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**MUTUALITY AND MOVEMENT:  
AN EXPLORATION OF SELF-HELP/MUTUAL AID GROUPS AND THEIR  
RELATIONSHIP TO SOCIAL POLICY**

by

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## **ABSTRACT**

### **Mutuality and Movement:**

#### **An Exploration of Self-Help/Mutual Aid Groups and their Relationship to Social Policy**

Since the 1970s all of the available literature suggested that the UK, in common with Europe, North America and Scandinavia, had seen significant growth of single issue self-help/mutual aid groups related to health and social care issues. Yet in the UK there appeared to be no real body of academic interest nor any sustained national policy initiatives. The aim of the study was therefore to enhance an understanding of the relationship of these self-help/mutual aid groups to UK social policy.

The study was constructed in two parts. Part One, a historical study critically appraised the way in which the state appeared to have viewed and responded to various manifestations of self help/mutual aid, both pre- and post- the welfare state. Part Two, a case-study of two UK grassroots self-help/mutual aid groups explored members' viewpoints, their reasons for joining, benefits derived and the impact they felt it has had on their lives and their relations with professionals and wider 'political' forums.

The result of the study suggests a fundamental reframing of the relationship between self-help/mutual aid and the state is required at both a conceptual and practical level by UK policy makers and academics. This would acknowledge: that contemporary self-help/mutual aid groups are part of the broader tradition of voluntary action in the third sector; self-help/mutual aid's unique contribution in terms of social relations, process and knowledge; its difference from philanthropy/formal voluntary sector and therefore distinct characteristics and relations with the state; and contemporary health and social care groups' potential dual identity with communities of interest and geographic communities and their relationship to and distinction from the contemporary service user and carer movements. The findings have implications for policy related to participation (citizen and health), social capital and citizenship.

**Keywords:** Self-help/mutual aid groups; voluntary action; reciprocity; experiential knowledge; social capital; citizenship; participation.

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**Dedication: this thesis is dedicated to my mother Joyce Giddings (1924-2002).**

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## **Preface**

In his last diary, 'Smiling in Slow Motion' (1991-1994), Derek Jarman muses that 'as the Establishment always writes the history... I wonder how I will come out?' Reflecting specifically on the history of queer (*sic*) politics he admonishes some of his peers for assuming and colluding with the view that 'steps forward' occur through parliamentary legislation. This, he comments 'is a mistake, steps forward come by the example in our lives... the aim is to open up discourse and with it broader horizons; that can't be legislated for' (p.43, 2001).

The central thread to this thesis is that social activity carried out in civic society, often 'hidden' from the mainstream, is a critical and often unacknowledged and underestimated factor in changing the discourse, conceptions and potential conditions for social change. This activity is also a largely unacknowledged influence on social policy formation. The medium/example for exploring this is the activities of self-help/mutual aid groups in health and social care groups that appear to be growing in number since the late 1970s.

Although there has been an academic interest in these groups by social psychologists and sociologists (predominantly from the USA), in the UK there is no growing or sustained body of academic work in this area – writing is predominantly by practitioners and diffuse in nature, concerned with the subject matter of the group (such as health issue) rather than self-help/mutual aid itself. The predominant academic interest that is shown is a concern (by social psychologists) of the 'therapeutic' nature of these groups and comparing 'results' from self-help groups with that from support offered via professions. Whilst American sociologists have shown an interest in the organisation and processes of groups it is only relatively recently that attention has been shown to the connections that this has with the wider society, most notably in the work of Thomasina Borkman. There is no similar sustained attention by social scientists in the UK, where the subject is marginalised, even in the new and influential 'constructions' of the history of voluntary action and organisations in this country. The relationship to social policy is marked by an

absence of exploration or theorising and contemporary self-help/mutual aid groups are often equated simply with the service user movement.

Understanding these groups in relation to social policy throws up the very dilemma/dichotomy expressed by Jarman. Social policy and even its most critical theorists tend to be preoccupied by the description and analysis of state provision. Self-help then is only ever considered in policy terms when it becomes visible and incorporated into understandings of the movements/shifts in welfare policy, such as currently by user movement and governmental initiatives in 'involvement/participation'. Whilst this interface will be explored in this thesis by locating self-help/mutual aid in both historical and contemporary relations to the state and the voluntary sector, the standpoint is from the activities in self-help/mutual aid groups, focusing on the ways in which activities in these groups affect an understanding of the social relations in welfare. This offers a more diffuse understanding of the interrelations between people, welfare and policy.

## INTRODUCTION

Many Ph.D.s begin with the author expressing some surprise that their final framing and understanding of the subject matter varies considerably from their initial starting point. This thesis is no different. My journey during this study has taken me in many directions that I could not have envisaged at the start. This is perhaps not surprising for a study that has been spread over six long years, seen a major change in central government and a shift in social policy priorities. At times it felt as if the journey would never end. Three years ago (three years into the study) my daughter Ella (then aged 10) posed me a riddle: “what is it that you are always doing but never finishing?” it was of course a very accurate description of my doctoral study! However, despite the length of time involved, the primary aim of the study is still as relevant as when I began. That is, to enhance an understanding of the relationship of self-help/mutual aid groups to social policy. An area that was and still is under-researched and under-theorised in the UK. This thesis aims to make a major contribution towards filling that void.

My primary motivation for the study was my background in research committed to service users’ and carers’ perspectives in service development. I viewed the contemporary single-issue self-help/mutual aid groups in health and social care as the natural roots of the disability, user and carer movement. However, although I had seen an incremental interest by both academics and policy makers in the user and carer movements *per se* and specifically in relation to their impact (or otherwise) on services, I was puzzled by the general lack of interest regarding the role and benefits of groups themselves. Service-led developments to involve users and carers focused on involving individuals as opposed to groups and there appeared to be little regard for the specific qualities that groups of people sharing the same health care or social condition could offer to either themselves or policy makers. Overall, the focus in social policy research seemed to be only on the *visible* aspects of the groups’ activities, which in this case was when they (rarely) interfaced with professionally led consultation or involvement agendas.

I began my study therefore, with a conundrum. All of the available literature suggested that the UK, in common with Europe, North America and Scandinavia, had

since the 1970s seen an explosion of self-help/mutual aid groups related to health and social care issues (Lieberman and Snowden, 1993; HBD, 1997). Although in the USA these groups had been the subject of much research and state-based policy-making, in the UK there appeared to be no real body of academic interest nor any sustained national policy initiatives. The literature that did exist on self-help/mutual aid groups was dispersed across disciplines and did not suggest it be viewed as a phenomenon in its own right. The existing literature (heavily dominated by US studies) was exciting and suggested that the groups offer a 'space' in civic society, through which members – by sharing their direct experience of the same health or social care issue – gained new understandings of their situation and ways of coping (Medvene, 1990; Humphreys and Rappaport, 1994).

Although the US literature was dominated by psychological research which focused on the individual benefits that accrued to members such as improvements in self-esteem and self-confidence, there was an emerging and complementary sociological literature which was beginning to explore the wider impact that groups might have on societies (Messer & Borkman, 1996). This latter literature 'located' the health and social care groups within the third sector of society (between the state and the private sectors) and began to make the links with the broader tradition of single-issue self-help/mutual aid movements such as the civil rights and feminist movements.

There were however two drawbacks to the simple application of this literature to the UK. Firstly, a wider reading of the literature suggests that the particular forms self-help/mutual aid groups take and the ways in which they are conceptualised will vary according to the cultural and welfare contexts in nation states. The UK and USA welfare systems are clearly quite different in both historical and contemporary form. Whilst both countries may have seen a concurrent rise in these groups, the reasons behind this might vary. Secondly, much of the US research was based on 12 step groups, such as Alcoholics Anonymous. Whilst these might be the majority form of self-help/mutual aid groups in the US, available literature suggested that this was not the case in the UK (see Chapter One). It was clear that to understand the relationship of self-help/mutual aid groups to social policy in the UK therefore, an understanding of the type of groups that exist in the UK and their place in the welfare spectrum was going to be important. Secondly, a further literature review made it apparent that

there had been no sustained or substantive body of work about the history of self help/mutual aid in the UK that either 'located' contemporary groups within their broader tradition, nor one that examined the relationship of the state to self-help/mutual aid over time. Rather it was diffuse and mixed into early labour histories (Gosden, 1961; Green, 1985; Kidd, 1999) and marginalised in the emerging and substantive history being built about the formal voluntary sector (Davis-Smith, 1995; Kendall and Knapp, 1996). In the latter self-help/mutual aid distinct history was obscured by the emphasis being given to philanthropy, which was replicated in the emerging theories about state-voluntary sector relations (James, 1987; Salamon, 1994).

Developing a specific UK understanding of where self-help/mutual aid groups are placed in relation to the state as well as both the individual and broader benefits of self-help/mutual aid groups seemed important complementary components of exploring the relationship between self-help/mutual aid groups and social policy. The study was therefore constructed in two parts. The first is a historical study (desk research) which critically appraised the way in which the state appeared to have viewed and responded to various manifestations of self help/mutual aid, both pre- and post- the welfare state. This was important both in terms of locating contemporary groups within their broader history and in giving a much richer depth to an understanding of how self-help/mutual aid potentially impacts on social policy. Secondly this was complemented by a case-study of two UK grassroots self-help/mutual aid groups where the viewpoints of members themselves were explored, looking at what they attribute as the reasons for joining groups, the benefits they derive and the impact they feel membership has had on their lives and their relations with professionals and wider 'political' forums. An additional component of the case study was the exploration of some of the key processes that occur within the group, which contributed to the benefits attributed to active group membership. Combined then, the two parts of the study have illuminated key concepts and themes that have important implications for the relationship between self-help/mutual aid and social policy theory and practice as the following outline of the thesis chapters illustrates.



## **Structure of the thesis**

This thesis is arranged in two parts reflecting the two components of the study outlined above. Part One provides an overview of contemporary self-help/mutual aid groups in health and social care. The roots of these groups are then explored through desk research, which consists of a historical analysis of other key forms of self-help/mutual aid in the UK. This analysis distinguishes self-help/mutual aid from philanthropic forms of voluntary action and shows the differential response of the state to these two activities. Part Two of the thesis contains the methodology and findings of the fieldwork part of the study – the case study. Whilst the two components of the study are presented sequentially it should be noted that they were developed alongside one another and the research process was iterative rather than linear, as outlined in Chapter Five. The concluding chapter (Chapter Eight) brings together the findings from both the desk and the field research to consider the overall implications of the study to the contemporary social policy agenda.

### **PART ONE: An overview of contemporary self-help/mutual aid groups and a study of their historical relationship to the state**

**Chapter One** provides an overview of contemporary self-help/mutual aid groups, setting out the core definitional and conceptual framework used in the doctoral study. The contested definition of groups is explored and their grassroots, self-organising and collective nature is emphasised, thus differentiating them from individual self-help, self-help organisations and support groups run by professionals. The different types of groups are outlined, as are their scale and demographic features. After a discussion of the gains attributed to membership of these groups, the known aspects of the processes of groups are then explored, such as their reciprocal social relations, use of storytelling and building of experiential knowledge. Throughout the discussion the current reliance on USA literature is highlighted and thus a set of core questions is derived that forms the basis of the UK case-study presented in Part Two. The Chapter concludes with a discussion of the issues raised for understanding self-help/mutual aid in relation to UK social policy. This includes an understanding of self-help/mutual aid as a form of voluntary action in civic society and as part of the third sector of UK society. A discussion of the current gaps and confusions in the UK literature builds the rationale for the historical study as a complement to the case study.

**Chapter Two** provides an overview of the two key philosophical positions adopted in relation to self-help/mutual aid embodied in the work of Peter Kropotkin and Samuel Smiles. Kropotkin's emphasis on the benefits of co-operative endeavour are contrasted with Smiles' concern with individual self-improvement. This 'duality' can be seen to lie behind the ambivalent and often contradictory state response to self-help/mutual aid, which recurs over time. The chapter concentrates on the modern period prior to the welfare state and focuses on the evolution of predominantly financial forms of self-help/mutual aid such as the friendly societies and the co-operative movement. It is noted that within these movements, women's profile and independent organisation was an important feature. The philosophy, class origin, values and form of organisation of self-help/mutual aid groups are then contrasted with the parallel developments in philanthropy. The chapter raises themes that are revisited throughout the thesis; in particular it looks at the historical context and socio-economic conditions that lead to the formation of self-help/mutual aid groups, their defining characteristics and the type of social relations and knowledge within groups.

**Chapter Three** builds on the previous chapter by tracing the relationship of other significant forms of self help/mutual aid that emerged from 1945 to the end of the Thatcher administration in 1990. It notes that this period began with the incorporation of the principles of self-help/mutual aid into the fundamental mechanisms of the 1945 welfare state. The various political ideologies of the ensuing administrations are critically appraised regarding their implications for policy on voluntary action. This highlights the significant difference in state response to the philanthropic movements and to self-help/mutual aid. The emergence of new forms of self-help/mutual aid, the single issue groups are traced, showing how these were a response to perceived structural and cultural inequalities in areas such as gender, race, sexuality and disability. The single-issue groups in health and social care are placed within the same tradition but related also to the increasing professionalisation of services at this time. The chapter also clarifies the relationship between grassroots self-help/mutual aid groups and the user and carer movement making it clear that whilst there is a strong relationship they are not merely synonymous. The chapter also details the only

national policy developments that evolved in 1986 during Thatcher's administration regarding contemporary self-help/mutual aid groups.

**Chapter Four** concludes the analysis of the New Right era by detailing the Major government's particular perspective on state-voluntary action relations. During this administration we see a consolidation of a form of partnership between the state and the formal voluntary sector, and a rise in consumerism in services. Whilst the latter offers opportunities for the user and carer movements the policy initiatives are individualistic in nature and fall short of the democratisation of services.

Concurrently we see the withdrawal of national policy support for self-help/mutual aid groups. The responses of self-help activists are detailed as are their policy recommendations (Hyatt and England, 1995; Wann, 1995), yet sadly we see this has no visible impact on national policy. This discussion is set against the backdrop of Major's notion of the active citizen, where individuals increasingly take responsibility for their own welfare.

The chapter concludes with an overview of New Labour vision of the 'Third Way' which sees a resurrection of the importance of voluntary action in civil society, the notion of the responsible citizen, particularly through the philosophy of communitarianism that underpins much of Blair's policy. However, whilst this is seen to lead to enhanced relations with the formal voluntary sector, the response to self-help/mutual aid is once again fragmented and *ad-hoc*. Thus we see a renewed interest in financial forms of self-help/mutual aid and activities defined as community self-help but the single-issue groups in health and social care once again fall off the agenda. The chapter concludes with a general discussion of the historical review, identifying recurrent themes and features in the relations between the state and self-help/mutual aid. Many of these are revisited in the fieldwork.

Together these chapters locate contemporary groups in the greater web and tradition of self-help mutual aid activities in the UK. Doing so assists us in understanding the richness and multiple expressions of this form of voluntary action, their shared characteristics and thus clearly distinguishes it from philanthropy. It also highlights the importance of seeing self-help/mutual aid activity as a part of voluntary action situated in a much broader web of community relationships. It therefore assists us in transcending the professional boundaries/categories in which contemporary health and

social care groups tend to be viewed and avoids their simple equation with the user and carer movements.

## **Part Two: A case study of contemporary self-help/mutual aid groups**

Chapters Five, Six and Seven present and discuss the findings from the fieldwork part of the study. This part of the thesis re-visits some of the key themes raised in Part One but this time from the perspective of those involved in self-help/mutual aid groups. **Chapter Five** restates the overall aim of the study and the research questions. The philosophy and methodology of the fieldwork research is outlined, as is the rationale for the case-study design. The methods used in the study (semi-structured interviews, postal questionnaire, taped group sessions and research diary) are described as each stage of the process of the study is outlined. A distinction is made between active (those attending meetings) and non-active members (those who receive notification of meetings and *ad hoc* newsletters only). The methods used for data analysis are also detailed. Finally, the ethical considerations and limitations of the study are discussed.

**Chapter Six** presents the findings from the study. The Chapter begins with an overview of the two carers self-help/mutual aid groups that form the case study. A table of the demographic characteristics of both active and non-active members follows this. The chapter is then structured into four sections. Section One explores the reasons why active members feel they were motivated to join the group and the key gains they feel have arisen from active membership. Section Two explores the key differences members attribute to this form of support as against what they can get from professionals. In both these sections the responses of active members are compared with those of non-active members. Section Three looks in more depth at the processes and issues of the groups and Section Four considers whether membership of the group has had an impact on the 'identity' of members and their relationships with the broader community.

**Chapter Seven** provides a discussion of the fieldwork findings and argues that there is a uniqueness in terms of social relationships, processes and forms of knowledge held and developed in self-help/mutual aid groups that could not be replicated by

either the state or the formal voluntary sector. The range of benefits attributed to active group membership concur with previous study findings but new areas also emerge such as the links between active group membership and previous voluntary action activity, learning to listen and to be non-judgemental. The 'holistic' nature of the groups was seen as vitally important, enabling members to transcend the 'roles' they are usually caught in with their relationships with professionals. New aspects of the processes in groups are revealed, such as the specific type of discourse in groups which was supportive and very subtle in terms of challenge. The gender differences are noted, with women introducing the emotional content to conversations and the perspective of the cared for. However, it is also noted that the discourse does not always reflect the body language and tone of exchange. It is noted from the fieldwork findings that very subtle forms of deconstructing the carer's identity occur within the group context. The importance of the dual identity that groups potentially hold is highlighted by contrasting the two groups and noting that the group which evolved from carers themselves, in a shared geographic community attributes as much importance to this as to their shared identity as carers, whereas the group originally begun by a professional shares only the latter. The consequences of professional involvement are therefore illuminated and seen to have an impact on the groups' motivation and ability to action issues as a collective.

**Chapter Eight**, the concluding chapter, weaves together the key findings from both the fieldwork and desk research to consider the implications for the overall aim of the study; that is, an enhanced understanding of the relationship between contemporary self help/mutual aid groups and social policy. It is suggested that as a result of the findings the fundamental reframing of the relationship between self-help/mutual aid and the state is required at both a conceptual and practical level by UK policy makers and academics. Such a re-framing would offer: an acknowledgement that contemporary self-help/mutual aid groups are part of the broader tradition of voluntary action in the third sector; self-help/mutual aid's unique contribution in terms of social relations, process and knowledge; its difference from philanthropy/formal voluntary sector and therefore distinct characteristics and relations with the state; and contemporary health and social care groups' potential dual identity with communities of interest and geographic communities and their relationship to and distinction from the contemporary service user and carer

**movements. This then leads into a discussion on the implications of the findings for the current New Labour policy agenda, showing how the findings have specific implications for policy related to participation (citizen and health), social capital and citizenship.**

## **PART ONE**

**An overview of contemporary self-help/mutual aid groups  
in health and social care and a study of their historical relationship  
to the state**

## **Chapter One:**

### **Definitions and Profile of Contemporary Self-help/Mutual Aid Groups in Health & Social Care**

#### **INTRODUCTION**

Mutual support and voluntary action have always been a part of human societies in one form or another. Since the 1970s the rise in single issue self-help/mutual aid groups has been observed and documented across Europe, North America, Canada, Japan and New Zealand (Borkman, 1999; Hastie, 2000). Sometimes these groups have taken the shape of 'social movements' such as the feminist, disability, user and carer, and civil rights movements. Alongside and beneath some of these visible pinnacles however is a proliferation of grassroots self-help/mutual aid groups that form the bedrock of self-help/mutual aid activities today.

This chapter provides an introduction to the thesis by giving a descriptive overview of the definition, type and key activities of contemporary grassroots self-help/mutual aid groups in health and social care, setting out the core definitions and conceptual framework used in the doctoral study<sup>1</sup>. The contested definition of groups is explored and their grassroots, self-organising and collective nature is emphasised, thus differentiating them from individual self-help, self-help organisations and support groups run by professionals. The different types of groups are outlined, as are their scale and demographic features. After a discussion of the gains attributed to membership of these groups, the key known aspects of the processes of groups are then explored, such as their reciprocal social relations, use of storytelling and building of experiential knowledge.

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<sup>1</sup> It should be noted that many of the texts quoted were not available at the outset of the study (1996/1997) and therefore were not instrumental in terms of the initial framing of the study. However, all of the 'new' texts referenced have been used to either develop the study at key points and/or contribute towards a richer understanding and discussion of the findings.



Throughout the discussion the current reliance on USA literature is highlighted and thus a set of core questions is derived that formed the basis of the UK case study presented in Part Two of the thesis. The chapter concludes with a discussion of the issues raised for understanding self-help/mutual aid in relation to UK social policy. This includes an understanding of self-help/mutual aid as a form of voluntary action in civic society and as part of the third sector of UK society. A discussion of the current gaps and confusions in the UK literature builds the rationale for the historical study as a complement to the case study. The chapter concludes with an outline of the key questions that are explored throughout the thesis.

