involved with, the Kottayam Chapter. Mohan was involved with the establishment of the ARDSI and remained active within the organisation until 1996. Mohan is hearing impaired and the interview was conducted by me writing questions*

down which he answered. I kept the schedule unstructured allowing Mohan to talk at length.)

## **CGN Interviews**

*(Similar interview schedules were used in the two contexts to interview the day care staff in their work experiences and their understanding of ageing and dementia. The Kerala schedule is written in such a way as to illustrate the structure and terminology used in the local language. These interviews were conducted with an interpreter who used the English version of the schedule to conduct each interview. Comparison of the schedules for Kerala and the UK illustrates the differences between the two contexts. There was little need to make major changes to the schedules, the experiences and attitudes in the two contexts shared many similarities.)*

### **Interviews with the Community Geriatric Nurses in Kerala.**

(xxxx – indicates a break during which the interpreter undertook translation of the preceding dialogue.)

#### **Section 1.**

1. How would you define or describe an older person?

2. What are the roles of older people in Kerala?  
(family life, social life, male/female differences)

xxxx

3. Where do older people in Kerala generally live?

Who do they live with?

What are the reasons for this?  
(tradition/culture/practical/financial)

4. Who are all living with you?

Where are your parents or husband's parents?

What are the reasons for this?

xxxx

5. What problems do older people in Kerala face?

6. What are the day to day activities of older people in Kerala?

xxxx

7. What are the government policies for people in Kerala?

What services are available for older people?

XXXX

## Section 2.

8. a) Why did you chose this job?

- other options
- motivations
- what training?

8. b) What are your duties and responsibilities?

- enjoyable
- difficult
- dislike
- important

XXXX

9. How do you plan a day at day care?

What are the different activities?

Why do you do different activities?

Which are popular and with whom?

XXXX

10. Which clients are difficult and why?

What are your options to help?

What is being done?

11. What is your personal input?

What are the responsibilities of the leader?

Where do you go for advice and help?

XXXX

12. What are your relationships with your clients and their family members?

Do you interact with them for special cases?

XXXX

What are the main motivation factors in your job?

- growth prospects
- salary
- job satisfaction

XXXX

## Section III

14. What is the purpose of this day care centre?

15. What is different about this day care centre and other day care centres in Cochin/India/Other countries?

xxxx

16. Why is this centre called a 'dementia centre'?

What is dementia?

In India?

In Western countries?

What causes dementia?

xxxx

17. Who are the dementia cases in your centre and why are they listed as dementia?

18. What are the consequences of dementia and the attitudes of the family members?

xxxx

19. How do you communicate to people in the community about dementia?

What is the terminology in Malayalam for dementia?

## **UK staff interviews**

### Section I

1. How would you define or describe an older person?

2. What are the roles of older people in the UK?  
(family, social, male/female)

What are the day to day activities of older people in the UK?

3. Where do older people live?

Who do they live with?

Why is that the case?

(own experience)

4. Who do you live with?

Where are the older people in your family?

5. What problems do older people in the UK face?

## **Section II**

6. Why did you choose this job?

What did you do before?

Other options?

Training specific to this job?

Motivations - promotion prospects

Salary

Job satisfaction

7. What are your duties and responsibilities?

What is - Enjoyable – about your job?

Difficult

Dislike

Important

8. How do you plan a day at day care?

Why do you do activities?

Which are popular and with whom?

9. Which clients are difficult and why?

What is being done?

10. What is your personal input in day care?

Who do you go to for advice and help?

Who is your boss?

11. What are your relationships with the clients and their relatives and carers?

## **Section III**

12. What is the purpose of this day care centre?

What is different about this centre, do you know about other centres?

13. What is dementia?

14. Who here has dementia?

How do you know that?

15. What are the consequences of dementia both for the person with dementia and their family and carers?

16. Is dementia recognised in the community?

How is dementia understood?