## **WHAT IS SELF-HELP/MUTUAL AID?**

Self-help/mutual aid can be seen as an idea, put into practice in different ways. As we shall see in Chapters Two, Three and Four, expressions and forms of self-help/mutual aid are related to the historical, economic and political circumstances from which they evolve. The term 'self-help' is used in a variety of ways to denote both individual and collective forms of support and development. Because the term has such a common usage and is used to depict quite different activities it is useful for us to make some distinctions. One way to do this is to look at and compare the ways in which individuals and groups may use self-help resources to assist them in coping with, alleviating or overcoming personal, health and/or social issues.

### **Self-help for individuals**

At an individual level self-help is often associated with the personal use of a range of books, audio-tapes, video-tapes and T.V. programmes that are specifically intended to provide individuals with useful information and suggested 'coping strategies', such as how to give up smoking, how to cope with recurrent health problems, how to cope with stress and so on. In the main these are written or presented by 'experts', although there are a few examples just emerging of self-help guides written by people who share the condition or circumstances of their intended audience. Self-help can also refer to an

**individual drawing on their own experience as a resource to help them manage similar situations 'better' (Borkman, 1999).**

### **Self-help/mutual aid for groups of people**

**Self-help/mutual aid groups involve meeting with other people who share the same or similar circumstances or conditions to discuss and to share ways of coping. This is usually done through face-to-face meetings but as use of the internet increases, some self-help groups hold 'virtual' meetings on-line where members can discuss issues with each other. Because groups are based on the principle of peer 'reciprocity' (see below), where members both offer and gain support, the relationships are quite different to those in traditional services where a 'user', 'client' or 'patient' is dependent on the advice, support or treatment of a professional. Sometimes other terms are used to describe the relationships in these groups, for example, self-help groups and mutual helping groups.**

**A further distinction can be made between self-help/mutual aid groups and what Borkman terms self-help organisations (1999). These are formally instituted organisations that are run for and by people who share the same health or social care issue. In the UK the dominant example would be the newly emerging user-run organisations, such as Wiltshire Network, that are formally constituted organisations holding contracts for service delivery with Local Authorities (Health and Social service Departments). These organisations' 'roots' are in local self-help/mutual aid groups, which have developed in a particular way to become service providers.**

**This study's main focus is on the grassroots self-help/mutual aid groups in health and social care. These grassroots groups are not formally constituted or instituted, although they may have links with and can form a part of, local and national organisations.**

## **CONTEMPORARY FORMS OF SELF-HELP/MUTUAL AID GROUPS:**

As will be seen in Chapters Two, Three and Four the form that self-help/mutual aid has taken differs in different historical periods. The current form taken by self-help/mutual aid groups in health and social care in the UK, North America and Western Europe tends to be that of single-issue groups. The following section gives a flavour of the ways in which these groups have been defined and categorised.

### **Definitions**

The Nottingham Self-Help Team in the UK adopted the following definition as a tool to guide its work; this definition is widely quoted in the UK's self-help literature and has been used as the definition for contemporary groups in this study:

A self-help or mutual aid group is made of people who have personal experience of the same problem or life situation, either directly or through their family or friends. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are run by and for their members.

Some self-help groups expand their activities. They may provide, for example, services for people who have the same problem or life situation; or they may campaign for change. Professionals may sometimes take part in the group in various ways, when asked by the group.

Some groups will hold regular meetings on a weekly, monthly or quarterly basis. Meetings may be in public venues, such as community centres, or in members' homes. Other groups will maintain support through letter writing, through a network of telephone contacts or through news groups and e-mail (1995/6 updated in 2000).

This is different to a 'professionally-led support group' – although they may begin as such. A support group is one that is led by a professional; these often contain a strong element of mutual support between members but the fact that they are headed by a professional makes an important difference. Ownership and power are crucial factors distinguishing the two types of group. Ownership arises from the sharing of personal

experience and the experiential knowledge generated from such activity. Professionals are unlikely to share this same experience or perspective and even sympathetic practitioners will have a vested and powerful interest in maintaining a professional discourse and knowledge base. However, many support groups hold the potential to evolve into self-help groups after the professional withdraws. The chances of this happening successfully increases if this is built into the support group process from the beginning (Wilson, 1995). It is important to note however that the semantic distinction is 'academic' and many groups run for and by their members refer to themselves as support groups.

There is, however, no single agreed definition of self-help/mutual aid. It is notable that in the main the dominant literature comes from the USA, chiefly from the discipline of psychology which tends to understand and frame self-help/mutual aid groups in relation to either therapeutic groups or human/social services (such as Katz and Bender, 1976; Killilea, 1976;). As Humphreys and Rappaport (1994) and Borkman (1999) pointed out this is problematic since groups are then only rarely viewed in the context of their role in broader society. Only a few studies have framed self-help/mutual aid groups in such an alternative paradigm.

Humphreys and Rappaport (*op cit*) have noted two main types of study that fit within such an alternative paradigm, those that understand self-help/mutual aid groups as 'normative socially supportive groupings rather than treatments' (p.225) viewing groups rather as a social network like a club, church or citizen action group (such as Antze, 1976; Richardson and Goodman, 1983; Kurtz and Powell, 1987; Borkman and Messer, 1996; Borkman 1999). These studies place emphasis on the learning that occurs within groups and are therefore interested in not only personal changes but also how group processes can affect the groups' views and perspectives on their situations. Borkman (1999) has more recently termed her own approach as a 'voluntary action one' which places emphasis on understanding these groups in their broadest relationship to society, she stressed the voluntary nature of these groups which she views as occupying an

important part of the third sector of society<sup>2</sup>. A related framework, but one which is concerned with self-help organisations (to which grassroots self-help/mutual aid groups have been the wellspring and to which other grassroots groups may have an affiliation) is the 'political action' framework. Studies in this framework are concerned with the evolution of campaigning groups and their location of the shared problems in the wider structures or cultures of society, such as the women's movement, disability movements and gay rights movements (Maton, 1993; Chamberlain and Rogers, 1990). The paradigms in which researchers have conceptualised self-help/mutual aid groups will clearly have an impact on the type of study carried out and the benefits and effects attributed to group membership, as we shall see below.

There are however also cultural differences between the broad, visible and overt orientation of groups. For example, discussing groups emerging in Eastern Europe, Zsuzsa Csato, President of the Down's Syndrome Association in Hungary and a worker at the National Institute for Health Promotion has observed that in Eastern Europe a self-help group is more like a working team:

What has to be changed outside the group is more important than what happened within the group. Therefore the self-help groups are putting issues such as new laws, new types of care and human rights on the agenda. The groups never remain on the level of just talking to each other, because their social needs are so strong (Csato, Z, 1993)

Situating and understanding self-help/mutual aid groups' form and activities in their relevant historical and socio-economic context then is also important. This can be highlighted by the current difference in form between the predominantly single-issue groups in North America, Canada, Scandinavia and Europe and the predominance of 'community' oriented groups of South America, Africa and Asia (Hastie, 2000; ISTR 1998/00). Nevertheless, different forms of self-help/mutual aid share some common characteristics that need to be recognised, as is explored throughout the thesis.

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<sup>2</sup>Borkman (1999) uses Lohmann's concept of the 'commons' as a way to place USA groups. Lohmann described the commons as a public arena of action where 'autonomous self-defining collectives of voluntary associating individuals'

Finally, the terms self-help and mutual aid are often used interchangeably in the literature, but as explored in Chapter Two, in terms of emphasis they have quite different ideological roots. As we shall see in the historical study this ‘duality’ and the tensions it embodies has been – and remains – a major contributing factor to the state’s ambivalence towards the phenomenon. In brief, self-help philosophy stems from liberal individualism and promotes ‘relying on one’s own efforts rather than that of others’; this is most closely associated with Samuel Smiles (1859). Conversely, mutual aid is often traced back to the writing of anarchist Peter Kropotkin (1902) who stressed the potential of collective and inter-dependent human action in bringing about change. The views of these two philosophers are looked at in more depth in the next chapter. In this thesis I am deliberately using both terms together, because I believe that it is the reciprocity (mutuality) of relationship with others and consequent processes within these groups that enables individuals within it to help themselves or, as Hastie (2000) stated:

individuals involved in self-help are helped and enabled themselves through the process of helping others (*ibid.* p.3).

### **Types of Self-help/Mutual Aid Groups**

Self-help/mutual aid groups are categorised in a number of ways but Wann (1995) noted that in the UK they tend to fall into seven main categories.

**Table 1: Categories of UK self-help/mutual aid groups**

Physical illness	Disability	Generalist
Mental Health	Carers’ Group	Addiction
	Social Issues	

Some examples of UK grassroots groups are given in Appendix 1. As Wann (1995) pointed out, although the areas above appear to fit with current care categories as defined

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create and maintain their own meaning perspective and sense of reality. (Lohmann 1992 as quoted in Borkman *op cit*).

by social care agencies, self-help groups do not slot so easily into professional boundaries and the typology may instead reflect the ways in which professionals understand and categorise groups.

Another way in which groups are sometimes differentiated in the literature is in terms of whether they are 'inward oriented' (or personal change) groups or 'outward oriented' (or social change) groups. Nylund (1998) provides a useful summary typology:

**Table 2: Summary of typologies of self-help/mutual aid groups (from Nylund, 1998)**

<b>Inward oriented</b>	<b>Outward oriented</b>
<i>Mutual aid groups</i> : self-fulfilment, personal growth, existential problems, egalitarianism	<i>Advocacy groups</i> : changing society, educating and building up social skills
<i>Personal change</i> : enable members to change their behaviour through mutual support, improve coping skills, self-esteem	<i>Social change</i> : advocate fundamental changes in the service system, empowerment, focus in on external environment and interaction with it
<i>12-step groups</i> : behavioural change oriented, spiritual belief, life-long membership, no (socio)political action	<i>Non 12-step group</i> : non-ideological, no precise meeting structure, temporary membership, (socio) political action, lobbying, demonstration, educational supportive
<i>Inner focus</i> : inward-turning and member centred, intense membership	<i>Outer focus</i> : social or mass goals, welfare reforms, loose membership

Drawn from typologies in Hasenfield & Gidron (1993); Katz (1993); Katz and Bender (1976); Kurtz (1990, 1997); Makela *et al* (1996); Smith and Pillemer (1983).

Whilst this is a useful summary typology, it is important to note that these features are based predominantly on studies of US groups and may or may not reflect groups in the

UK. Secondly, as Wann (*op cit*) has indicated above, groups may have difficulty in defining themselves in these terms since the ‘anarchic’ nature of groups means they may move within and between categories over time. Implicitly the typology reflects the concerns of Humphreys and Rappaport and Borkman (*op cit*) that since most grassroots groups in the US and Europe would appear to fit with the ‘inward looking’ characteristics their wider implications for society are negated. As the definition provided above by Self Help Nottingham also suggests, self-help/mutual aid can be seen as part of a spectrum of activities, linking and overlapping with self-care, group therapy, befriending, advocacy, community development, lay participation in local decision-making and campaigning (Wann, 1995). Self-help activities may therefore vary from one category to another, as they are adapted to meet particular needs and conditions.

The limitations of these types of typology were reflected in Nylund’s own doctoral research where, in her study of 178 groups in Finland, none identified solely with the term of ‘inward groups’, since all of them attributed an importance to (although only some of them engaged in) campaigning or public lobbying. This led her to make a simpler distinction between inward groups and mixed oriented groups and conclude that typologies are only ever ‘ideal types’ (p.6). This echoes Richard and Goodman's (1983) view that typologies tend to ‘obscure a proper understanding of the nature of self-help groups as a whole’ (p.141). They highlight the ability to perform more than one function at any one time as one of the self-help/mutual aids group’s most significant features.

Another distinction that can be made is in relation to 12 step and non-12 step groups. In America many self-help groups are based on the 12-step programme established by Alcoholics Anonymous (AA) primarily for people with addictive behaviour, which entails the adoption of and adherence to a set of ‘spiritually-informed’ ‘steps’ the first of which is the members’ acceptance of their life-long addiction. Group meetings and ‘mentors’ with the same addiction aid this management. Much of the US literature is based on studies of these groups. In the UK however, it would appear from the available and recent literature (Elsdon *et al* 2000) that very few groups follow this model, which distinguishes their development from those in the USA.



**Self-help/mutual aid groups also operate in different ways, in terms of scale and longevity. Groups may come to a natural end or exist for many years. Some are long established, others very new. Vincent's (1986) UK research showed a high birth and death rate of self-help/mutual aid groups. Borkman (1999) attaches significance to the differences in what she terms 'fledgling', 'developed' and 'mature' groups (and individuals within groups). Borkman differentiates between these stages in terms of the likely features in member composition, organisational basis; the authority members vest in their experiential knowledge and their 'meaning perspective' (the way in which they understand their condition or situation). She noted that fledgling groups have a high quota of new members who are likely to be both insecure in the authority they invest in their knowledge and comparatively unreflective regarding conventional understandings of their condition/situation. In contrast, by the time groups mature they will have a large number of members who together have developed both a confidence and an authority in their own knowledge base and moved towards a new perspective on their ascribed situation or condition.**

**Finally it is important to note that some groups that began as grassroots local groups have expanded into national and international organisations, such as Alzheimer's Society, Women's Refuge Movement and perhaps the best-known, Alcoholics Anonymous (AA). AA originated in the 1930s in middle-class North America but now has an estimated membership of two millions worldwide. Whilst it is not yet clear what causes some groups to evolve from small grassroots groups in the UK into national or international groups, it does appear that the common processes in self-help/mutual aid groups hold the potential for groups to do so.**

**The diversity of groups then is staggering, drawing on both the definitions and categorisations of self-help/mutual aid groups they may be:**

**Table 3: Diversity of self-help/mutual aid groups**

local	national	international
transitory	developing	
large	small	
personal	social	
fledgling	mature	
political	non-political	

However it appears that they can be understood in relation to three commonalities:

Firstly, they are run for and by people who share the same health or social issue; secondly their primary source of knowledge is based on direct experience.

Thirdly, as we shall explore further below they occur predominantly in the third sector of society as opposed to the statutory or private sectors.

### **THE SCALE OF SELF-HELP/MUTUAL AID**

Partly due to the lack of academic and policy interest and partly because of its inherently volatile nature it has proved notoriously difficult to document and map self-help/mutual aid activity. With the exception of bodies that represent self-help groups at the national level, such as Alzheimer's Society or the National Carers Association, self-help/mutual aid at the grassroots level tends to be an invisible activity, taking place 'in private' and usually in the members' 'own time'. Only a few regions in the UK have organisations that exist to facilitate and support self-help/mutual aid (see below) and there is no national database on grassroots self-help/mutual aid groups<sup>3</sup>, the resource that previously existed being closed in 1994 (see Chapter Three). However, there is strong anecdotal 'evidence' from practitioners in the health and social care fields that these groups are increasing; for example, the database held by Help for Health in Winchester in Hants, UK, estimated in 1997 that there were at least 1,500 national self-help groups and an estimated 1,000 local self-help groups per million of the population - by this figure an estimated 49,000 local self-help groups. However, these figures cannot be substantiated with empirical evidence.

Another estimate from a recent study by Elsdon *et al* (2000) in the Nottingham area found 259 groups in the area or 0.4 per 1,000 population. From this they estimate approximately 23,400 self-help groups in the UK. Since it is predominantly adults who join self-help groups they go further in suggesting that of the adult population in the UK 1 in 25 are likely to belong to a self-help group. Elsdon *et al* have argued that in the context of 11 years spent studying the voluntary sector in Britain, self-help/mutual aid groups are growing more rapidly than any other kind of voluntary organisation (*op cit* p.5). Based on the Self-Help Nottingham Directory of self-help groups an up-to-date though partial trend is shown of growth rates in the Nottingham area of an average of 9% per year during the years 1982–1999.

North America and Europe show similar trends. Lieberman & Snowden (1993) estimated that in 1992, 7.5 million Americans were participating in self-help groups. In Europe also, writing primarily by practitioners in the field indicates their development (Hastie, 2000). Groups are also developing in post-communist countries. In Hungary alone, some 30,000 voluntary organisations including 2-3000 self-help groups had registered by 1993. In the former Soviet Union national disasters and war have stimulated the formation of numerous independent organisations, including self-help/mutual aid groups set up by the ‘victims’, for example, in relation to Chernobyl, the Armenian earthquake and violent ethnic conflicts (White, 1993 p.790).

In Scandinavia there also appears to have been both an increase in self-help/mutual aid groups and a parallel interest in researching the phenomenon (Nylund, 1998; Karlsson, 2000). In Sweden, the Skondal Institute has a government grant to conduct research on self-help groups, which includes an inventory of a representative sample of geographical areas nationally. Similar exercises are under way in Denmark and Londonderry in Northern Ireland but no published figures are yet available.

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<sup>3</sup> Although G-Text have recently produced a guide to 780 national self-help groups (Help, May 2002).

The reasons for this growth have been explained variously. For example, Nylund (2000) suggested that in Scandinavia this might be a reaction to the hierarchical, bureaucratic, professionalised and impersonal nature of public services. Although as Adams (1990) noted about the UK groups, whilst these are sometimes an alternative to services, they can also be complementary. Morgan *et al* (1985) tend to support Nylund's observations viewing self-help/mutual aid groups as contributing to a more general protest against the dominant values and institutions in society. Vincent (1992) suggested that in the UK the move towards a pluralist approach to welfare policy encouraged enhanced roles for informal and voluntary activity, but equally noted that whilst this might accelerate growth, the phenomenon already existed. Elsdon *et al* (2000) suggested that self-help/mutual aid groups have always been important to those who participate in them; what is changing rather is an awareness of their importance.

### **Demographic features of groups**

As groups are informal and tend not to keep records it is difficult to state their demography with any certainty. However, both in the US and UK women are claimed to form a bigger proportion of the membership of most groups than men (Wann, 1995, Gartner, 1985). In Elsdon *et al's* (2000) recent survey of self-help/mutual aid groups in Nottingham the gender balance was found to be 63.2% women to 36.8% men. A recent directory of groups from Self-Help Nottingham had 18 entries for women-specific groups and three for men (Hastie, 2000). In the USA Wuthnow (1994) also found that nearly half of the adult female population claimed to be in a self-help group.

This gender imbalance may partly be explained because many self-help/mutual aid health groups arose alongside the women's movement, particularly in North America. Gartner (1985), a feminist writer on self-help/mutual aid, claimed that activities which embody the values of co-operation and collaboration that challenge the patriarchal norms of competition and hierarchy are common features of women's self-help both inside and outside of formal structures. There is also a much stronger tradition of women sharing and supporting one another in groups. In particular, given the public scrutiny and critique

of women's bodies, related self-help groups, such as breast cancer groups, may pose less of a threat to women than to men.

Winsbury (1995), a sole man in a cancer support group, expressed concern about the lack of men in self-help groups and was struck by the way in which women 'give and receive moving and informed support to each other and me'. His observations led him to conclude that women 'place more confidence, more readily, in alternative, complementary and holistic approaches (to cancer)' (p9). This is perhaps not surprising given the continued critique of the sexism inherent in much of the professional theory and practices on which health and social care treatment is still based (Pascall, 1997).

Winsbury stated that in his own experience, most men look to themselves for a solution to a crisis but when that fails are reluctant to seek a solution elsewhere. Since men do take part in self-help/mutual aid groups this is not a claim of an essential difference between men and women, but forms part of the context in which self-help/mutual aid may be seen to have a particular relevance for women. These assumptions are explored as part of the case study.

In terms of the UK we have little information on the age breakdown of groups except that again only recently provided by Elsdon *et al* (*op cit*). This study found that 57.2% of the groups surveyed (sample size 113 groups) had a mixed age range and outside of this there was a preponderance of over 55s. On the surface it would therefore appear that self-help/mutual aid groups in health and social care are an ageing movement but this is not borne out by the overall growth and is more likely to reflect bias in the respondents to the study.

Since Elsdon's study did not address ethnicity or class, no up-to-date figures are available in the UK on this matter. Wann (1995) claimed that self-help/mutual aid groups in the UK have a particular importance for minority ethnic groups. Although there is no empirical evidence to back this up the contemporary history (see Chapter Three) would make this very likely. As Appendix 1 also illustrates, ethnic-specific groups are visible, such as the Asian Women's breast cancer groups. As will be seen in the case study,

despite the stereotype of these groups as being the preserve of the middle-classes, they have a broad socio-economic mix and if anything, tend towards the lower social-economic classes. Similarly in the USA Makela writing on AA notes that it now has a culturally- and class-diffuse membership since, unlike traditional organisations, membership is based on:

individual life experiences and existential identity rather than... one's position in the social structure (Makela *et al*, 1996, p.3)

## **ORGANISATION AND PROCESS**

Although the size of self-help/mutual aid groups can vary, given their ascribed characteristics it is not surprising that grassroots groups tend to be 'small'. Whilst 'small' is not defined as such, as Karlson (2000) noted, this would tend to be a group comprising between 5-15 active members. Also, there may well be a much wider membership, who receive for example information, newsletters, minutes of meetings but who attend meetings rarely or not at all. In Elsdon *et al*'s (2000) recent UK study it is noted that the overall average of attendance tended to be around 15 members (p.25). Although traditionally self-help groups have been face-to-face groups, technology and people's personal circumstances (such as being unable to leave the house because of caring responsibilities, or condition-specific such as groups for agoraphobics etc) have expanded the form that self-help groups are taking and potentially the numbers involved. An example would be The Depression Alliance website which claims to receive over 500,000 page views every month and the women's health network which is run primarily through a telephone network (Hastie, 2000).

Organisationally groups are very interesting as the philosophy leads (in theory) to a non-hierarchical, democratic form for the group. Whilst this is not always borne out in practice (see findings) these potential features are a source of interesting comparison with mainstream organisations (see for example Borkman's 1999 analysis of the success of AA built on the antithesis of modern bureaucracy). Borkman's model of fledgling,

developed and mature groups suggests that as groups mature they *tend* to become more formal in nature with ascribed and clear roles for different members.

### **Experiential Knowledge**

At the core of the processes in all self-help/mutual aid groups is the sharing of personal knowledge of one's own experience, what Borkman in 1976 termed experiential knowledge:

experiential knowledge is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation or reflection on information provided by others... it is subjectively based (*ibid.* p.446).

The opportunity to share direct experience has for some time been seen as having an intrinsic value or therapeutic value in and of itself. Whilst this is important, this focus reflects yet again the psychological and rather individualistic nature of much of the self-help/mutual aid literature. By contrast, Borkman's building body of work in the US about experiential knowledge views the collective knowledge built over time in a group as critically affecting the group's (and therefore individuals within it) potential to reconceptualise the issues they face.

Knowledge gained from the experience of having and living with a problem is important. Borkman (1990) suggested that the importance of this knowledge is underestimated. She makes a distinction between three forms of knowledge: professional, lay 'folk' and experiential, as shown in the following table.

**Table 4: Experiential, Professional and Lay Perspectives**

<b>Perspective</b>	<b>Relationship to Problem</b>	<b>Form of Problem</b>
<b>Experiential Self Helper</b>	Personal experience or significant other experiencing the problem	Concrete, pragmatic, Existential, Philosophical, Conveyed in oral stories
<b>Professional</b>	Theory based training, Clinical reasoning	Abstract, objective generalised. Codified in journals/books
<b>Lay</b>	Bystander; no first hand knowledge	Hearsay, media, “recipe knowledge”, second hand from anecdotes

*Reproduced from Borkman, 1999.*

This illustrates that there are significant differences in these different ‘actors’ relationship to the ‘problem’ (sic) and therefore their understanding of ‘it’. This will affect the way in which knowledge about a problem/situation or issue is conveyed and developed. Wilson, (1995) has also noted that professional and experiential knowledge bases are very different in the UK. Drawing on a number of theories from adult education and learning (Kolb, 1984; Bandura<sup>4</sup>, 1977, 1993, 1995) Borkman conceptualises self-help groups as ‘learning communities’. As Borkman (1999) stated, self-help/mutual aid groups do the equivalent of reflecting upon their practice – which is the practice of living. In this theory self-help/mutual aid groups first develop their knowledge about their problem and how to deal with it, then their members apply that knowledge. The difference between an individual’s experiential knowledge and that held by the group is also made explicit, as the following quotation illustrates:

It is “subjectively based” knowledge that integrates the feelings, thoughts and ideas about the experience... a reflective process is necessary to convert “raw experience”, which is often a jumble of inchoate images, thoughts, impressions and feelings, into knowledge (which implies some form, coherence and meaning). The reflective process can be done by

<sup>4</sup> It should be acknowledged that Thomas Powell (1987) also suggested Bandura’s social learning theory as applicable to self-help groups.



oneself or with others, as when one talks about one's experience. A key point about self-help groups is that the reflective process is done with others who have shared the same experience and thus have specialised knowledge about it and a personal stake in its interpretation. (*ibid.* p.15/16)

This communal learning can produce what Borkman terms "disciplined subjectivity", which is qualitatively different from one person's idiosyncratic interpretation of their own experience

...the definition includes the sense that the person has some conviction that the experience he/she has reflected upon and processed is in fact knowledge and understanding (*ibid.* p.16, 1999).

An important aspect of knowledge held, distilled and shared in a self-help/mutual aid group is that it will become part of the collective knowledge, passed on even when the initiators leave the group.

Most recently Borkman has been applying this conceptualisation to fledgling and developed groups (as outlined above), where she notes that in fledgling groups professional knowledge and authority is accepted as there exists an uncertainty or insecurity about members own knowledge base. In contrast, developed groups who have gone through the reflective processes indicated above, have a confidence about experiential knowledge and therefore the use and acceptance of professional knowledge is limited. Another way to look at this that does not necessarily view experiential and professional knowledge bases as always competing with one another is that confidence and prioritising of an experiential knowledge base means that professional knowledge can be used where helpful and challenged, adapted or rejected where not so. Whilst Borkman noted that this confidence can lead to individuals or groups forming a new dogma about their condition or situation these same processes can lead to both confidence and authority being vested in experiential knowledge with an openness to other views.

## **Storytelling**

As is suggested in Table 4 (p26) the mode in which self-help/mutual aid groups communicate is by telling their stories; this has been noted and illustrated by many self-help/mutual aid researchers (Cain, 1991; Humphreys, 1992; Rappaport, 1993). However applying the study of narratives to self-help/mutual aid groups is still in its infancy. As Borkman (1999) noted the literature in this area (mainly humanities and behavioural sciences) all emphasize that human experience is rendered meaningful through the narratives or story-telling (Bruner, 1990; Polkinghorn, 1988). Existing narrative analysis also suggests that for both individuals and communities (groups) narratives are a vehicle for framing or constructing the world (Bruner, 1990; Reissman, 1993).

This process in self-help/mutual aid can be contrasted with the formal dialogue in professions. Professional encounters often decontextualise 'information' about one's health or social situation whereas experiential knowledge is utterly contextualised. Brody (1987) argued that medics devalue personal narratives by expecting patients to restrict their litany of symptoms to a medical history; we will see this replicated in the case study where one group struggles to reframe its stories as 'issues' for a service-led consultation exercise. However, in the UK in the past few years it should be noted that there has been an increasing interest in the relevance of service users' narratives, the narratives between service user and professional and narratives *within* professions<sup>5</sup> (CARN, 2000). Whilst this acknowledges both the content and form of experiential knowledge, it should however be noted that the emphasis of this work is on individuals or individual encounters rather than the collective narratives that may arise in groups.

Although there is a literature emerging on the use of narrative in relation to self-help/mutual aid groups, very little attention has been given to the type of discourse or communication that occurs within groups (Borkman, Zoher, Ney and Bender, 2000) this appears to be a very important area for developing theory on how groups build their

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<sup>5</sup> There is also a related interest in harnessing practitioner's experiential knowledge through fictional story (see Winter, Sobiechowska and Buck, 1999).

knowledge base. As Borkman (1999) noted, the building of experiential knowledge is a matter of both content and process. Despite the absence of work in this area at the start of the study, new work began to emerge towards the end of the fieldwork on 12 step groups (Borkman *et al, op cit*) which will be outlined and discussed in more detail in relation to the findings in Chapter Seven below.

## **Reciprocity**

One of the many features attributed to self-help/mutual aid groups but seemingly rarely expanded upon is the reciprocal nature of the social relations in self-help/mutual aid groups. Reciprocity is not only a feature of group relations but can also be seen as an important part of the process of groups that builds the trust that enables active members to exchange their stories and experiences. And yet as Gouldner, a sociologist, remarked in 1960

few concepts... remain more obscure and ambiguous (*ibid.* p.161).

Yet the concept has been used by philosophers for more than 3,000 years. As Kildal (2001) observed, there has been a normative expectation of mutuality as an organising principle in social life which is basic to the idea of reciprocity. Reciprocal relations involving gifts and return of gifts, rights and duties are deemed to be a basis for social cohesion (p.2).

The form that reciprocity takes in grassroots self-help/mutual aid groups can primarily be seen as two-fold. Firstly, because membership is voluntary, active members who attend group meetings engage in a series of freely given 'exchanges' of stories, support, advice and so on, the process is therefore one of a pattern of reciprocal exchanges. Active members are in the position of both giving and receiving support and advice. Much of the US literature refers to these exchanges as the 'gift' culture of self-help/mutual aid groups. The benefits attributed to groups (discussed below) indicate that some professionals may seriously underestimate the importance and benefits to be derived from the reciprocal interchange that goes on within groups.

Secondly, some studies of self-help/mutual aid groups suggest that the reciprocity in groups is not always 'direct' but rather entails what is termed 'serial reciprocity'. This is where a new member receives support and advice from her peers but 'repays' this at a later stage in her own development by reciprocating the support either to her established peers or to a new member of the group (Katz, 1976; Gartner & Reissman, 1977; Richardson & Goodman, 1983).

## **INDIVIDUAL AND GROUP GAINS**

Many American studies have explored the impact of group membership on the active members of self-help/mutual aid groups. In the main the studies have been framed in a paradigm that reflects the predominance of the psychological model of conceiving self-help/mutual aid in relation to 'therapy' and human services; the studies therefore have been mostly concerned with personal or intra-personal effects of groups. A significantly smaller body of work reflects those studies in the alternative paradigm noted above ('normative social networks', 'voluntary action' or 'political action groups'). A summary table below shows commonly-attributed benefits from attending groups. These benefits are drawn from studies on a wide spectrum of self-help/mutual aid groups and a variety of methodologies, reflecting both self-reports and measured outcomes.

**Table 5: Benefits derived from attending self-help/mutual aid groups**

<b>PERSONAL</b>	<b>INTRA-PERSONAL</b>	<b>COLLECTIVE</b>
improved self-esteem	mutual support	broader world view
improved self-confidence	mutual sharing of experience	collective perspective and mobilisation for social change or service innovation
improved emotional well-being	comradeship	Opportunity to influence services
practical information	friendship	
practical support	not feeling alone	
emotional support	Sharing coping mechanisms	
feeling less isolated		
spirituality		

(Drawn from: Suler, 1984; Denzin, 1987; Trojan, 1989; Medvene, 1990; Humphreys and Rappaport, 1994; Wann, 1995; Wilson, 1995; Kurtz, 1990; Elsdon *et al*, 2000)

The first two columns of the table also reflects the results of UK studies (Thoburn, 1987; Wann, 1995; Wilson, 1995; Elsdon *et al* 2000<sup>6</sup>; and Charlton & Barrow, 2002).

Additionally, a number of studies in health areas have made claims that attendance at a self-help/mutual aid group leads to an improvement in aspects of the condition and/or management of the condition. For example, in a broad review of mental health studies which compared the differences in such things as mental health episodes and admissions to hospital between those who do and do not attend groups, there was a consistent finding that active group membership resulted in reducing members' use of services (Mental Health Net, 1999 & 2002).

It is important to note that writers who are moving to 'locate' self-help/mutual aid within alternative paradigms stress the links that need to be made across the various findings, that is, the impact of personal gains on the broader society. Borkman and Messer (1996)

<sup>6</sup> Elsdon *et al* in 2000 were still noting that in the UK there exists only limited UK research on self-help/mutual aid (preface)

for example, argue that the types of skills members acquire in groups, such as organisational skills, understanding others' perspectives and comradeship, are building a form of 'social capital'<sup>7</sup> in the community that can be translated into other areas. This view is discussed further in Chapters Seven and Eight in relation to the findings from the case study. Elsdon *et al* (2000) in the UK have made a similar point: they define the types of learning that go on in-group as related to content (about the issues being faced), occupational (what is required to assist them in carrying it out), social and personal learning (such as self-knowledge, social skills) and political learning (managing problems of authority and conflict). They view social and personal learning, such as the intra-personal benefits attributed to groups as the vehicle for all other learning and see these attributes, plus those potentially derived from participating, taking responsibility and running democratic organisations, as developing leadership skills that could transcend the group setting.

Given the listing of potential and actual advantages it is still unclear why some people choose to join groups and others do not. As Gonyea & Silverstein (1991) observed, few studies have been successful in specifically identifying either demographic variables or other factors that account for membership/non-membership. A variety of suggestions have been put forward ranging from factors that may inhibit membership to critiques of the limitations of groups. In the former it has been suggested that access may be a problem for some people either due to geography, social skills or literacy (Jacobs & Goodman, 1989). Levy (1992) and Jacobs and Goodman (1989) believe that those who join groups are probably more actively motivated to change as well as having greater social skills. Charlton and Barrow's (2002) UK study of groups for people with Parkinson's disease suggests that members are more likely than non-members to acknowledge their illness rather than deny it and be prepared to engage in the long-term consequences of their illness. Finally, Wilson (1995) suggested there are also practical

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<sup>7</sup> Putnam, a political scientist used the theoretical concept of social capital as an explanation of his findings from a 20-year study of regional government in Italy (1993). Social capital is viewed as features of social organisation, such as the trust, norms and networks that contribute to develop the health, wealth and industry of a community. These networks are seen as encouraging an enabling an active and participative civil society. Reciprocity is an important component of social capital – either direct or serial; where in the latter people will undertake activities that are of no immediate personal reward but will directly benefit others, with a belief that they in turn will also do so (Campbell, Wood and Kelly, 1999).

problems that inhibit groups attracting members, such as, inexperience in running groups, resources and loss of 'expertise' as core members leave.

However, the few critiques<sup>8</sup> or discussions of potential disadvantages of self-help/mutual aid groups suggest some alternative reasons. Wann (1995) suggests that groups may be perceived as stigmatising and therefore actually increase isolation from mainstream society rather than reducing it (Wann, 1995). In a similar vein there has been a critique from some feminists who have argued that self-help is an apolitical variety of cultural feminism or identity politics (Taylor 1996). Critics such as the historian Echols (1984) and Kitzinger & Perkins (1993) see groups as stressing private and therapeutic solutions over public and institutional ones. Particularly critical of 12 step organisations, Wolf (1994) for example, sees groups as colluding with 'victim feminism' that exaggerates gender oppression and leads to all-female solutions that paradoxically value traditional notions of femininity. Taylor (1996) and Borkman (1999) vehemently reject this view claiming it is a partial and inaccurate understanding of groups, which does not perceive or acknowledge the broader impact of group membership. It is also arguable that women may make particular gains from groups where they may experience a sense of 'control' and change over their lives in a society. However, such groups still do not give equality of access to or equality of representation in the public institutions that define situations and make policies that impact on many areas of their lives (Munn-Giddings, 1998).

As the earlier discussion has indicated, there are likely to be tensions between professionals and self-help/mutual aid groups. It is also suggested that professionals may not alert service users to relevant groups as they fear 'misinformation' or increased emotional distress resulting from attendance (Wann, 1995). Wilson (1995) pointed out that professionals and self-help/mutual aid groups inhabit two very different worlds. Self-help/mutual aid groups provide important services that can complement or challenge those traditionally offered by human service organisations. Yet for ideological and

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<sup>8</sup> It is rare to find written critiques of self-help/mutual aid groups, particularly in the UK. The literature is therefore dominated by researchers who promote their activities and is a drawback in developing critical theorising. Whilst studies suggest that many professionals are wary if not threatened by self-help/mutual aid groups (Wilson, 1996; Elsdon *et al* 2001) this is rarely reflected in the accessible literature.

structural reasons there is a tension between self-help groups and services, which may evolve under certain conditions towards either conflict or co-operation.

Perhaps the most fundamental of more general issues is the underlying tension in the relationship (self-help and the statutory sector) ignored by many authors. The nature of professionalism endorses the professional as expert, using knowledge refined through long years of practice and gained through training. The self-helper uses experiential knowledge, and has expertise from living with a problem. Professionals who seriously want to work with self-help groups will have to reappraise their own roles, accept the strengths and potential strengths of their clients and be prepared to give up some of their power

Wilson (1995, p58)

Wilson's UK study of 49 groups and 50 professionals concluded that professionals found it difficult to perceive groups outside of their own frame of reference. They assumed, for example, that people joined groups in order to influence services, whereas members' primary concern was mutual support and information. The importance that members attributed to giving as well as receiving support was also underestimated. More recently Elsdon *et al* (2000) have come to similar conclusions, noting the incongruity between the initial motivation for joining a group if referred by a professional to the actual benefits from group membership.

## **SUMMARY**

Self-help/mutual aid groups then appear to be a growing phenomenon both in the UK and world-wide. The dominant form appears to be in single-issue groups that transcend class boundaries but, it has been suggested, may have a particular significance for women.

The dominant research has been primarily concerned with understanding their relationship to professional organisations whilst the findings from studies that see them as part of the wider fabric of society attribute a particular importance to self-help/mutual aid as a form of voluntary action and social change. In the UK there is no such body of work, although Wann (1995) suggested that the importance of self-help/mutual aid groups be recognised by the UK policy makers and Elsdon *et al's* (2000) study hints at this agenda. The processes in groups are clearly important in effecting change at a



personal, collective and societal level. The process that is most theorised, the building of experiential knowledge, is likely to lead to some groups challenging existing understandings and bodies of knowledge about their particular condition or situation. Active participation in self-help/mutual aid groups therefore affords a route and process through which redefinition of medical and social conditions may occur, or that at the very least 'place' the condition in the circumstances of people's lives. However, these understandings are currently heavily reliant on the US knowledge base which has been developed from a different culture and welfare system and cannot therefore be simplistically transferred to the UK. Whilst the few UK studies that do exist attribute similar characteristics and personal/intra-personal benefits to self-help/mutual aid groups, none to date have explicitly placed them in a wider framework that examines both the place of groups and their broader impact on society. This is the terrain of social policy.

If these groups have such a range of 'benefits' attributed to them and even the potential to change their own and others' conceptions about conditions and situations – what is the relationship of these groups to social policy? This seems an important and currently under-researched area generally but particularly in relation to the UK. In the latter, whilst there has been a burgeoning interest in the related service user movement (such as Ramon, 2000 & 2002; Barnes, 1997), no such interest has been shown in the activities of self-help/mutual aid groups *per se*. This may well be because, as the review showed, the activities of grassroots groups are largely 'hidden' unless they become campaigning groups. In addition UK social policy and even its most critical theorists tend to be pre-occupied by the description and analysis of state provision (Backwith, 1996). Self-help/mutual aid then is only ever likely to be considered in policy terms when it becomes visible and incorporated into understandings of the movements/shifts in welfare policy, such as, currently by user movement and governmental initiatives in 'involvement/participation'.

However, as the review of the literature has illuminated, the activities of groups are not solely about or concerned with service involvement and change, rather there are a range of gains and benefits to be derived from groups. But even this picture of self-help/mutual

aid is incomplete, because a focus on the benefits (individual, collective or broader) leaves out the underlying and surrounding historical, social and economic political and cultural context of evolution which it has also been suggested is significant. These factors are all significant in terms of developing a broad framework for understanding self-help/mutual aid groups in relation to social policy in the UK as the final section of the chapter now illuminates.

## **UNDERSTANDING SELF-HELP/MUTUAL AID GROUPS IN RELATION TO SOCIAL POLICY**

The overview of contemporary self-help/mutual aid groups in health and social care helped to define some of the gaps that exist both generally and specifically in the UK literature. The core of these issues is the focus for the case-study in Part Two of this thesis. However, in terms of understanding self-help/mutual aid in relation to social policy this was only one side of the story. We need to understand not only how the groups perceive themselves and the benefits that they attribute to membership, but also how the UK state has perceived self-help/mutual aid groups and responded to them. Developing an understanding of ‘both sides of the story’ enables a much richer dimension of the relationship to emerge.

This raised the conundrum posed in the introduction, that despite the continued rise in the profile and scale of these groups in the UK they were not and are not a major area of academic study or of national policy initiatives. As the following chapters (Two, Three and Four) will illuminate, with regard to the contemporary groups there has only ever been one piece of short-lived national policy in 1996 to support these groups. This stands in contrast to some other countries’ national support, for example, Germany and some states of the USA who provide clearing-houses to support, advise and network groups. In the UK only a few such regional initiatives exist, such as, Self Help Nottingham who are joint funded to provide support and advice to local self-help/mutual aid groups (see Chapter Three).

This lack of interest cannot be understood in a vacuum. Both the general and UK review of the profile and activities of grassroots self-help/mutual aid groups suggested that they are small-scale groups, meeting either outside or independently of mainstream services. In terms of social policy it therefore seemed limited to analyse them only through the lens of their relationship to professional services. Moreover to adopt the 'therapeutic' or 'human service' paradigm was likely to confine an understanding of their 'role' solely in relation to their members rather than the broader society. Whilst these paradigms gave useful insights they offered little explanation about the relationship of self-help/mutual aid to social policy.