## Appendix D - Staff and clients from the four day centres

	Cochin	Trivandrum	Jura	Iona
<b>Cost to clients</b>	0 – 1500 rupees per month (0 - £20)	35 rupees per day for lunch and travel (50p)	£1.50 per day for food	£2.00 for food and £1.00 for travel per day
<b>Staff title</b>	Community geriatric nurses	No official title	Day care organisers and day care workers	Day care organisers and day care workers
<b>Age of staff</b>	24 – 36	38 – 48	47 – 67	31 – 63
<b>Staff sex</b>	All female except driver	All female	All female except driver	Day care workers both male and female, driver male and day care organisers female
<b>No. of care staff each day</b>	3 or 4 and the driver	2	2 plus 2 students	3 plus 2 students or volunteers
<b>Staff education and training</b>	Basic school plus one year CGN training course	Older member of staff is qualified nurse, other has basic education	Basic school education plus some unrelated qualifications and AS-AD training	Basic school education plus some staff have SVQ Level II and others have unrelated qualifications and AS-AD training
<b>Age of clients</b>	63 – 86	78 – 90	67 – 99	61 – 92
<b>Sex ratio of clients</b>	2 men to 1 woman	1 man to 3 women	1 man to 5 women	4 men to 5 women
<b>Average no. of days each client attends</b>	6	5	3	3
<b>No. of clients each day (capacity)</b>	7 – 10 (15)	4 (N/A)	8 (8)	12 (12)

## Appendix E - Details on research methods

### Observation

At each fieldsite observation was carried out in two-hour blocks spread over all times of day that the day centres operated. These times are given below and indicate the time period during which I undertook observation. In Kerala I was not able to observe all the transport, at Trivandrum as clients were brought in taxis and rickshaws without space for me and in Cochin I was collected by the day care bus at 9.15 when some clients had already been picked up. The bus journeys to and from the centres were included in this. The details of this observation work and the nodes used for analysis are given below.

Day centre	Dates of observation	Number of hours completed	Day centre timings
Cochin	October – December 2000	59	9.15 – 4.30
Trivandrum	February 2001	18	10.00 – 4.00
Jura	April – May 2001	37	8.45 – 4.15
Iona	June –July 2000	42	8.45 – 5.00

### Observation codes

#### *Free nodes – Kerala and Scotland*

cgj interviews

cgjs ignore

Confidentiality

family situation  
health and safety  
hidden dementia  
Kerala  
my presence  
scot confidentiality  
scot staff meetings  
scot structure  
staff meetings  
structure  
visitors

*Tree nodes - Kerala*

- (1) /four parts
- (1 1) /four parts/transfers
- (1 2) /four parts/on the bus
- (1 3) /four parts/activities
- (1 3 1) /four parts/activities/newspaper
- (1 3 2) /four parts/activities/prayer
- (1 3 3) /four parts/activities/sing and chat
- (1 3 4) /four parts/activities/exercise
- (1 3 5) /four parts/activities/TV
- (1 3 6) /four parts/activities/ballpassing
- (1 3 7) /four parts/activities/wordbased
- (1 3 8) /four parts/activities/games
- (1 5) /four parts/necessary

- (1 5 1) /four parts/necessary/tea
- (1 5 2) /four parts/necessary/lunch
- (1 5 3) /four parts/necessary/toilet
- (2) /client moods
- (2 1) /client moods/leaving
- (2 2) /client moods/verbal
- (3) /physical
- (3 1) /physical/control
- (3 2) /physical/gentle
- (3 3) /physical/client aggression
- (3 4) /physical/helping
- (3 5) /physical/cgn calming

*Tree nodes - Scotland*

- (7) /scot
- (7 2) /scot/four parts
- (7 2 1) /scot/four parts/activities
- (7 2 1 1) /scot/four parts/activities/games
- (7 2 1 2) /scot/four parts/activities/housework
- (7 2 1 3) /scot/four parts/activities/ball passing
- (7 2 1 4) /scot/four parts/activities/sing and chat
- (7 2 1 5) /scot/four parts/activities/newspaper
- (7 2 1 6) /scot/four parts/activities/exercise
- (7 2 1 7) /scot/four parts/activities/wordbased
- (7 2 1 8) /scot/four parts/activities/TV
- (7 2 2) /scot/four parts/necessary
- (7 2 2 1) /scot/four parts/necessary/toilet

(7 2 2 2) /scot/four parts/necessary/tea

(7 2 2 3) /scot/four parts/necessary/lunch

(7 2 3) /scot/four parts/transfers

(7 2 4) /scot/four parts/on the bus

(7 3) /scot/physical

(7 3 1) /scot/physical/gentle

(7 3 2) /scot/physical/helping

(7 3 3) /scot/physical/client aggression

(7 3 4) /scot/physical/control

## **Interviews**

### **Key individuals**

The key individuals in Kerala are listed and described within Appendix B. The coding system by which their interviews were analysed is shown below.