The question of definition, of the 'place' of self-help/mutual aid in both the welfare and wider societal spectrum was therefore important. Drawing on the 'alternative paradigms' that emerged in the mid 1990s (p.20), this study therefore implicitly adopted *and* developed an approach that would fit within the 'voluntary action' paradigm outlined above. Rather than locating self-help/mutual aid groups solely in relation to professions, this approach places them in a broader societal context, as a form of voluntary action in the third sector of society. It is useful therefore to outline these terms before turning to the historical component of the study.

### **Self-help/mutual aid as a form of voluntary action in civil society**

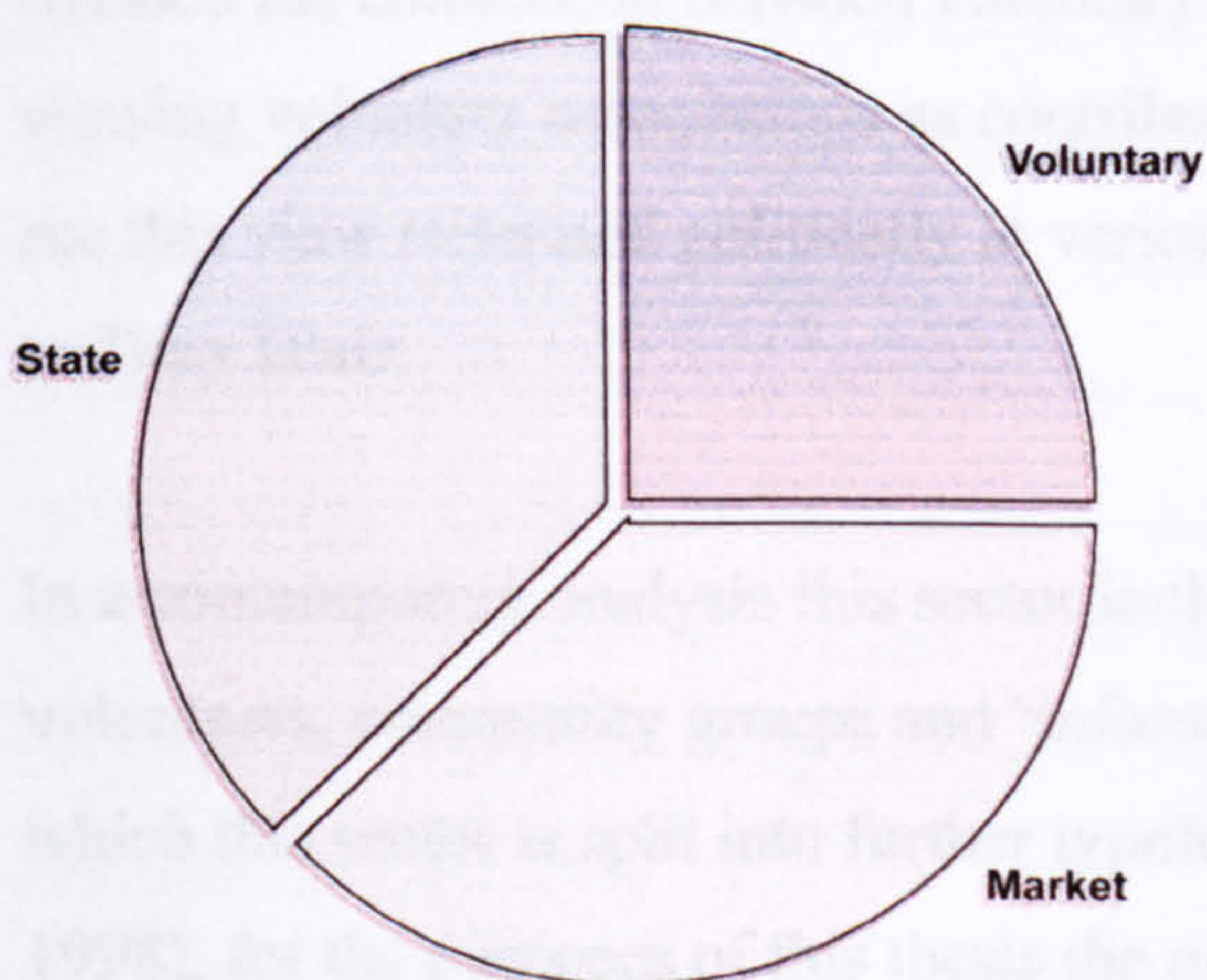
O'Ferrall (2000) described voluntary action as a 'human impulse' where individuals or groups act to meet the perceived needs of other human beings. As O'Ferrall noted, this suggests that voluntary action embodies a moral quality as it implies 'actions that are guided by advantage to others rather than simply to the actor' (p.2). This action can be seen in both philanthropic and self-help/mutual aid actions. Volunteering is perhaps an obvious example of this, where for no payment one person 'gives' their time, labour or other skills to another. Borkman (1999) has termed self-help/mutual aid groups as a form of peer volunteering where the principle of reciprocity is enacted, members of groups both gaining and giving something in an exchange based on equal relations.

Supporters of voluntary action, from de Tocqueville (1835) to Etzioni (1995), have viewed it as a necessary and essential contributor to the health of democratic societies, assisting people in taking responsibility for their affairs, as a source of education and character development and limiting the government's power and influence over the freedom of citizens. The diverse forms in which voluntary action occurs are also seen as a source of progress and creativity. We will see some of these ideas reiterated in the philosophy of different UK administrations in the next three chapters.

Voluntary action is often seen as a part of 'civil society', a concept which is perhaps most associated with Vaclav Havel who stressed both responsible citizenship and a pluralist civil society. Civil society is envisaged as a network of associations creating social ties between individuals and fostering organisations and political skills. Havel proposed the value of plural spheres in society rather than an over-riding commitment to a single sphere of politics. For Havel, civil society is a source for political initiatives and therefore a check on state oppression (Carter, 1998).

### **Self-help/mutual aid as part of the 'third sector'**

The phenomenon of voluntary action is at the heart of what is known as the third sector. The third sector is that part of society that lies between the state and the market.



**Fig. 1: Three-Sector Model from Wuthnow (1991, p.6)**

The three sectors are attributed various characteristics and whilst there is a plethora of theories about each of these sectors, I am using Wuthnow's definitions which are both succinct and relevant to the arguments in this thesis. He defined the state as the range of activities organised and legitimised by formalised (and in modern societies, centrally co-ordinated) coercive powers<sup>9</sup>; and the market, as the range of activities involving the exchange of goods and services for profit, based on a pricing mechanism linked to relative levels of supply and demand. The voluntary or 'third sector' thus becomes defined as activities that are indeed voluntary in the dual sense of being free of coercion and being free of the economic constraints of profitability and the distribution of profits (p.6-7, 1991).

This simple three sector model is derived from Alexis de Tocqueville (1835) an early theorist about the relations among voluntary associations, political participation and democracy (Wuthnow, 1991). He was impressed by the diversity that he saw in this third sector, in which he included the church, community groups, fraternal associations and civil organisations, and saw these activities as having specific political importance. De Tocqueville considered third sector activities as an essential indicator and feature of a vibrant democracy, where people banded together to do things for themselves or others, rather than relying on the state. As Wuthnow has stated, many scholars since have stressed the connection between voluntary associations and political participation, viewing voluntary associations as contributing to the cultural health of a nation. We will see this view reiterated politically at various points in the thesis from William Beveridge to Tony Blair.

In a contemporary analysis this sector includes self-help/mutual aid groups, charities, volunteers, community groups and 'informal networks'. Whilst there are many ways in which this sector is split into further typologies<sup>10</sup> (see for example, Burns and Taylor, 1998), for the purposes of this thesis the main distinction within the sector that I wish to

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<sup>9</sup> In this thesis I am predominantly discussing the state at a national level.

<sup>10</sup> I acknowledge the importance of looking at the inter-relations between self-help/mutual aid and other parts of the sector, but this is beyond the scope of this thesis.

highlight is the difference between philanthropic/charitable associations and self-help/mutual aid associations. This is generally important in terms of trying to distinguish the particular role and relationship self-help/mutual aid has in relation to the state. It is specifically important in the UK since, as we will see below (in Chapters Two-Four) there is a confusion in the existing literature which at times subsumes self-help/mutual aid activities within the broader philanthropic/charitable traditions.

Traditionally, philanthropy concerned giving, characterised by altruism and relationships of dependency, in the sense that one person was giving to another. Whilst we will see this clearly reflected in earlier forms of philanthropy, contemporary developments of charities are more complex<sup>11</sup>. However, as Elsdon *et al* (2000) noted there are still significant differences in the UK between self-help/mutual aid groups or organisations who provide solutions or at least coping strategies based on direct experience, mutual support and learning and other forms of organisation which are developed to meet their needs (statutory or voluntary).

In the UK, the third sector is sometimes referred to and equated with the voluntary sector. However, as we shall see in the following chapters although once in the UK the terms third sector and voluntary sector were used interchangeably to denote a variety of third sector grassroots activities including self-help/mutual aid, the new and influential definitions developed in the US by the John Hopkins Comparative Nonprofit Sector Project and now used extensively in the UK omits all grassroots activities (Horton-Smith, 1997 & 2000; Munn-Giddings, 1998; Morris, 2000). Throughout the thesis I have termed bodies that are formally constituted organisations, officially registered with the state and whose 'roots' are in philanthropy as the *formal voluntary sector* to differentiate them from self-help/mutual aid groups. Whilst this definition might include the new self-help organisations (as opposed to groups) it is one way in which to capture their different relations with the state.

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<sup>11</sup> Borkman, for example, has recently noted ((2002) that a broader conceptualisation of philanthropy is developing (O'Neill 2001, Schervish and Havens 2002) one that encompasses a more complex notions of caring and why people give to each other and what they gain from this exchange. This is leading to a broadening of the notion of philanthropy to include self-help/mutual aid activities.

## **Implications of locating self-help/mutual aid within a voluntary action approach**

Locating self-help/mutual aid groups within a voluntary action approach had several implications. Firstly, in terms of the design of the study it was translated into a concern not only with individual benefits from self-help/mutual aid groups but also in exploring the wider implications of the groups' activities. Viewing groups as a form of voluntary action also led to their placement within the much broader tradition of self-help/mutual aid activities in UK society. One way therefore to shed some light on the current absence of policy was to consider whether there are any patterns or themes that arise over time in the relationship between self-help/mutual aid and the state. However, indicating again the general lack of interest in these groups as a phenomenon there was no critical literature in the UK examining the relationship of self-help/mutual aid to the state *over time*. Rather it was dispersed among early labour histories (such as Gosden, 1961; Green, 1985; Kidd, 1999)<sup>12</sup> and the new histories of the UK voluntary sector (Davis-Smith, 1995; Kendall and Knapp, 1996). In the latter, despite acknowledging early forms of self-help/mutual aid, the emphasis (similar to the USA) was on tracing and constructing the history of philanthropic movements and their relationship to the state. This was reflected in the dominant theorising on state-third sector relations (James *et al*, 1987, 1989; Hansmanns, 1987; Salamon, 1987; Salamon and Anheier, 1994) the conclusions of which had limited applicability to self-help/mutual aid<sup>13</sup>.

Drawn from these discussions, therefore, the overall aim of the doctoral study was to explore the relationship of self-help/mutual aid groups to social policy – with a focus on contemporary single-issue groups in health and social care. This was to be tackled by:

1. Desk research that explored the historical relationship of the state to self-help/mutual aid *over time* and located contemporary grassroots groups within their

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<sup>12</sup> Towards the end of this thesis I became aware that there has been a renewal in early forms of self-help/mutual aid by the Voluntary Action History Society.

<sup>13</sup> Nevertheless, a number of themes were drawn from these theories and formed a part of the critical analysis. These included, whether self-help/mutual aid relations are reducible to absences in state provision, whether self-help/mutual aid has qualities not replicable by the state and whether there are patterns of conflict or co-operation with the state.

overall tradition and distinguished their relationship with the state from that of philanthropic traditions of voluntary action.

2. Fieldwork research that explored, from the perspectives of members of two self-help/mutual aid groups, the significance and impact of group membership on them, their personal, professional and 'political' relationships. The key research questions were:

- (i) Why they join and stay in groups
- (ii) What they feel they gain from being in a group (that is not available elsewhere)
- (iii) The impact/consequences of membership in terms of personal and 'political' relations (with professionals, community)
- (iv) The dominant concerns of the group
- (v) The key processes involved

We turn now to the first of these, the historical study that will give an overarching context to the in-depth case-study of contemporary groups presented in Part Two of the thesis.



## **Chapter Two**

### **Self-help/mutual aid before the foundation of the British Welfare State**

#### **INTRODUCTION**

Self-help has an eclectic political and theoretical background; it has been associated with the ideas of Samuel Smiles, a liberal, who advocated individual self-improvement (1859), as well as those of Russian anarchist Peter Kropotkin, who favoured co-operative endeavour (1902). Its eclecticism poses a dilemma for both the Left and the Right, who can see self-help principles as embodying elements of their own philosophy and ideology. This 'duality' may be seen to be behind the ambivalent and often contradictory response to self-help/mutual aid as a form of voluntary action in society – which is repeated over time. Commenting on contemporary forms of self-help/mutual aid groups Wann (1995) pointed out that it is an interesting phenomenon as:

contrary to the conventions of charities, voluntarism or post-war welfare states, self-help is about personal responsibility and interdependence as well as direct, local action. Its ethos is empowering and enabling rather than protective, prescriptive or philanthropic (*ibid.* p.ii)

Distinguishing the particular nature of self-help/mutual aid as a form of voluntary action, is therefore an important part of 'placing' it in the broad welfare and socio-political spectrum.

This chapter begins with an overview of the two key philosophers most quoted as promoting self-help/mutual aid. This provides a useful context for assessing the forms of self-help/mutual aid that manifest themselves in the modern period described in the second part of the chapter. The historical review will concentrate on the 19th Century – the period of industrialisation that can be seen as having given rise to the formation and development of mutual movements that were organising during the period in which Kropotkin and Smiles were developing their respective theories. After a review of the

key mutual aid organisations of the time (Friendly Societies and the Co-operative movement) I discuss their relationship with and to the state. The similarities to and differences from the emerging charity sector are also examined in some depth. I conclude with a discussion of the implications for understanding and 'situating' contemporary single-issue self-help groups that flourish today.

## **PHILOSOPHICAL BACKGROUND**

### **Kropotkin (1842-1921)**

Kropotkin was considered by many to be the leading theorist of the Anarchist movement in Europe. Much of his political thought is developed in his book '*Mutual Aid: A factor of evolution*', published in 1902, which explained the way in which his theories work and importantly how his theories and political views were developed from his observations of animal and human life. Kropotkin came from a privileged social background (a prince) and as a young man serving in the Cossack army also spent five years (from 1862-1867) as a naturalist studying the geology and zoology of eastern Russia (Logan, 1993). It was during this period that he made his observations that living things coped best with the harsh Siberian environment primarily through co-operative behaviour. This conclusion is contrary to the powerfully influential conclusion reached by Kropotkin's predecessor Darwin, that progressive evolution of the species rests on the struggle for life and the law of mutual contest.

Coming from such a background, Kropotkin was a well-educated man and before he began his own observations, and while crossing Siberia, read Darwin's book '*The Origin of Species*' (1859). He therefore began his studies looking for the struggle between individuals of the same species but could not find it.

...I failed to find... although I was eagerly looking for it ... that bitter struggle for the means of existence among animals belonging to the same species, which was considered by most Darwinists as the dominant characteristics of the struggle for life and the main factor of evolution (*ibid.* p12, 1993)

**Kropotkin did not wholly dispute Darwin's zoological thesis; rather he concluded that the struggle for survival has two opposing sides. He did observe that individuals of the same species struggled and competed where limited resources existed but, on the other hand, the struggle between individuals and their environment led to co-operation within the species (Freedom, 1997). Despite the fact that war and extermination exist in nature he claimed that mutual aid was prevalent and moreover that this is what results in creativity and development:**

**...we see that, in the animal world, progressive development and mutual aid go hand in hand, while the inner struggle within the species is concomitant with retrogressive development (*ibid.* p232, 1993).**

**Kropotkin therefore continually emphasised the importance of collaboration, which he believed could benefit isolated individuals as well as the species as a whole.**

**Kropotkin became particularly concerned about the differences of his own observations and those of Darwin's because of what he saw as the appropriation of Darwin's work by social philosophers, classically Huxley's essay 'The Struggle for Existence in Human Society' published in 1888 in the journal *The Nineteenth Century*. In this article Huxley used Darwin's work to develop the notions of 'the struggle for existence' and the 'survival of the fittest' to humankind. Kropotkin originally replied in the same journal with his mutual aid argument as a series of articles hoping that Huxley would engage in a dialogue, an invitation which the latter declined, despite being invited to do so by the editor.**

**In his resulting book *Mutual Aid: a factor of evolution*, begun in prison in Clairvaux, France and finally written whilst in exile in England, Kropotkin began to link his own zoological observations with a critical social philosophy of humans. In this work he specifically attacked the way in which social Darwinists were using the so-called natural law of competition and 'the survival of the fittest' to justify acts of racism (such as slave trading), the growing power of the state (based on the notion that competitive humans**

need regulation via a higher authority) and the miseries of the industrial revolution theories. He viewed the appropriation of Darwin's work as a specifically Anglo-Saxon development which tried to explain in pseudo 'scientific' terms the disasters being experienced because of capitalism and colonialism.

Kropotkin attacked Hobbes' notion of primitive humans as ferocious beasts, grouped in small families fighting each other for territory until a wise man/men (*sic*) imposed harmony via the state. Kropotkin traced the various stages of human evolution and claimed that human life outside of community or a society was impossible and that integrated societies existed before *Homo Sapiens*.

The mutual aid tendency in man has so remote an origin, and is so deeply interwoven with all the past evolution of the human race, that it has been maintained by mankind up to the present time, notwithstanding all vicissitudes of history... whenever mankind had to work out a new social organisation, adapted to a new phase of development, its constructive genius always drew the elements and inspiration.... from that same ever-living tendency (*ibid.* p.180)

In contrast to the contract notions of Hobbes and Rousseau he claimed that there is no point at which society was founded, citing hundreds of examples of mutual aid amongst insects, birds and mammals in societies that were barbarian and civilised (Freedom, 1997).

Rather than the state enabling harmonious relationships he claimed that from a historical perspective it has always been the function of the state to eliminate communitarian institutions and cited many example of the way in which hierarchical relationships stifle the initiative and capacity of both individual and mutual aid associations.

In barbarian society, to assist at a fight between two men, arisen from a quarrel, and not to prevent it from taking a fatal issue, meant to be oneself treated as a murderer; but under the theory of the all-protecting State the bystander need not intrude: it is the policeman's business or not to interfere (*ibid.* p183)

and (Kropotkin takes from French examples given in the *Journal de Economistes* April 1893, p.94)

**It is hardly credible, and yet it is true, that when, for instance, a peasant intends to pay in money his share in the repair of a communal road, instead of himself breaking the necessary amount of stones, no fewer than twelve different functionaries of the State must give their approval, and an aggregate of fifty-two different acts must be performed by them, before the peasant is permitted to pay that money to the communal council (*ibid.* p.187)**

**Kropotkin then viewed co-operation/collaboration as fundamental to human and social development and the majority of examples he cites are of 'equal' citizens engaged in mutually beneficial acts or behaviour (with some altruistic examples for emphasis). He also noted that forms of localised co-operation endure or re-appear even after the rise of bureaucratic government. For example, he described how, in the Kursk district of Russia, whole communities, rich and poor, on a given day combined their skills and produced to provide for the local community large-scale systems of drainage and irrigation across villages (p.205); he documented further examples from across Europe and claimed that they were prevalent across the world (p.209).**

**He differentiated this 'reciprocity' from acts of charity that he termed:**

**...a character of inspiration from above, and accordingly, implies a certain superiority of the giver upon the receiver (*ibid.* p.222)**

**This is the antithesis of the 'equal' practices of mutual aid, where people are not cast in the roles of either 'giver' or 'receiver' but are both simultaneously – a practice which can be seen to be 'empowering' in contemporary terminology. Interestingly, he attributes the motivation to undertake charitable works as not only related to the desire to acquire notoriety, political power or social distinction but also the desire to fill a gap not satisfied by acquired wealth:**

men who have acquired wealth very often do not find in it the expected satisfaction... the conscience of human solidarity begins to tell... (*ibid.* p.229)

For Kropotkin this underlined the human need for social relationships that cannot be fulfilled through individualistic behaviour.

Unlike Darwin's work, Kropotkin's work received little institutional support in either the UK or Russia at the time it was published. He was supported by the Director of the journal *The Nineteenth Century* and by the Secretary of the London Geographical Society but in general his arguments were ignored in academic circles as he was reproached for his ideological interests which were seen to deny the objectivity science required.

Despite this, *Mutual Aid* was widely circulated in workers' and syndicalist circles with hundreds and thousands of editions published and read out loud for illiterate people. His work has been claimed as the foundation of the modern anarchist movement and was influential in mid 20th century Spain as well as with the New Left theorists from the 60s onwards (Freedom, 1997).

### **Smiles (1812-1904)**

Samuel Smiles was the son of a Haddington shop keeper and during a diverse career that included being a surgeon, a newspaper editor and a secretary for a railway company, he consistently devoted his leisure time to the advocacy of political and social reform (Sharp 1999). He published *Self Help "The Art of Achievement"* illustrated by accounts of the lives of great men in 1859 and it has been widely seen as reflecting the ethics and aspirations of mid 19th century bourgeois individualism. In essence it preached industry, thrift and self-improvement and particularly perseverance. He attacked over-government which he viewed as debilitating personal effort and did not think that people should invest too much trust in state support but rather he favoured meritocracy:

Whatever is done for men or classes, to a certain extent takes away the stimulus and necessity of doing for themselves; and where men are

subjected to over-guidance and over-government, the inevitable tendency is to render them comparatively helpless  
(*ibid.* 1866, p.1)

Thus, Smiles also felt the value of legislation in terms of its contribution to the advancement of humans had been much over-rated, rather he placed his faith in the practice and efforts of individuals.

Old fallacies as to human progress are constantly turning up. Some call for Caesars, others for Nationalities, and others for Acts of Parliament.... This doctrine means, everything for the people, nothing by them, - a doctrine which if taken as a guide, must, by destroying the free conscience of a community, speedily prepare the way for despotism...a far healthier doctrine would be that of self-help

(*ibid.* 1953. P.37)

Halsall (1998) sees the book expressing the spirit of self-help as the root of all genuine growth in the individual and exhibited in the lives of many. The latter is important as the book illustrates gains to be had. Personal motivation was not exclusively for the middle classes but also the spirit and prerogative of working men (sic). It was published in the same year as Darwin's *Origin of the Species* and John Stewart Mills' essay on liberty. By the end of the 19th century it had sold almost a quarter of a million copies.

Whilst Smiles shared Kropotkin's concern about too much state intervention, his focus was on the effects on individuals' capacity to secure their own welfare through their own conduct. He therefore saw that biographies of great and good men were the most useful and instructive guides and incentives to others. As Asa Briggs pointed out, the purpose of self-help was clearly stated in Smiles' autobiography (1905) to illustrate and enforce the power of perseverance. The illustration through individual stories was supposed to promote the notion that nearly all human individuals through the energetic use of simple means and ordinary qualities could achieve self-improvement. His references were drawn from art and music, industry and engineering, the aristocracy, the middle classes and skilled artisans and interestingly, foreigners as well as Englishmen. This, as Briggs noted, formed part of "success" literature on both sides of the Atlantic designed to

provide readers with sound values and knowledge about how to get on in urban and industrial life.

Although his examples include some drawn from across the continent most are examples from Britain and Smiles' work had an implicit nationalistic flavour to it that must have been welcomed in Victorian England. The spirit of self-help as illustrated through the energetic action of individuals he sees as an enduring feature of the English character and the true measure of England's power as a nation. Smiles' saw the nation as nothing more than the aggregate of individual conditions, and civilisation as the personal improvement of the men, women and children of whom society is composed.

Indeed all experience shows that the worth and strength of a state depends far less upon the form of its institutions than upon the character of its men (*ibid.* 1953, p.36)

However, as Briggs also pointed out, Smiles had a radical background against which his work should be assessed and he did not equate success with simple financial success. During his time as a journalist he became editor of a radical newspaper, the "*Leeds Times*", and was working in the provinces during the economic depression. He held considerable sympathy for Chartism but not for its supporters' use of physical force and worked to bring the middle class and the working class together in a campaign against social privilege. The European Revolutions of 1848 and the failure of the Chartists confirmed in him a growing distaste for political panaceas and he became convinced that self-help was preferable to socialism. Self-help as Briggs noted was bound to be popular in the mid-Victorian years where in the UK little faith was placed in government and almost unlimited faith in individuals. Smiles did not abandon all his earlier views and continued in self-help to condemn superficial respectability and to praise manual labour and dexterity and to urge working class progress. His belief was that everybody could benefit from self-help.

Smiles met with opposition not only from socialists but also from critics of selfishness and was rebuked for not talking about failure. Smiles, addressing the latter of these



criticisms in the revised edition of his book published in 1866, stated that he praised the good rather than the best. He was concerned with the will to labour energetically and perseveringly. He made it clear that he did not consider that these characteristics were necessarily innate but something that should be striven for and taught by example, but it was dependency on others that he saw as enfeebling (hence the continued criticism of state socialists). In the preface to the reprint of his book in 1866 he expressed his dismay that critics had judged his work on the title of the book which had proved unfortunate, he stressed that the duty of helping oneself in the highest sense also involved the helping of one's neighbours.

However, his conception of inter-dependence is clearly quite different to that of the mutuality/solidarity expressed by Kropotkin<sup>1</sup>. Smiles died in 1904 on the eve of the first moves towards the creation of the welfare state.

## **KEY HISTORICAL FORMS OF SELF-HELP/MUTUAL AID**

Given the different ways in which self-help/mutual aid was philosophised, we can begin to pick out the tendencies and expressions in both historical and contemporary manifestations of this form of voluntary action. But as the above discussion (particularly on Smiles) has also indicated, it is not always easy to clearly delineate the two. However, the differing emphasis on the purpose and consequence of self-help/mutual aid has led to different ideologies becoming associated with this term. Arguably, both historical and contemporary forms of self-help/mutual aid embody both individualistic and collective

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<sup>1</sup> In terms of the locations in which the studies were carried out, it is perhaps not surprising that the study designs and environments lent themselves to such different conclusions i.e. Darwin carried out his studies in the tropics which exhibit the greatest number of animals and plants per square metre; by contrast Kropotkin was in an immense area, sparsely populated, agrarian and with vast amounts of unexploited resources where climatic and ecological conditions are frequently capable of wiping out large spaces and inhabitants. The interpretation of the research also took place in rather different political and philosophical contexts. Darwin was an Englishman inevitably influenced by Western European moral philosophers of the day particularly Malthus (whom he acknowledged reading *during* the course of his studies) and his overt concerns with population control in the late 19<sup>th</sup> Century. Darwin was also living in a country that was over populated during a period of the industrial revolution and the birth of modern capitalism. The theory of Natural Selection fitted into the tradition of Thomas Hobbes, David Ricardo, Adam Smith as well as Malthus. (Freedom, 1997). Kropotkin was living in pre-Revolutionary Russia, in a hierarchical system dominated by the Czars at a time when the socialist movement was emerging. He by contrast, was moving towards anarchism during the course of his scientific studies and became very politically active post this period. He credits the biologist KF Kessler as being highly influential on scientific thinking (Kropotkin, 1902, p.14) and politically was particularly influenced by his readings by example of William Godwin, Alexander Herzen and the French anarchist Pierre Joseph Proudhon (see Fosl, 2000)

tendencies, which perhaps accounts for the confused and contradictory nature of state response, which tends to favour the former and be suspicious of the latter. The general emphasis of this thesis is on the mutuality aspects of voluntary action.

### **Medieval forms of self-help/mutual aid**

The early history of self-help/mutual aid is generally traced back to the mutual aid and friendly societies. Justin Davis-Smith *et al* (1995) trace self-help back to the fraternities, confraternities and religious guilds of Medieval England. They state that these fraternities were essentially religious gatherings with the purpose of offering prayers to the dead. But they also had social and welfare functions, and therefore can be seen as early examples of mutual aid, even as prototype friendly societies. Fraternities had basic democratic structures, which mirror the later development of voluntary organisations. Significantly, unlike virtually all other institutions of the time, women could hold office and be members in their own right. There is therefore the general impression that guilds were an important part of civil society. Their legacy of mutual support and democratic control lived on and was to re-emerge with the development of the friendly society movement in the late 18th century.

### **Friendly Societies**

The Friendly Society was both one of the most important social movements in the Victorian era and also perhaps the most significant working class movement during and since the industrial revolution and as such will form the emphasis of this chapter. Gosden in 1961 estimated that in membership terms, friendly societies had quadruple the membership of Trades Unions and eight times that of the co-operative movement (4 million, 1 million and .5 million respectively). All however, were important to the working class and stemmed from the same principle of mutual support amongst those facing a similar situation. Friendly Societies worked through the pooling of members' weekly contributions and enabled sick pay, the possibility of medical attendance during sickness and the payment of a 'proper' funeral to avoid a pauper's burial. They afforded

welfare benefits to the working classes that they would not have had access to or be able to afford as individuals.

Although Friendly Societies had their origins in the late 17th century it was during the later 18th century and early 19th century that they began to flourish; this was as Kidd (1999) noted, partly tied up with the growth of industrial occupations but also related to changes in the organisation of work, especially the migration of labour associated with rapid urbanisation. In the 18th century although wages were rising in towns, there was an increase in job insecurity and lower levels therefore of social security. This contrasted at the time with agricultural workers in rural areas of the UK who had comparatively better job security and access to the more inclusive welfare system under the old Poor Law (Kidd, 1999).

Friendly Society membership reflected this social divide and was highest in the regions where the population expansion was at its greatest, such as the Midlands and North West and was lower in the South and South East. Gosden (1961) traced a four-fold increase during industrialisation and noted that these societies were mainly (but not exclusively) concentrated around the developing urban centres in the Midlands and the North. This is interesting since we will see in Chapter Three that in the UK it appears to be in these same areas where contemporary single self-help groups still cluster; it is certainly where the remaining self-help resource centres are located.

Although the size and organisation of the societies varied over time they were formed around particular trades and with specific purposes. The classic organisational form was the local 'sick club' or the provision of 'decent' burials. Dying a pauper was a major fear amongst the working classes who saw their middle class counterparts begin to differentiate themselves even in death with payment for a 'decent' burial which included a good coffin, attendance by the emerging funeral service which provided the necessary 'pomp and ceremony'. Paupers without means were buried in unmarked graves, and ran the risk of being used for scientific study by the anatomists. Green (1985) provides a fascinating account of medical mutuality provided via better-off friendly societies where

members were able to hire doctors on contracts and in larger societies members were able to choose their doctors from a panel (based on experience/reputation). This leads Green to the conclusion that early forms of democratised services are unparalleled (even with user participation) since the rise of professions. Moreover, this practice established the mutual provision of health care as a universal concept amongst the working classes (Backwith, 1996).

It is really difficult to come by reliable evidence of the size of the movement and different texts quote different sources and indeed figures on this, but there is no doubt that Friendly Societies were the key agents of social insurance in the 19th century. Because they registered voluntarily, even official statistics based on registration are likely to be an underestimate. Johnson (1985) estimated made using local research in England and Wales calculated the proportion of sickness benefit members in Friendly Societies in 1901 as 41% of all adult males, whereas other sources based on the Royal Commission on Friendly Societies records in 1874 concluded there were around four million members and eight million beneficiaries which would equal 60% of the adult male population in England and Wales. Whichever figure is correct, certainly these self-help/mutual aid communities dwarf the proportion receiving state welfare through the Poor Law and overshadow those receiving support through charities and indeed, as Green has noted above, outstrip all other working class institutions.

Although the membership was predominantly male, where women's trades emerged so did similar societies. Davis-Smith noted that membership was also largely restricted to the 'better off' working class, such as skilled artisans and tradesmen/women who could pay monthly dues. Rowntree's poverty study in York in 1901 found the very poor unable to join these societies.

That said, there are differences of opinion as to whether these societies only catered for artisans and the better-off strata of the working class. Backwith (1996), for example, argued that institutionalised forms of mutual aid such as the Friendly Societies were mostly the preserve of the 'respectable' working class, reflecting the social divide explicit

in the Poor Law of the 'deserving' and 'undeserving' poor. Kidd (*op cit*) noted that the situation may have been more complex because commentators failed to distinguish between health and burial insurance and that there is likely to have been county and regional variation based around employment patterns, therefore social status is likely to vary with the type of society. Certainly one division within the societies was based on gender - with membership as shown above predominantly relating to men. This however, hides women's activity in these groups and although there is little research in this area there has been a recent attempt to explore this.

As is often the case the history of friendly societies has generally failed to look beyond class as Kidd (1999) noted the fact that they grew from certain occupations had the knock-on effect of excluding many women from their membership as shown above. However, whilst female members may have been a minority in the dominant friendly societies, women-only societies were formed. From the beginning most offered comparable mutual benefits, some with the addition of a childbirth allowance. In addition, reflecting women's dual role they took into account the performance of household chores when calculating sick pay. They ran along the same lines as the male societies, however, as most women were illiterate, men recorded their proceedings. It was more radical at the time for women to be associated with these organisations because they stood outside the family circle. Kidd stated that they were at their strongest when women's wages were higher than average but also when male employment was secure (otherwise the woman's wage would be used to cover the male loss of earnings). Geographically their prevalence corresponded with women's economic position and again mirrored the concentrations of their male counterparts e.g. they were strongest in the North and the Midlands where for example in Stockport 1794-1823 they were a third of all societies (37) and 27 % in Cheshire compared to London where they were 15% in 1794 and only 3% in 1837.

The little evidence that does exist (a seriously under-researched area) shows that female participation fell in the second half of the century and societies run by and for women became rare by the late 1800s. This is in direct contrast to the growth of male friendly

societies. By 1919 there were less than one in a hundred women were involved although there was still evidence of women as part of the membership in Lancashire and Cheshire (working in the cotton mills) but no women represented amongst the leadership. This was specifically related to the 19th century ideology of separate spheres of work for women and men endorsed through statutory legislation and pronouncements (see below in relation to the state).

The Poor Law embodied the ideology of the male 'breadwinner' and correspondingly negated female economic independence and confined female occupation to that of running households and bringing up children and as carers to members of the extended family. This led to the notion of the 'family wage' which, ironically, women became responsible for administering as part of the budgetary duties associated with running the household. This ideology and message was conveyed not only through legislation but also through charity workers, health visitors, medics and other 'experts' and formed part of the education and domestic training offered to women.

Despite its cultural dominance this model was in conflict with the everyday life of working class people where wages were low and many men were not in a position to earn enough to keep the family afloat. For most of the 19th century married women were forbidden by law from owning property in their own right. Not surprisingly, strategies for survival were diverse and included working, credit and pawning. In addition to the women's friendly societies other womens' mutual aid networks within local communities also became an important source of support. As housing districts became more segregated along class lines, the overcrowded, close knit communities the working class were a part of or joined, shared a common need for sharing and support. Such networks were supportive as well as regulative (for example, of behaviour). Examples of the types of support offered were small sums of money, domestic necessities, shared care for children or other family members (Ross, 1983). As Kidd says these were not like receiving alms because there was a cultural expectation that the service would be returned at a future date (p.153, 1999); this is known as serial reciprocity:

**Within families it became enmeshed with notions of duty and love. In mutual-aid networks outside the family, such reciprocity need not be immediate or between the same individuals, it could be deferred or mediated, but always integral to the gift was the obligation to reciprocate... a form of social credit (*ibid.* p.154)**

**It is important to note that there is documentary evidence of poor women being in the forefront of informal or non-institutional forms of self-help/mutual aid or as Backwith terms it 'distress communism' (Backwith, 1996)**

**Significant changes in organisation and size took place in the Friendly Societies in the 1830s. Early ones were local and independent but the movement in the mid to late 18th century came to be dominated by affiliated orders, that is societies with a central body to which individual and local societies could affiliate, becoming branches or lodges. These at the time afforded economies of scale spreading risks and costs and affording a wider spread of benefits; for example the Manchester Unity of Oddfellows by the 1870s had half a million members. The most rapid growth of affiliation during the 1830s and 1840s was in the Northern and Midland counties where there were trade depressions and unemployment.**

**By 1875, the societies were mirroring their philanthropic counterparts, centralising control and being dominated by matters of insurance. This, as Davis-Smith (1995) noted, led to loss of member control and the spirit of mutuality and increasing domination by the middle-classes. The demise of these societies came towards the end of the century when they were taken over by large affiliated organisations run by the middle-classes; the latter perhaps sharing more in common with modern day formal voluntary organisations and national self-help organisations.**

**Building Societies are frequently aligned with the same mutual aid beginnings. These were smaller in number but had the same pattern of development as the friendly societies. They consisted of a small number of skilled tradesmen (a maximum of 20) joining together to help themselves and each other buy a house. Early models closed after all members had built their houses. The real growth was from 1840 when they became**

permanent and were taken over by middle-class professionals; by 1875 they were commercial interests.

What is significant here is that friendly societies developed around 'working-class' trades and concerns (albeit more skilled working class). This demarks it from the philanthropic roots of charities that emerge almost exclusively from the middle classes. Towards the end of the century these trade clubs were joining together to become trades unions, increasing their power and their threat to the ruling classes. Whilst I will not cover this in detail trades unionism is clearly another expression of mutual aid – what is important to note is that in this period some trade unions offered the same benefits as Friendly Societies related to sickness, accident and unemployment and often funeral grants although, as Kidd comments, this may well have been a way for them to mask their trades union activities during periods of illegality (1799-1824) and official hostility such as the Tolpuddle Martyrs. Similarly the Webbs noted how craft unions in the engineering trade had originated as local benefit clubs.

### **Co-operative Movement**

Whilst I will not be looking at this in the same depth as Friendly Societies, it is important to mention the co-operative movement and its links with expressions of mutual aid. Most documentation has been of the Owenite co-op before the 1840s although the numbers involved in this communitarian phase were actually quite small. After a brief overview of that stage of the movement I will look at the consumer and retail co-operative movement which held many of the same principles as the Owenite experiments but which by 1850 had 20,000 members and one and a half million by 1901 (Kidd, 1999).

With the move from feudalism to industrial capitalism, as we have seen above land workers had nothing to sell but their labour. Alongside the formation of the Friendly Societies Robert Owen recognised the human costs of industrialisation as outweighing the economic gain and the concentration of wealth in the hands of owners. Owen was a social reformer, a Welshman who had made his fortune in cotton. He was convinced that



working class people - given the right environments - could form co-operative communities (Hall, 1999). He put this into practice in New Lanark, Scotland, where his own business was based. He provided his employees with schoolrooms, public halls, community centres and a nursery school. This would have been very radical for the time, although as Hall noted he paid no attention to political power and had negligible effect on 'the establishment'. There was however an explicit vision in his endeavour - he saw these co-operatives as an alternative vision to the capitalist society, a new moral world that he replicated in America and Glasgow as part of a socialistic vision. Although subscriptions from philanthropists underpinned the establishment of many communities he failed to get investment from new capitalists. This lack of funding alongside the internal contradictions meant that eventually the movement foundered. Nevertheless, he had communicated the underlying values of co-operation, which have led into other parts of the co-operative movements.

One of the most significant of these was the formation of the Rochdale Equitable Pioneer Society by the weavers in Rochdale after they failed to secure improvements in wages and living conditions through strikes. The 28 original subscribers set up their own shop (the Toad Hall Lane shop) and in doing so established a number of fundamental principles.<sup>2</sup> At this stage the Pioneers were differentiated from Robert Owen because they did not derive their model from middle class philanthropy. They were a working class group and their system of co-operation was designed to suit their own needs (Hall, 1999). However as Backwith (1996) noted, the last two of their principles effectively excluded the poorest sections of the working class.

This led to other initiatives for example in 1861 as co-operative housing for members, and by 1863 the Co-op Wholesale Society was formed, providing a federal wholesale agency, and in 1867 the Co-op Insurance Company, both of which exist today. The practice of the retail co-operatives involved the pooling of income by multiple families and the sharing of dividend and profits by the co-op society. The regular quarterly

dividend also enabled a degree of financial planning. By 1870 its successful expansion led to concerns that it might be in danger of losing its original vision in the midst of its material success. It was agreed that a national organisation was needed to bind the movement together and emphasise its wider role in society and thus the Co-operative Union was formed.

Women were also active alongside this movement and in 1883 Alice Ackland founded the Women's Co-operative Guild, fed up with purchasing food being the only decision delegated to women. The Guild set out to remedy this by educating and raising the confidence of women in their own autonomous guilds attached to their local co-op society and later by sponsoring women as candidates for places on co-op boards of directors and CWS directors. Mary Llewellyn Davies, elected secretary in 1899, had a significant impact in her 32 years in the post and linked her work there to broader feminist issues which included research into women's suffrage and women's trades unions. Among the achievements during her period of leadership were getting maternity benefits included in the 1911 Insurance Act and changing divorce laws to benefit women. Broader initiatives associated with CWS included the establishment of the Workers' Educational Association and convalescent homes for retail societies' sick members plus the CIS started to offer death benefits from 1904. This welfare provision extended to payments during the First World War that brought employees' army pay up to their usual wage. The state leant heavily on the successful co-operatives during the First World War, when Co-op Halls were requisitioned for troops and Co-ops turned out suits and blankets at prices as close as possible to cost for the Government. They were however, not well-treated in return (see State section below) and this is seen to have led to a change in the stance on political neutrality (Hall, 1999).