(5) /ki

(5 1) /ki/p transfer

(5 1 1) /ki/p transfer/gen

(5 1 1 1) /ki/p transfer/gen/evid

(5 1 1 1 1) /ki/p transfer/gen/evid/UK

(5 1 1 1 2) /ki/p transfer/gen/evid/elsewhere

(5 1 2) /ki/p transfer/day care

(5 1 2 1) /ki/p transfer/day care/evid

(5 1 2 1 1) /ki/p transfer/day care/evid/elsewhere

(5 1 2 1 2) /ki/p transfer/day care/evid/UK

(5 3) /ki/dementia

(5 3 1) /ki/dementia/diagnosis

(5 3 2) /ki/dementia/consequences

(5 3 3) /ki/dementia/services

(5 3 4) /ki/dementia/definition

(5 3 5) /ki/dementia/terms

(5 4) /ki/day care

(5 4 1) /ki/day care/development

(5 4 2) /ki/day care/acceptance

(5 4 3) /ki/day care/model

(5 4 4) /ki/day care/purpose

(5 5) /ki/ARDSI

(5 5 1) /ki/ARDSI/development

(6) /carers

(6 1) /carers/needs

(6 2) /carers/what they do

### **Day care staff – Kerala**

**In addition to the key individuals, some of whom were also day care staff, nine community geriatric nurses and the driver were interviewed about their role and experiences of working in day care. The coding system by which their interviews were analysed is given below.**

(4) /cgn

(4 1) /cgn/motivation

(4 1 1) /cgn/motivation/growth prospects

(4 1 2) /cgn/motivation/general

(4 1 3) /cgn/motivation/salary

(4 2) /cgn/dementia

- (4 2 1) /cgn/dementia/what is it
- (4 2 1 1) /cgn/dementia/what is it/India
- (4 2 1 2) /cgn/dementia/what is it/West
- (4 2 2) /cgn/dementia/causes
- (4 2 3) /cgn/dementia/diagnosis
- (4 2 4) /cgn/dementia/consequences
- (4 2 5) /cgn/dementia/communicate
- (4 2 6) /cgn/dementia/terms
- (4 3) /cgn/duties
- (4 3 1) /cgn/duties/enjoy
- (4 3 2) /cgn/duties/difficult
- (4 3 3) /cgn/duties/dislike
- (4 3 4) /cgn/duties/important
- (4 3 5) /cgn/duties/activities
- (4 3 6) /cgn/duties/difficult clients
- (4 3 7) /cgn/duties/carers
- (4 5) /cgn/purpose of day care

### Day care staff – Scotland

The day care staff in Scotland included the manager and driver at each centre. In addition at Jura three day care workers were interviewed and at Iona four day care workers were interviewed. The coding system by which their interviews were analysed is given below; it mirrors that for the day care staff in Kerala.

- (8) /dcw
- (8 1) /dcw/motivation
- (8 1 1) /dcw/motivation/general
- (8 1 2) /dcw/motivation/promotion

(8 1 3) /dcw/motivation/salary  
(8 2) /dcw/duties  
(8 2 1) /dcw/duties/difficult clients  
(8 2 2) /dcw/duties/clients  
(8 2 3) /dcw/duties/carers  
(8 2 4) /dcw/duties/enjoy  
(8 2 5) /dcw/duties/difficult  
(8 2 6) /dcw/duties/dislike  
(8 2 7) /dcw/duties/important  
(8 2 8) /dcw/duties/activities  
(8 3) /dcw/dementia  
(8 3 1) /dcw/dementia/what is it  
(8 3 2) /dcw/dementia/communicate  
(8 3 3) /dcw/dementia/consequences  
(8 3 4) /dcw/dementia/causes  
(8 3 5) /dcw/dementia/diagnosis  
(8 4) /dcw/day care plan  
(8 5) /dcw/purpose of day care



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