Generally this has been seen as a movement for the better-off working class but Kidd (*op cit*) suggests regional variation is again likely. London consisted of predominantly skilled workers (Kirk, 1985) but the situation was different in the North West where rank

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<sup>2</sup> Rochdale Society principles included: Democratic control, Open membership, Limited return on capital, Distribution of surplus in proportion to a member's contribution to the society, Cash trading only, Selling only pure, unadulterated goods,

and file membership was made up of operative workers. Again, the concentrations of members were in the Midlands and the North, which suffered the worst impact of the cotton famine in the 1860s. Purvis (1990) calculates membership of 20% of the population in exceptional areas such as Rochdale. Credit extension was a more controversial area of the retail co-ops and was frowned upon by the founders and leadership. However, in a survey by the Co-operative Union in 1891 societies admitted to giving credit for a variety of reasons including to members in times of sickness or temporary distress.

By 1917, partly as a result of their treatment by the state during the war and the strength of membership (4 million) a supported proposal was made at the Annual Congress to seek representation at local and national government – within a year the Co-operative Party was formed. In 1922, despite previous reservations the Labour Party and the Co-operative Congress each passed a joint working scheme that formalised their links, including producing Labour and Co-operative MPs at every election. During the Second World War CWS officials were active on many advisory boards. 1942 saw the introduction of the first supermarket pioneered by the Co-op and based on observations of American retail.

Whilst these are not the only examples of self-help/mutual aid during this period their prominence and legacy encapsulates a relevant context in which to begin to place single-issue groups in their wider societal context.

## **THE STATE AND EARLY MUTUAL AID**

The relationship between the state and early mutual aid has been an interesting one with parallels in the late 20th century. Attitudes have fluctuated over the course of time depending on whether they were held to be a threat or a support to the established order (Davis-Smith, 1997).

The state had welcomed self-help/mutual aid activities as mechanisms to encourage and support people to help themselves, but were cautious if not fearful, that they might provide a setting for plotting and even revolutionary behaviour. This is interesting considering Kickbusch (1983) also described contemporary single-issue groups as variously in the system, next to the system or in opposition to the system. Whilst middle class moralists had no problem with the insurance principle or the relation of self-help to thrift (the Smiles version of self-help), the collective organisation appeared to be more unsettling to the authorities. Local Friendly Societies, for example, would meet either weekly or monthly usually in the local inn or public house. This was a regular occurrence and indeed a condition of membership. Reports were that they were very congenial and encouraged an atmosphere of social cohesion and solidarity, with all the benefits this held for members and the risks perceived by this collective activity by the middle classes. This was particularly true of the women's Friendly Societies where the meetings in pubs and inns without children were seen - and indeed were - an act of independence by women (Kidd, 1999). The state response was therefore one of ambivalence – of cautious support.

In terms of mutual aid societies, the first General Act in 1793 aimed to encourage their formation (and remove the burden on the poor rate) and is the first legislative use of the word 'mutual' the historian Bob James could find (2000). He posits the view that Government may have been 'recognising' friendly societies because of concerns about dislocation caused by industrialisation. He also noted the French Revolution was 'in full swing' across the Channel. Therefore the 'secret society' aspect to the mutuals would have been of concern. Finally, James believes they were trying to encourage and support 'good worker' combinations but discourage 'bad workers', the latter of which might use their federal structure to relay information.

The period 1815-30 was one of great social unrest and friendly societies were again viewed with increasing suspicion. As stated above, Trades Unions were seen as potentially organising under the guise of a friendly society. Kidd sees the proliferation of

groups in the 1830s and 40s as largely a response and hostility to the New Poor Law – ironically since it was the intention of the Poor Law to encourage the self-help institutions, as well as discouraging relief applications.

According to Kidd, there had been preliminary concerns about the subversive possibilities inherent in the organisation of the working classes and a view that the middle-classes would be better organising such institutions. However, the obvious ‘thrift’ element embodied in those self-help/mutual aid activities eventually led to a belief that the state would be better as an enabler rather than as a provider. Therefore in the 1830s with laissez-faire politics, the view was to leave them alone with interference only in administrative matters. Although the Registrar John Tidd Pratt was hailed as the ‘Minister for self-help to the whole of the industrial classes’, as Kidd (1999) noted, it was the insurance elements of the friendly society practices that were approved of rather than mutual conviviality.

Self-governing bodies were, however, as much concerned with fraternity as insurance and there is evidence that they undertook, for example, special collections for members in need or extended funds to keep older members out of workhouses. Legislation was enacted ostensibly to protect the societies e.g. in return for voluntary registration friendly societies were exempt from rates and their funds protected. However, this also enabled the profiling of groups and it is interesting that many chose to remain unregistered (James, 2000).

Despite the concerns of the bourgeoisie of the potential these groups held for civil unrest, in fact the evidence shows that they offered alternative means for support and alternative ways of coping with common situations but they did not amount to a disruptive movement. An explanation may be that the interventions by the state in the regulation and recording of institutions mitigated the possible effects. James certainly views state intervention as ‘crippling’ even if not intentionally so. He shows that increasing surveillance, measurement and regulation continually tightened the definition and left

mutuals little room for spontaneity and innovation. It may however also be that very few of these movements were consciously proffering a threat to the state.

James (2000) suggests that it is useful to make a distinction between the aim and the method. 'Mutual aid' is a goal, the means to obtain it involves politics i.e. the method is a question of decision-making power. In his discussion (related to the contemporary de-mutualisation debate of friendly societies in Australia but drawing on UK history) he views the inclusion of co-operatives as mutuals as a romanticisation pointing out that the pooling of resources to benefit more than oneself is primarily motivated by self-interest rather than concern for others. Otherwise, as he stated, companies listed on the Stock Exchange could equally be seen as Mutuals. He contrasts co-operatives with Friendly Societies and sees both the motivation of members and structures as being quite different, even if the original retail co-operatives were set up by 'idealists'. The basis of the Friendly Societies not only involved each member having compulsory equivalent inputs and benefits but also was structured to benefit those 'in need'. Equally, until the great expansion of the Friendlies the organisations were run on democratic grounds until they began to parallel the representative democracy of the Co-ops and wider society.

## **PARALLEL DEVELOPMENTS IN PHILANTHROPY**

It is important to note that these activities took place alongside philanthropic initiatives that evolved to fill the gap in welfare provision due to the absence of any state welfare, bar the Poor Law, during this period. A brief and selective overview of developments of this other form of voluntary action during the same historical period highlights the differences as well as their shared history. There are many excellent accounts emerging of the formal voluntary sector's history (such as Taylor & Kendal, 1996; Davis-Smith, 1995) but what is striking however, is that the starting point and emphasis in these historical accounts is the tradition of philanthropy. Davis-Smith provides one of the few accounts of self-help/mutual aid as part of voluntary action in understanding the voluntary sector's history but their inter-relation is not fully explored.

**Philanthropy which forms the basis of charity as a form of relationship is quite different to that of mutuality. The former is based on a relationship of giving or receiving, whereas the latter is based on reciprocity of both giving and receiving in kind (peer-volunteering). The historical accounts reflect this, attributing medieval forms of philanthropy to concerns for the donor's 'fate of their souls' (Rosenthal, 1972). The concern for either social or spiritual prestige is reflected throughout the history of philanthropy and modern day charity, as is a concern with tempering threats to the social order and stability. This is particularly characteristic of the 16th, 17th and 18th century (in the wake of the French Revolution) and during the Industrial Revolution.**

**Similarly to self-help/mutual aid forms of philanthropy preceded the 17th century and existed as embryonic charitable organisations organised around monasteries and religious houses (Davis-Smith, 1995). The 16th century saw the emergence of the charitable trust in the context of the state's deliberations on the 'deserving' and 'undeserving' poor and also on the respective roles of charity and the state in dealing with poverty. For example, the Tudor period saw an unsuccessful attempt by the state to outlaw the giving of alms to all but the 'deserving' (Slack, 1988). There were also attempts to regulate charity out of concerns with potential fraudulent activity and too casual 'doles'. The basic form was a charitable trust or bequest. Jordan (1959) detects a change in emphasis in this period away from gifts related to religions to a concern with poor relief and education. In the 17th century, newly emerging merchant classes began a new form of relief by putting their money into trusts named after the benefactor.**

**The 18th century saw an explosion of a different form of philanthropic organisation from which modern day organisations can be seen as direct descendants. Groups of wealthy philanthropists joined forces in setting up voluntary organisations such as the Charity School Movement of 1729 which provided 1400 schools in England with 22,000 pupils. Andrew (1989) in her analysis of London based charities 1680-1820 detects three distinct phases, reflecting the different pre-occupations of philanthropists: 1680-1740 – promotion of education and employment; 1740-1760 – a concern with maternity and child welfare services; and 1770's-1820 – a concern with moral reform and discipline.**

Situating these in economic and political context she equates them with concurrent establishment concerns about labour for the military and colonies and the state's growing concern with the possibility of civil unrest. This not only puts philanthropic action in political context but also suggests that its activity often reflects the dominant concerns of the state.

By the 19th century the charitable sector was significant. *The Times* noted that in the 1880s the income of London Charities was greater than that of several nation states – voluntary action was therefore a significant feature of both the economy and society in Victorian times. As we have seen above, the political and economic context was the growing visibility of social need created by industrialisation's rapid urbanisation and population growth. The dual response to this situation 'outside' the state was mutual aid and the new form of philanthropic organisations. Politically, this fitted with the current ideology of economic liberalism with its emphasis on self-reliance and distrust of the state. Davis-Smith (1995) suggests that the philanthropists' motives were likely to be a complex mixture of altruism, a concern for a recognised position in society but also the convivial and social aspects of voluntary participation. He again noted that alongside the philanthropic organisations there was also a rich strand of voluntary action concerned with campaigning and political protest, involving the same strata of people such as factory legislation, sanitary improvement and prison reform.

The social composition of voluntary action is a contested area, but formal volunteering seems most likely to have been the preserve of the middle-classes and skilled working class. Mutual aid, on the other hand, can be viewed as the 'poor man's voluntary action' (Davis-Smith, p.17). There are accounts of distinct hostility by the working-classes to some of the philanthropic activity, viewing it as an attack on their leisure time and lifestyle. This would accord with the view that this form of voluntary action was primarily motivated by and afforded a 'social control' over the working classes (see for example Thompson, 1981 and Laqueur, 1976). Davis-Smith noted that although this is not clear, with different examples lending weight to different views, there was undoubtedly a strand of philanthropic action concerned with reforming rather than simply



relieving poverty (p.17). The ambivalence is also mirrored in the activities of women in these groups. Substantial numbers of middle-class women were involved (Prochaska, 1980 puts it at 500,000) the groups afforded them a role and position denied to them in the wider patriarchal society. Similarly to mutual aid societies however, there was resistance from within to womens' inclusion and a number refused women the opportunity of sitting on their committees.

## **THE STATE AND EARLY FORMS OF PHILANTHROPY**

The relationship of the philanthropic voluntary sector to the state is complex. Davis-Smith noted that there was a strong tradition of state support in the early 19th century. In the mid 1850s the Poor Law Board certified a list of schools, reformatories and refuges and gave assistance to 200 charitable institutions. By 1850 the Royal Commission passed the Charitable Trust Act and the Charity Organisation Society (COS) was established to act as a clearing-house for charitable activity. Partly prompted by the *ad hoc* growth of charities the COS also explicitly promoted a distinction between state and charitable activities – for charities to help the ‘deserving poor’ and the state to deal with the rest. The COS was therefore supposed to ‘filter’ all applications for relief (although this didn’t happen in practice as smaller charities were loath to give up their independence).

The latter years of the 19th century and early 20th century saw increased calls for more state provision. Led by the Fabians, social democrats and other socialist groups the shortcomings of the voluntary response were highlighted. Accompanying – and now famous – surveys of poverty (Booth, 1889-1903; Rowntree, 1901; Mearns, 1883) profiled the extent of poverty which could not be explained by fecklessness alone. A growing acceptance of the structural causes of poverty was therefore addressed by the series of Liberal Reforms in the early part of the 20th century. Jane Lewis (1993) also noted a shift in ideology from ‘undeserving/deserving’ to ‘helpable/unhelpable’.

The Minority Report written by Beatrice Webb and George Lansbury argued for a very different relationship between the state and the voluntary sector. By 1912 the Webbs

were arguing that the state should meet all basic needs, with voluntary organisations providing the 'top-up'. The Dean of Norwich, sympathetic to this view envisaged "the volunteer as aiding and supplementing the public authority; never as a substitute or alternative". The wave of state intervention in health, pensions, and school meals etc. did not cause the demise of the voluntary agencies; rather they appeared in a different form and in a partnership role with the state. Cole (1945) argued that they changed to focus on 'special needs' rather than general ones – filling the 'gaps' in statutory provision. Relationships were marked by inter-dependence though not all voluntary organisations welcomed this because they feared a loss of independence.

The National Council of Social Service (now the National Council for Voluntary Organisations) was established in 1919 with the intention of co-ordinating voluntary action around the networks of social services and rural development but also to have closer ties with the government. By 1934 Braithwaite (1938) estimated that charities were receiving 37% of their total income from the state as payment for services.

Voluntary associations therefore, were getting bigger due to an increase in state funding, taking on more paid members with the associated bureaucracy that this entailed. During the two world wars this close relationship was used by the state to assist them with the war effort.

The history of philanthropy then, can be seen to precede, run in parallel with and form a partnership with, the state in terms of welfare provision. It has held within it opposing ideologies of preservation and reform and this dialectic has provoked in the past a similar ambivalence by political parties to that suffered by self-help/mutual aid groups (Davis-Smith, 1995), the left in particular being wary of the gaps being filled by this sector that they felt should be undertaken by the state. There has however, always existed a tension between those for whom maintaining the *status quo* through voluntary activity was the aim and those who wished to use this form of voluntary action to address and promote social change.

## **SUMMARY COMPARISON BETWEEN EARLY FORMS OF SELF-HELP/MUTUAL AID AND PHILANTHROPY**

Whilst there is no doubt that mutual aid and other forms of voluntary action have an interlinked history they clearly have significant features that differentiate them.

Self-help/mutual aid then has a differential form and history to both the paid voluntary sector and the volunteer movement which has been unpacked in order to clarify the distinct contribution of self-help/mutual aid to the third sector. These distinctions can be seen in relation to the history, philosophy, social origins, values and organisational form that underlies activity in self-help/mutual aid groups. The following diagram is derived from the above discussion as a way of clarifying the links and differences.

**Table. 6: Distinctive and shared features of self-help/mutual aid and philanthropy**

<b>History</b>	<b>Philanthropic/ Formal Voluntary Sector</b>		<b>Self-Help/Mutual Aid</b>
	<b>Distinctive features</b>	<b>Shared features</b>	<b>Distinctive features</b>
<b>Philosophy</b>	charity philanthropic	voluntary action	mutuality inter-dependence
<b>Social origins Values</b>	middle class protective prescriptive status quo	high proportional membership of women	working class empowering anarchic movement
<b>Organisation</b>	hierarchical funded formal	identifying unmet need grassroots	democratic self-supporting informal

Both form a significant part in the history and tradition of voluntary action in the UK, a tradition that the social philosopher de Tocqueville saw as an important counter to state power and that Cobden (Anti-Corn Law protester) viewed as an essential part of 'healthy political existence' (as quoted in Harrison, 1971: p34). Davis-Smith pointed out that historians have either ignored or underestimated voluntary action in the history of the Welfare State, seeing the state and voluntary sector as unrelated. In 'reclaiming'

voluntary action as part of the project however, it is equally important that we unravel the relationship and the role self-help/mutual aid has in this tapestry.

## **CONCLUSION**

How might we understand this historical overview of self-help/mutual aid in a way that usefully contextualises contemporary single-issue groups and illuminates their relationship to the state and social policy? Tracing historical forms of self-help/mutual aid has raised themes and questions that can be re-examined in the next chapter and throughout the thesis. These are useful characteristics to re-examine as we explore contemporary forms in the next two chapters. However, given the changing nature of self-help/mutual aid over time we can propose that the forms of self-help/mutual aid are likely to be linked to the economic, social and political conditions from which they emerge. In the 19<sup>th</sup> century and early 20<sup>th</sup> century self-help/mutual aid can clearly be seen to be a response to the shared experience and knowledge of poverty. It was a class-specific expression – these were actions by the working class in response to the changing social relations created by the move from feudalism (itself a form of mutual obligation) to industrial capitalism. They occurred in the absence or limitations of welfare provided by state and charitable sources. But they did more than this in two important ways:

- They actively created *new* ways, indeed *strategies*, of *surviving* poverty and protecting members from the worse ravages of deprivation: in this sense they were also both *preventative* mechanisms as well as *strategies for coping* with poverty. The ideas embodied in some, such as contributory social insurance schemes, were later to form the backbone of the British welfare state
- Their *form of organisation* and *mode of operation*, in terms of its basis in *mutuality*, ran counter to that being propounded by the state and charitable organisations which were informed by the dominant ideology of the time bourgeois liberalism and its economic and political *laissez-faire* counterpart.

**These additional characteristics – the creation of new and different ways to cope with ‘problems’ and alternative/oppositional ways of organising (and their inter-relationship) are a recurrent feature of self-help/mutual aid over time. With regards to the latter point, little has been written about the content, experience and impact on members of their ‘meetings’ whether formalised for the societies/organisations or informal for neighbourhood networks. However, these were clearly highly relevant as it is the meetings, the expression of solidarity, that the middle-classes feared as potentially subversive. Kidd (1999) refers to the ‘conviviality’ of proceedings in friendly societies, the shared networks and reciprocal understandings (p.109). As was mentioned in Chapter One, for modern-day self-help groups it is the group meetings and associated processes in relation to sharing ‘experiential’ knowledge that have led to or hold the potential to offer such different conceptions/solutions of shared health or social ‘problems’. Kidd also noted that as well as being suspicious of these activities, it is likely that the dominant (propertied) classes just didn’t understand their form. This suspicion and incomprehension led to the belief that the working class did not know how to help themselves. It led to the ironic situation of**

**moralists and charity reformers preaching self-help to the masses in the face of overwhelming evidence of self-reliance and mutual assistance arising from within the working class itself (*ibid.* p.110).**

**This is not only an injustice to self-help/mutual aiders but also serves to hide the active way in which people were shaping their own lives. The hidden or obscured nature of self-help/mutual aid activity will be revisited in chapters three and four.**

**Whilst the forms of self-help/mutual aid in this era are class-based, we have seen that this was crosscut by gender. Women’s self-help/mutual aid evolved in both the friendly societies and co-operative movement and flourished by necessity in the private sphere, the informal networks of the neighbourhoods. Patriarchy replicated its ideology and form in the self-help/mutual aid movements, just as it did in the broader society, by excluding women from friendly societies (by virtue of trade) and positions of power in formal organisations.**

It is useful to conclude with a summary of the common features that expressions of self-help/mutual aid have shared in this historical overview. This is drawn predominantly from Backwith's exploration (1996) of how working-class people have contributed to the shaping of social policy: 'the people's welfare'. He identifies the following shared characteristics:

- **Independence:** people acting independently of the state
- **Empowerment:** by acting to effect change people gain power (formally and informally)
- **Collective:** usually based on social groups or communities; people with a common interest acting to influence social welfare
- **De-commodification:** an alternative to (individualist) market provision – primarily through poor working class activity such as health and housing

However, just as in contemporary times, we can see that expressions of self-help/mutual aid are not homogeneous but occurred in a variety of settings. There were those within formal structures such as friendly societies and co-operatives and non-institutional forms of self-help/mutual aid, such as the informal women's networks based on 'distress communism'. It does appear that as institutional groups expanded, particularly into a national form they began to mirror the structure and bureaucracy of their statutory counterparts. The common characteristics identified above are a potentially powerful binding force but there is little evidence of links being made across these different forms of mutual aid – rather the concern is predominantly with the subject matter (in this period poverty) rather than the philosophy and practice of self-help/mutual aid, the exceptions being in the founders of the co-operative movement.

In terms of social policy, these groups as Morris (2000) states are an early form of social capital. Their contribution to welfare provision and development can hardly be over-estimated. Yet as Davis-Smith (1995) stated the predominantly Whiggish accounts of the foundation of the welfare state (such as Thane, 1982 and Fraser, 1973) view self-

help/mutual aid and their charitable counterparts as something that led up to the founding of the welfare state, because of their failure and decline. In fact, similarly to voluntary organisations, self-help/mutual aid groups do not disappear with the establishment of the welfare state, rather they re-appear in diverse forms in the 20th century. Whether they are a response to failings or gaps in the welfare state or a phenomenon that transcends this relationship is an important issue I will consider in the next chapter. The following chapters then provide an overview of the developments since 1945 with a focus on the single-issue groups in health and social care that are the starting point and end point of this thesis. Some of the key issues are then explored with members of groups themselves in the case-study that forms the second part of this thesis.

## **Chapter Three**

### **The social policy response to self-help/mutual aid – from Beveridge to Thatcher (1945-1990)**

#### **INTRODUCTION**

This chapter builds on the previous one by tracing the relationship of key forms of self-help/mutual aid to social policy from 1945 to the end of the Thatcher administration in 1990. The social context and various ideologies underlying the different administrations are examined. In doing so, I critically appraise the similarities and differences in state response to the two main arms of voluntary action – philanthropy and mutualism – and revisit some of the themes identified in Chapter Two. The emergence of a new form of self-help/mutual aid, single-issue groups, is traced showing how in the first instance these were a response to perceived structural and cultural inequalities in areas such as gender, sexuality, race and disability. Single-issue grassroots groups in health and social care (outlined in Chapter One) are placed within this tradition because they share the same form and processes as these groups but they can also be seen to have emerged alongside the increasing professionalisation of services. The broad base of these single-issue groups transcends the class-based financial forms of self-help/mutual aid examined in Chapter Two.

The similarities and differences between the health and social care groups and the emerging service user and carer movements are explored showing that a key difference is that the dominant concern of the user and carer movements was and is to change service delivery and structures, whereas grassroots self-help/mutual aid groups' dominant concern was/is with the welfare of their membership. Therefore, while self-help/mutual aid groups form an important part of the service user and carer movements, I argue that they are not simply to be equated with them.



The chapter revisits some of the themes raised in Chapter Two. We will see that despite early ambivalence, the state increasingly moves towards a partnership model with the formal voluntary sector leading to policies that both support and constrain the parameters within which the formal voluntary sector operates. The response to self-help/mutual aid is, however, *ad hoc*. Despite Beveridge's explicit acknowledgement of their role and contribution to both the emerging welfare state and civil society, thereafter both the Left and Right engage only selectively with forms of self-help/mutual aid as directed by their own political agendas. In particular we will see this demonstrated in Thatcher's contradictory policies towards self-help/mutual aid which clearly embrace Smiles' notion of individual self-reliance, but show an unease with the collective nature of groups.

It is by necessity, a selective history, in two key aspects: the emphasis is on the relationship of self-help/mutual aid to social policy, therefore, the relationship with philanthropy/charity is related to trends in state/voluntary sector relations rather than policy details. Secondly, whilst referring to the dominant forms that self-help/mutual aid has taken since the Second World War, the detail of this chapter relates to its most prolific form since the 1970s, self-help/mutual aid groups in health and social care, which form the case-study component of the thesis.

## **THE BEVERIDGE YEARS (1945-1950)**

As was noted in the last chapter, although voluntary action in both its key manifestations (i.e. philanthropy and self-help/mutual aid) formed an important part of the WWII effort, there was growing political agitation for the state to provide for basic needs. The end of the war saw a coalition government, debating the importance of extending state provision into health, social services, unemployment (social security), education and housing. These debates were soon to come fruition with the Attlee Labour Administration (1945-51) that saw the state assume a greater role in the lives of its citizens than ever before. Inevitably this began to change the relations between the state and the voluntary sector <sup>1</sup>.

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<sup>1</sup> I am taking the view that the definition of the 'voluntary sector' should cover both philanthropy and self-help/mutual aid. This is a political point as the unfolding history will reveal. For the purposes of the text, to differentiate between the two 'arms' of the sector, I am referring to 'self-help/mutual aid groups' as the grassroots sector and define philanthropic/charitable organisations as the 'formal' voluntary sector.

Whilst the Beveridge report of 1942 drew heavily on the principles and schemes developed principally by the mutual aid societies of the 18th/19th century (friendly societies and co-operatives) to inform the development of the backbone of the new welfare state that is, the social insurance and assistance schemes; it appears that the dominant ideological position of the Labour Party was that the development of a comprehensive state policy and provision should and would negate the need for voluntary action (Davis-Smith, 1995; Taylor and Kendall, 1996; Thane, 1982). Lewis (1999) sees this as a fundamental shift in general political ideology. She concurs with Harris's view (1990, p.67 in Lewis) that late 19th century political leaders conceptualised voluntary action as part of the fabric of the state, with governments being perceived as providing the framework, rules and guidance to enable society to effectively run itself. As state influence and provision extends, so welfare pluralism becomes more difficult to achieve. In particular once welfare benefits are controlled by the 'central bureaucracy' so it becomes more difficult to 'tie in voluntary action' (p.258).

However, whilst the Labour Party generally viewed voluntary action as an activity that essentially preceded the development of appropriate state provision, it is important to note that a particularly prominent member of the administration viewed voluntary action as an integral part of societal development.

William Beveridge in his 1948 Report *'Voluntary Action: A report on the Methods of Social Advance'* explicitly acknowledged both the significance of voluntary action to both welfare and broader societal development. He also acknowledged the distinction between philanthropy and mutual aid and the contribution of each form of voluntary action. Both are seen as providing a vital 'check' against state control and the profit motives of the market.

It (the state) should in every field of its growing activity use where it can, without destroying their freedom and their spirit, the voluntary agencies for social advance, born of a social conscience and of philanthropy. This is one of the marks of a free society (Beveridge, 1948 p.318)

Whilst Beveridge's report, in terms of self-help/mutual aid concentrates predominantly on Friendly Societies, (which he felt had been badly treated by the developing Welfare State and deserved compensatory policy), he also refers to Trades Unions, Building Societies, Housing Societies, Consumer Co-operatives, Trustee Savings and Hospital Contributory schemes.

It is certain that the spirit of mutual aid among all classes, which inspired these schemes, must continue in one form or another, if the Britain of the future is to be worthy of the past (Beveridge, *op cit* p.117)

As Morris (2000) noted, Beveridge's concern with the contribution of these organisations to the health and happiness of a democratic society is similar to the interests that civil society theorists have in third sector organisations today (p.40).

Beveridge's distinction between the contributions of philanthropy and mutualism is important, since from existing literature it does appear that Labour objections to voluntary action were both a concern with the need for the state to meet basic needs (rather than the 'by necessity' forms of self-help/mutual aid) AND an ideological objection to charitable forms of voluntary action which were equated with middle-class patronage and hierarchical forms of organisation that reinforced class divisions. There were additional pragmatic concerns with the *ad hoc* nature in which voluntary sector provision had grown across the country unevenly and seemingly without accountability. However, it is likely that Party positions were not as homogeneous as some reports suggest, apart from Beveridge, Davis-Smith for example, noted that Clement Attlee had himself engaged in support of the voluntary sector (1995, p.28). Taylor and Kendall (1996, p.52) quote Prochaska (1992) as detecting that some parts of the Labour Party saw part of the philanthropic sector as progressing to a more egalitarian, less socially divisive ethos following the war. Therefore there was some support for encouraging more 'progressive agencies'.

This mixed response is supported by the policies that followed in 1944-48, of which the NHS Act of 1948 was key, bringing the voluntary hospitals under state control. The

ensuing policies saw the preservation of the formal voluntary sector role in education and health and social services but its replacement in health care and income maintenance by the state (Taylor & Kendall, 1996 *op cit.*). In terms of state-voluntary sector relations, this period then appears to be characterised by the enactment of the general acceptance that the state should have a central role in meeting the needs of its citizens and a recognition that collective endeavour would be the order of the day (Deakin, 1995, p.40). The principles of mutual aid drawn from the examples of the Friendly Societies and Co-operative Movement can therefore be seen as underpinning the development of the national welfare state.

Philanthropic organisations were treated with ambivalence, with the state/society negating their role in some areas and retaining it in others. Retention of the 'formal' voluntary sector however was based on new notions of the sector's role in complementing and supplementing state provision, carrying out tasks delegated to it by the state. Some agencies saw their role diminished, some carried on as before without the state and others came into closer contact with the state. Taylor and Kendall (*op cit.*) view this as an example of the sector thriving by adaptation and pioneering. They point, for example, to changes in the emphasis of the sector such as where services were taken over, charitable funds began to be used towards research and training (p.54). Areas that were not initially considered a state priority (such as Personal Social Services (PSS) residential sector) stayed beyond the reach of the state either in terms of governance or financial support. Taylor and Kendall also noted how the state in many fields needed advice and information services and drew on the formal voluntary sector to provide this knowledge. How did the 'formal voluntary sector' respond to this newly delineated role? Whilst welcoming the 'partnership' with the state there were understandably some concerns in parts of the voluntary sector about potential 'collusion' and the loss of independence and accompanying roles as innovators and critics of the government. Lewis (1999) also noted how it undermined the social principles of charity, which viewed the helping of others less fortunate as a 'civic duty'. In her words 'voluntary action as a social principle and a key constitutive element of citizenship got lost (p.259). We will see these themes re-occur as partnership measures increase during the latter part of the

20th century. Overall, there had been a fundamental shift away from earlier notions of 'separate spheres' of the state and formal voluntary action to forms of collaboration with the state (as dictated by the state).

Voluntary sector histories focus almost exclusively on philanthropy, referring to self-help/mutual aid only when drawing on the principles operated by the Friendly Societies/Co-operative Movements for the National Insurance Act 1946 and the National Assistance Act 1948. One can propose that the Labour Party/Fabian response is likely to be that most mutual aid preceding the establishment of the welfare state was a direct response to poverty. As one of the primary objectives of the welfare state was to eradicate poverty, there would be no need for such activities to continue. A much reduced or negated role and need for such activities outside of the state structures was envisaged. Beveridge was, however, keen to see the Friendly Societies supported alongside state welfare developments but despite this, perhaps inevitably, growing state provision saw a dramatic reduction in their numbers (from 18,000 in 1940 to around 300 in 2000). However, it is important to note that they did not disappear altogether and to this day continue to provide savings facilities, pensions, healthcare, insurance and banking (FSRG 2001). Membership today is perhaps motivated as much by ideological commitment as by necessity. Friendly Societies have remained mutual, non-profit distributing organisations, with no shareholders to pay and are owned and managed by their members. Similarly, the co-operative movement endured in its retail form and gave rise to new forms of co-operation in the 1970s (see below) – motivated by both necessity and ideology.

As critical theorists have noted, the fundamental contradiction of the welfare state from its inception, was the apparent attempt to embody socialist principles within a capitalist society (such as Mishra, 1990). In this view, the welfare state was never going to eradicate the problems caused by the system and held within it inherent dangers of collusion with the capitalist project. Expressions of self-help/mutual aid could be seen as both a response to the inevitable failings of a welfare system that seeks to operate in a system driven by and subject to the vagaries of finance capital AND an expression

(conscious or otherwise) of a challenge to dominant ways of conceiving of or providing welfare. From another perspective, Beveridge thought that these groups are intrinsically valuable in society. Deakin (1995) noted that the Beveridge reports have been subject to two rather different interpretations. Some see them as stemming from a disillusioned and tired farewell to social policy (Harris, 1977 as quoted in Deakin). Others view these reports as indicative of Beveridge's political position (liberal collectivist) finding a critical place for voluntary action between the state and the market, interestingly termed by Deakin in 1995 as a 'third way' (p.46).

Davis-Smith rejects the 'simplistic' view that voluntary action is only ever associated with the rise and fall of state provision. Rather, he proposes that the rise of the state saw the formal voluntary sector carving out a new if altered role. We also see this in self-help/mutual aid where new forms begin to appear from the 1950s onwards.

However, the close relationship between the state and the formal voluntary sector, as Deakin points out, meant the state had the power to change the shape and size of the space within which the formal voluntary sector operated. Self-help/mutual aid until it is formally instituted manages to escape this and (short of a fascist state) its activities can hardly be legislated (see this theme also in Chapter Two). This period did mean however, for a while, the end of voluntary action in having any substantive role in addressing poverty in the direct sense of meeting need. We will turn now to the 1950s onwards where we see the beginnings of new forms of self-help/mutual aid based on a response and challenge to various social relations in society, that cut across traditional class boundaries.

## **THE CONSENSUS YEARS (1959-1979)**

This period saw seven changes of government<sup>2</sup> and yet, as Kendall and Knapp (1996) argue, from the 1950s to the end of the 1970s a 'corporatist' era emerged which legitimised the state as the dominant partner in formal welfare legislation. Partnerships

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<sup>2</sup> Labour 1950-51 (Attlee). Conservative 1951-1955 (Eden & Macmillan). Conservative 1959-64 (Macmillan & Home). Labour 1964-1966 (Wilson). Labour 1966-1970 (Wilson). Conservative 1970-1974 (Heath). Labour 1974-1979 (Wilson & Callaghan).

were formed with trades unions and businesses but relations with other voluntary organisations were viewed as peripheral. The 'statist' or 'collectivist' model (Taylor and Lansley, 1992) appeared to be widely accepted and the Conservatives did not present a concerted counter-ideology, until their administration in 1979, although the momentum for a new Conservative ideology was building up throughout the 1970s. It can be argued that at least on the surface, a 'welfare consensus' amongst the main parties had been arrived at. The generally accepted role for Central government was as the funder, deliverer and monitor of income maintenance and health services and Local Authorities were the responsible bodies for Social Housing and Personal Social Services. Kendall and Knapp state that the growing state provision overshadowed any services that remained in the hands of the voluntary sector and residual services had a relatively low political profile (1996).

However, if there was a 'welfare consensus' amongst political leaders, there was growing unrest amongst sections of the general population about 'exclusions' not confined to class divisions but based on gender, race, disability and sexuality. Neither were they confined to welfare relations, rather they saw the source of their oppression in the broader structuring of a capitalist society whose welfare policies reinforced (both explicitly and implicitly) these divisions. Building from the 1950s and visible from the late 1960s and early 1970s these developments were informed by and informed parallel developments across Europe and the States. The impact of the civil rights groups is significant not just in terms of the well recognised legal and social rights that ensued but also in terms of what Borkman terms 'cultural rights' - 'the right to define themselves, to name themselves and to give voice to their experiences as valid' (Borkman, 1999).

These movements were a new form of self-help/mutual aid leading to more 'politicised' aims and the identification of either structural inequalities or social stigmatisation that marginalised specific groups in society. It is important to note that the contemporary self-help/mutual aid groups in health and social care mirror the processes involved in these movements.

Alongside these movements there was a concurrent development in the professionalisation of health and social services. Borkman noted the increasing dominance of 'experts' - those with power in governmental and agency settings who use a privileged and elite knowledge base to justify both their own positions in the hierarchy and to maintain the status quo. The rise of 'professionalism' in the statutory services during this period was to have its impact in two ways. Firstly, by 1964, a new Labour administration was back in office. Despite its expansionist plans an economic crisis curtailed state spending. A series of recommendations arose from a rigorous overview of social conditions and the range of welfare services to meet them in Britain by a number of Royal Commissions and Departmental Committees. Deakin (1995) noted how this led to plans for another role/place for the voluntary sector. Questions began to be raised about the distinction between 'professional' and 'voluntary' activity in meeting welfare needs and this occurred in the context of renewed debates on 'professionalism' particularly in the 'caring' sectors of welfare such as Social Work. Debates ensued about the 'use' of volunteers in statutory organisations and the training needs of voluntary sector workers. The role of the media in spreading ideas at this time is given some significance by Deakin who views the convergence of media exposés, TV programmes and academic studies as cumulatively challenging the view given in official reports and by professionals of social and health conditions and their solutions.

These debates were informed by wider events, which provided both a broader context for understanding shifts in state – voluntary action relations at the time, and new ways of and models for addressing social issues.

Firstly, the demise of former British Colonies and moves to independence developed a political and pragmatic interest in community development approaches honed by international voluntary organisations such as Oxfam and VSO. The ideals, organisational skills and techniques of these groups developed with local people informed approaches in UK such as Community Services Volunteers and, as Deakin pointed out, led to new ways of identifying deficiencies in services for example for homeless people and minority ethnic groups. Secondly, urban unrest was growing, as it was becoming clear that the



promises of the Welfare State to eradicate poverty were failing. Additionally, 'displaced communities', resulting from large-scale housing projects and new road developments, were vocalising their concerns. As Taylor and Kendall (1996) pointed out, this led to a spate of governmental policy in the late 1960s that directly invested in and supported community development such as the Urban Programme, National Community Development Project and saw the growth of community development workers. This funding supported new community-based mutual aid organisations and groups that formed specifically to address some of these concerns such as Tenants Organisations, Claimants Unions, black and minority ethnic groups, women's groups etc. Finally, this period saw the rise of other single-issue groups, 'new social movements' which had been forming since the 1950s based on common concerns with the environment (Friends of the Earth, Greenpeace, CND etc) and consumer associations based on notions of citizens' rights such as the Consumer Association.

It is in the context of these social changes that we see the emergence of two major new forms of voluntary action. One clearly in the tradition of self-help/mutual aid movements – new single-issue self-help/mutual aid groups which included those in health and social care – and a 'hybrid' form embodied by the new 'pressure groups' which held within their origins elements of both self-help/mutual aid and philanthropy.

### **The rise of single -issue self-help groups in health & social care**

A resurgence of self-help/mutual aid groups took place in both Europe and N America in the 1960s and 1970s. This time, however, they were focused on single social or health issues such as fertility, disability and mental health and are the groups outlined in some depth in Chapter One. Significantly, the origins of these organisations were the shared experience of the same social or health condition and groups were formed by the people directly living the experience rather than by others on their behalf. Whilst they shared this in common with previous forms of self-help/mutual aid, such as the civil rights movements, they were not motivated solely as a response to poverty/deprivation and their membership transcended traditional class boundaries. However, it would be fair to say

that they first arose in areas that were either 'stigmatised' (such as mental health, disability) or 'privatised' (such as fertility, bereavement) and where state intervention had either aggravated or not appropriately addressed the condition.

In the United States, Borkman's work (1999) has linked the growth of self-help/mutual aid in the same time period closely with the civil rights movement for people from black and minority ethnic groups, the Anti-Vietnam war campaigners and the women's movement. All involved the sharing and developing of an experiential knowledge base through the processes involved in self-help movements or groups. Wann (1995) made similar links and point out the particular significance these groups have had for women and minority ethnic groups (p.58). As we have seen from Chapter One, it is of interest that women appear to comprise the majority of membership of the groups in health and social care.

The activity of women both in the feminist movement and in the new health and social care groups is explicable as a reaction to both the explicit and tacit ideology that lay behind the UK welfare state. Wilson (1977) described the Beveridge Report (1942) which formed the foundation of the welfare state as one of the most crudely ideological documents of its kind ever written. For feminists, far from the welfare state being viewed as simply a set of services and policies, it equally embodies a set of ideas about society, men and women and the family. As Gartner (1985) stated, drawing on the broader context of the women's movement, self-help groups sought to restore women's sense of autonomy over their lives, restore their self reliance, and lessen their dependency on institutions that define their lives. Gartner perceives a critical step in the growth of the women's movement as being the development of self-help groups dealing with women's issues, particularly in the area of health. In consciousness-raising groups, women worked to regain control of their bodies in a society that medicalised many aspects of the female life cycle including menstruation, infertility, pregnancy, birth, menopause. For example, in the UK 'Well Women' clinics blossomed in the 1980s in response to issues raised by the feminist movement and self-help groups and provided information about all aspects of health care and female-only medical service. At first these were run on a voluntary

basis by female GPs and other volunteers and offered a free alternative service, but by the late 1980s and early 1990s such initiatives in the main were incorporated in GPs' clinics and run by female members of staff. Alternative services for lesbian women tend to be still run outside of mainstream services.

An important principle underlying the formation of women's self-help groups is that 'knowledge' about a situation facing an individual or group of people, is not just the preserve of the professional but that such knowledge should be shared amongst all who want it and can be challenged through the sharing of experiential knowledge, which may offer a very different conceptualisation and definition of the same situation (Gartner, 1985). An example of this is the self-help movement that arose in the U.K. in relation to domestic violence against women. This movement was successful in reconceptualising the reasons for domestic violence, and moved the emphasis in research and practice terms away from a pathological model and one in which the primary question is why women stay with men who abuse them to a broader examination of socio-political factors that legitimises male violence against women. This reconceptualisation has had an important impact on welfare provision and social policy in the areas of health, housing, police and social services (Dobash and Dobash, 1992).

The 'experiential' knowledge base and the processes involved in self-help groups to build this knowledge appear to be what makes self-help/mutual aid so potentially threatening to experts - whether these are located in professions or governments. For Borkman, an important by-product of the 1960s/1970s civil rights movement is that 'people saw they could benefit from mutual help based on personal experience rather than professional expertise' (Borkman, 1999). Whilst forms of self-help/mutual aid based on structural issues (civil rights, feminism) and the emerging groups in health and social care clearly share much in common it is important to note a key difference. The wellspring may be the same, but those groups which were based on structural issues have tended to evolve into lobbying groups with both a national/international profile. However, the majority of grassroots self-help/mutual aid groups in health and social care have always been primarily a support forum for their membership. Quite why some groups have evolved

into lobbying bodies and others have not is still a much-needed research area. Such groups can arguably however be seen as political in and of themselves, since their very existence, particularly at this time challenged professional control.

### **The emergence of pressure groups**

The new pressure/campaigning groups that formed as charities in this era straddled conventional forms of philanthropy and self-help/mutual aid. Their membership tended to be a mix between those directly experiencing the social or health condition themselves or via their care for someone in that position and sympathetic/empathetic members who were consciously working with and on behalf of others; the groups include Gingerbread, CPAG, DIG, MENCAP and Shelter (Deakin, 1995). Their challenge to statutory services in terms of both the conceptualisation of the issues and the relevance of services embodied an explicitly 'political' intention. Although not party political the challenges these groups presented, on the whole either explicitly or implicitly implicated the capitalist system in marginalising specific groups and had strong overlaps with and formed part of the civil rights movements referred to earlier. Deakin noted a significant change in voluntary sector-state relations in this period in which, as state provision spread into new areas such as direct care for discharged prisoners so, concurrently, new pressure groups emerged to represent their rights such as NACRO. This broke the emerging trend in which 'pioneering' by the voluntary sector was followed by take-over and assimilation in the statutory sector (p.50). Not surprisingly then, these groups found themselves in an uneasy relationship with both government and the existing formal voluntary sector.

Overall, Taylor & Kendall (1996) note that trends in the voluntary sector in the 1970s favoured self-help, specialist conditions and lobbying and secularisation, all of which grew significantly during this period. They note that new forms of organisations such as the National Council for One Parent Families and National Council for Civil Liberties 'developed innovative ways of operating in a new, enfranchised, political environment' (p.50). Because the new pressure groups had their 'roots' as much in the earlier civil rights/social movements in traditional philanthropic voluntary organisations, they were

**'unfettered by previous assumptions' and provided a new image of the voluntary sector (Younghusband, 1978, p.263) which was more in accord with the Labour Movement than the philanthropy of the past. However, they were still organisations developed by the educated middle-classes and this differentiates them from either the class-based movements of co-operatives, credit unions etc or the class-diffuse groups that arose in health and social care. As Taylor and Kendall stated, in this context:**

**increased government intervention in a wide variety of aspects of social and economic life triggered reaction: consumers and communities knew where to direct their dissatisfaction and had been led to expect they had a right to do so (*ibid.* p.55).**

**Whilst the state tried to distinguish itself by increased professionalisation of its services the voluntary sector responded in a variety of ways to carve out its own niche. For example, by providing more selective/specialist roles such as Barnardo's and National Children's Home providing services the state did not. Other groups in the spirit of the pressure groups/civil rights movements provided a service that both met expressed 'needs' but lay outside of or 'against' state services: these included Welfare Rights work and Neighbourhood Law Centres which, as Deakin points out, did not readily accept paternalistic assumptions about what limits should be set on voluntary action (p.50, *op cit*).**

**Two key reports, commissioned and written by the voluntary sector indicate the way in which the voluntary sector viewed its relationship to the state: the Wolfenden Report (1978) and Voluntary Action in a Changing World (1979). The Wolfenden Report was commissioned by two large charitable foundations (Joseph Rowntree Fund [JRF] and Carnegie) and was concerned to review the relationship between the state and the voluntary sector. The analysis was based on the view that four major sectors of activity existed (informal, state, commercial and voluntary) in society and the concern was about the future relations between those sectors. The context for both reports was a struggling Labour government that was wrestling uneasily with trying to move forward genuine public participation and trying to stem potential unrest, the seeds of which were also held in these movements. In the Wolfenden Report the weaknesses of the state were discussed**

and identified as the potential to monopolistic bureaucracy and diminished accountability to users of services deterring closer public involvement. Deakin (1995) noted that at the same time, official reports were peppered with references to the importance of public participation (such as Skeffington, 1969) and a promotion of community development as a way to sustain and supplement what is being done 'top down'. Deakin also recognises a broader critique concerned with governmental effectiveness and the dependency potentially created by state provision.

The idealism of state welfare being the answer to all social problems was also faltering with the failure of successive governments to manage the economy and cope with rising unemployment. The late 1960s and early 1970s had been a continued period of economic expansion, but the mid-1970s saw the beginning of an era of financial austerity with the worse unemployment rates since the war. Kendall and Knapp believe that the report reflected a consensus model, in which the voluntary sector continued to be a partner in pluralism and its contribution was defined in terms of innovation, flexibility, pioneering nature and cost-effectiveness.

In 1979 the National Council of Social Service (NCSS) soon to be the National Council of Voluntary Organisations (NCVO) conducted a review of options for the future, published as 'Voluntary Action in a Changing World' (Gladstone, 1979). This took a more radical view on welfare pluralism seeing it as dissolving the close relationship between the voluntary sector and the state and striking out in the direction of self-help and community development. It also proposed that future development in the 1980s should be primarily a question of localised initiatives. The report suggested looking again at the institutions of mutual aid, defined here as co-operatives. Drawing on Beveridge's ideas, Gladstone rekindled the concept of the 'third way' which doesn't follow the path laid down by the state or business but values the spirit and efforts and achievements of voluntary action, despite the inherent problems with this (such as gaps and unevenness). This was viewed as preferable to the disabling uniformity of the state sector, which was perceived in any case as being in decline.

Although such sentiments were not explicitly politically aligned, Deakin saw them as making a substantial impact. Certainly 'welfare pluralists' in response to the Wolfenden Report wanted a rebalance of power in favour of voluntary organisations. As Kendall and Knapp pointed out, for these proponents (Gladstone, 1979; Hatch, 1980) whilst decentralisation and participatory initiatives within statutory sectors were crucial, the benefits of welfare pluralism and citizen participation, mutual aid, proximity to need, flexibility, responsiveness and empowerment were particularly closely aligned with the activities of voluntary organisations (p.138). They advocated service delivery by voluntary organisations whilst leaving the state to provide the necessary regulatory and financial frameworks.

However, Kendall and Knapp (1996) maintained that although the ideas in these reports informed local levels of policy planning, at the national level the impact was minimal except for their adoption as a welfare philosophy by the fledgling Social Democratic Party (SDP). The Left generally viewed the thinking as naïve, failing to recognise the weaknesses and shortcomings of the voluntary sector (which appears to be equated with the traditional formal sector and therefore perceived as middle class, paternalistic, and oligarchic), providing no analysis of power relations or an unjust society or details of how any relationships would be 'operationalised' (Webb & Wistow, 1987; Johnson, 1987).

It is important to note here that new forms of co-operative organisation came into being during the mid-1970s most probably as a response to the growing unemployment and harsh economic situation. These 'new' movements consisted of housing co-ops, workers co-ops, credit unions and community co-ops and were all backed by the Co-operative Party (established in 1917 – see Chapter Two). Until this point the co-operative movement since the war had consisted mainly of the retail societies with their large resources. However, the mid-late 1970s saw the Industrial Commons Ownership Acts and the Housing Co-operatives Act and Credit Unions Act passed (Co-operative Party, internet 2001). The National Co-operative Development Agency was founded at the same time; it had existed as a proposal since the 1969 Labour Economic Strategy where

these forms of self-help/mutual aid appeared to be viewed as complementary community resources in achieving a socialist project. It was considered that co-operatives had a role in reducing unemployment and preventing the collapse of small firms. Examples include Merriden in the UK and Mondragon in Spain.

In summary, we could see this as the 'heyday' of self-help/mutual aid – the growth of single-issue groups in a supportive and optimistic environment, where the potential for change felt possible. It was also one of the few times since the war that the formal voluntary sector explicitly embraced self-help/mutual aid as part of voluntary action and the voluntary sector.

### **THE THATCHER YEARS (1979-1990): A NEW WELFARE IDEOLOGY**

There are plenty of excellent accounts and critiques of the "Thatcher years" (such as Pierson, 1998, Alcock, 1997). This section attempts to look in the broadest of terms at the overarching philosophy/ideology that informed her administration and policy initiatives and how this relates to developments in voluntary action. Interestingly, Margaret Thatcher's second term led to the only concerted but short-lived national policy response we have seen to date relating to self-help groups in health and social care. It is crucial to see that development in the context of the ideology that informed it and the expectations that the government may therefore have had about its outcomes. This helps to explain why the intervention was short-lived.

#### **The First Term: (1979-1983)**

Margaret Thatcher began her administration during a period of fiscal crises. This encouraged popular support for the New Right ideology, and viewed the expansion of the state as fundamentally problematic. In particular, state welfare spending was seen as having distorted market processes, as had trades union action, having the power to hold both public and private sectors 'to ransom'. Further it was argued that state welfare mechanisms had taken away individuals' responsibility to provide for themselves and



created a 'dependency' culture. Given the growth in self-help/mutual aid activities outlined above, there is a repeated theme here from Chapter Two about middle-class concern with the 'attitudes and behaviour' and 'dependency' of the populus. Deakin (1995) identifies the key features of Thatcher's administration as a commitment to 'roll back the state' by reducing public expenditure as part of Gross Domestic Product (GDP) and centralising power and decision-making at central government level, whilst reducing the power of both trades unions and local government. This radical departure from post-war consensus politics inevitably brought in its wake a re-assessment of the state's role with voluntary action and the voluntary sector.

From an early point, Thatcher indicated her intention to capitalise on the voluntary sector's capacity for delivering welfare. This showed an apparent reversal of the position in which the state led welfare provision to one where the state was more of 'an enabler'. However, coupled with the move to draw back power to central government it was clear from the outset that the state would yet again be setting the parameters within which the voluntary sector developed and operated. The first administration was predominantly concerned with economic policymaking and the overhaul of fiscal and labour markets, both of which had implications for the formal voluntary sector. Fiscal measures were positive in the sense that tax concessions for charities were given to encourage individuals to take responsibility for welfare, and innovative schemes were introduced to reflect this such as payroll giving in 1987.

The new government recognised that the formal voluntary sector had been able to develop innovative ways of working because it had managed to bypass formal state structures. New partnerships were formed as the state drew on these models, giving voluntary agencies the lead roles in their development, such as the introduction of the Community Programme (CP). Voluntary organisations were funded to provide much of the service but with conditions attached – they had to be explicitly non-political and no campaigning was allowed. By the time the CP closed in 1988 voluntary organisations were providing half of the services. Deakin (*op cit*) noted how switches in rules and contents of schemes proved fatal for many small organisations. This rekindled the

concerns of some parts of the voluntary sector about the power relations inherent in 'partnership' with an unequal partner who ultimately calls the shots.

As a response to the radical measures associated with the New Right, a counter-politics evolved within the left, which also marked a departure from traditional labour thinking. Known as the 'Urban Left' (because of their control of prominent municipal local authorities) rather than viewing Parliament as the route to achieving their goals they came to see activities that lay outside the state as a way of pursuing socialism (Hain, 1980). This also led to changes in local level state-voluntary sector relations. Members of the urban Left saw the potential in becoming allies with 'disadvantaged groups' and organisations that purported to represent them (Kendall and Knapp, 1996). These groups were predominantly self-help/mutual aid groups and included trades unions, single-issue groups, women's groups, gay and lesbian groups, minority ethnic groups and tenants' and residents' associations. Although this may have been a 'political' intention and was certainly perceived as such by the Conservatives, Kendall and Knapp (*op cit.*) note that empirical research by Wistow *et al* (1994) showed that it did not really affect funding decisions to the voluntary sector and most local funding appears to have actually been driven by more mundane, apolitical rationales identified in Wolfenden (such as efficiency and response to local needs). However, these initiatives were particularly important for Black groups who had often been over-looked in previous partnerships.

As Deakin noted, this counter-political strategy drew on long-standing relationships between local government and the voluntary sector that had been built during the 1970s. Local government had been the primary point of contact and funding for many groups both formal voluntary sector and self-help/mutual aid. Unell (1989) noted that from the mid-1970s many SSDs had Voluntary Sector Liaison Officers and formal Voluntary Groups were often involved in joint planning. Many workers in the statutory services had been influenced by, or learnt their politics through, community action. Under Equal Opportunities policy there were many more consultations with both formal voluntary groups and self-help/mutual aid groups specifically related to equal opportunities issues such as women's groups and minority ethnic groups.

Locality support for self-help/mutual aid emerged as a new mechanism and most local CVSs were the key bodies that liaised and supported self-help groups locally. There is no documentary record of this work but it is likely to have varied across the country. It is of interest that the specific support/resource centres that emerged were based in the Midlands and the North of the country – precisely where there were strong traditions of financial self-help/mutual aid (see Chapter Two). From example in 1982, in recognition of the growing number of self-help/mutual aid groups in the Health sector, Nottingham Self-Help Team was established. Its origins were as an integral part of the local Council for Voluntary Services although it became an independent organisation with funding predominantly from the Nottingham Health Authority. It aimed to be an intermediary, putting groups in touch with service providers, networking them with other groups and assisting in gaining access to resources (Wann, 1995).

These new alliances at the local level contributed to the already strained relations between central and local government and led Thatcher to introduce an ever-increasing set of ‘constraining measures’ on local government (such as rate capping, Inspection), which culminated in the eventual abolition of the Metropolitan Counties and the Greater London Council (GLC). As Knight (1993) noted, voluntary organisations straddled these debates uncomfortably and many combusted through internal turmoil.

### **The Second Term (1983-1987)**

By the time Thatcher entered her second-term the Conservatives had effectively achieved their primary aims. As the state continued to roll back its welfare services a new enhanced role for the formal voluntary sector emerged as that of providing services. As Deakin (1995) noted, by this stage the government had a clear idea both about what the voluntary sector could do and some ideas about restricting its capacity to act. The cornerstone of the election campaign had been the promotion of an ‘enterprise culture’ in the UK, informed by American models. A variety of policies ensued based on neo-Liberal values that ‘recognised that people needed rewards but also needed to be

reminded of their responsibilities'. Deakin discerns three key objectives to the programme:

- a. The need to revive philanthropy and encourage more investment in business such as business-led philanthropic initiatives and socially responsible business
- b. The need to improve standards of management resulting in the introduction of new managerialism into the formal voluntary sector, a move strongly resisted as it appeared to cut across the core values of voluntarism (Knight, 1993). This also resulted in a new and crucial role for intermediary bodies ,with a new generation of Chief Executives.
- c. The need to remotivate individuals to take more responsibility (beyond fiscal measures)

The re-motivation of individuals became known as the 'Active Citizen' project and was at heart a balance between 'rights and responsibilities'. Resting heavily on Smiles' notion of self-help, the active citizen was viewed as one who ultimately accepts his (*sic*) responsibility for the welfare of himself and his family because it is more rewarding and reinforcing of character to do so through his own efforts. In doing so he is then recognised and entitled to citizenship from the state. The Conservatives then supported this philosophy through cuts in direct taxation and a concurrent rise in the use of public funds to support private sector housing, education, health and welfare. However, a new clause was added: a citizen's responsibility also implied a duty to invest in the social fabric of society so voluntary work, fundraising and providing professional expertise to the management of voluntary organisations was to be encouraged (both morally and pragmatically).

Any form of voluntary action that was not seen as explicitly threatening to the social order was therefore to be welcomed – viewed through a lens of 'people helping themselves' which should allow the state to be comfortably rolled back and provide only facilitative mechanisms. However, against this backdrop and the attempts by the Thatcher government to de-politicise the voluntary sector came yet another new form of

**self-help/mutual aid with its roots clearly in the civil rights movements and its beginnings in the self-help/mutual aid groups in health and social care - the service user movement. Self-help/mutual aid showed yet again its ability to evolve and develop in the face of initiatives by the state. What the state could control was the interface between informal voluntary action and the formal structures it sought to challenge.**

### ***The Service User Movement***

**The seeds of the user movement lay within the rise of the civil rights movements and the single issue groups of the 1970s though as yet there have not been any comprehensive histories written which make the links explicit. User groups emerged in this period around mental health, disability and learning difficulties – although each sees their starting point as somewhat different<sup>3</sup>. Whilst there is considerable diversity within and between the elements of the various groups that make up the user movement (see Barnes, 1997) they have some distinct characteristics as collective organisations operating within civil society. Some of these characteristics they share with self-help/mutual aid groups generally but others make user groups distinct and these similarities and differences need to be made explicit. Barnes (1997) lists three key characteristics of user groups which distinguish them from the earlier civil rights movement but to which they are inextricably connected.**

- a. Members of these groups have previously been assumed to be incapable of self-organisation because of the incapacity thought to be an essential feature of their condition such as mental health, learning disability and physical disability.**
- b. They explicitly identify themselves in opposition to voluntary organisations that were apparently run for them by people that do not share the condition.**
- c. They explicitly place emphasis on collective action as both a means and an end.**

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<sup>3</sup> The Mental Health Movement has been identified as stemming from the mid 1980's (Rogers and Pilgrim, 1991), the World Federation for Mental Health/MIND in Brighton being seen as the catalyst. The Disability Movement generally see 1981 as the key year when the International Year of Disabled People (IYODP) lead to the founding of the British Council of ODP) run for and by disabled people.

**Overall therefore, the user movement comprises people from socially excluded groups who have sought to have their voices heard and become active participants in decision-making forums about services that are apparently for their benefit.**

**Whilst an important unifying purpose across different user groups is the articulation and campaigning for the inclusion of people previously excluded socially, economically and spatially from mainstream society the shared dominant concern is either to transform or improve the day-to-day experience of those in contact with health and social care services. The emphasis differs amongst user groups: for example, the mental health and learning disability movements are concerned with influencing the nature and pattern of services and provision of support to members, whereas the disability movement (Oliver, 1990; Shakespeare, 1996) is concerned with replacing the medical model of disability which constructs disabled people as dependent, with a social model of disability which locates the problem within society. All are concerned with the social relations that give rise to these exclusions, whether these are conceived of in terms of welfare relations between users and professionals, or in the broader social context.**

**In terms of the user movements' connections with self help/mutual aid groups in health and social care we have noted above that the latter groups' processes hold the seeds within which the user movement arose. Common to all of these groups (civil rights, user groups, self-help groups) is that it is the experience of a condition (medical, social, economic, conceptual) that brings people together and it is the coming together that validates experiential knowledge as a source of expertise. For the user movements it is experiential knowledge that should be respected in determining how services should be provided (Barnes and Shardlow, 1996). Just as we saw in the earlier history of self-help/mutual aid, the processes of sharing experiential knowledge give rise to new ways of looking at things and strategies for both prevention and coping. For example, people with learning disabilities have challenged professional assumptions about the basis on which it is possible to claim knowledge and understanding.**

The emphasis on changing welfare relations has tended to occur within professional boundaries: Campbell (2000) pointed out that although user groups share common features and concerns they tend not to work together. Campbell saw this in the mental health area as resulting from:

... activists seeming to see themselves as service users rather than as citizens and have only been peripherally involved in civil rights campaigns. Another consequence has been that, although action groups have become quite accustomed and skilled at working with mental health professionals, they have limited experience of working with other groups and are not used to presenting their case to the public...any attempt at broader social change will require new skills and, in particular, new alliances with other oppressed and disadvantaged groups (*ibid.* p.12)

This has important implications for self-help/mutual aid groups in health and social care since many have arisen around professional categorisations of health or social problems. Professional boundaries cut across shared experience and confine support and action to the very 'category' or 'role' to which people have been assigned by powerful groups; this potentially limits the broader effect that either user groups or grassroots single issue health and social groups could have. As Barnes (1997) noted, (as did Jarman in the prologue to this thesis), getting legislation on the statute books is far from the end of the battle to achieve equal rights (p.63). Whilst there has been considerable movement in national and local policy, changes in wider discrimination and stereotyping have not followed equally in response to the user movements.

It is important to note however that the user movement preceded the embracing of consumerist ideology (see below) and was one of the pressures behind its adoption. But the raft of legislation and policy related to user participation has been predominantly aimed at individual rather than collective involvement, with little regard for the particular expertise that may be built in self-help groups over time. Why some self-help groups have developed into campaigning/advocacy groups related to the user movement and others have not is still a subject for research but it is important not to see them simply as interchangeable. Self-helpers may or may not be service users; they may be concurrent service users or potential service users. Self-help/mutual aid groups may exist because

there is no service or they may provide an alternative to an inappropriate service; additionally they may be a conscious alternative with different aims and direction to mainstream services. Self-help groups and their members may or may not want to influence services; they may positively choose separation. They may or may not want funding. Whilst the user movement groups now see self-help groups as part of their repertoire, not all self-help groups see themselves as part of the user movement. However, as Campbell (2000) stated:

There are considerable overlaps between the ideology of self-advocacy and the ideology of self-help, and most service user/survivor groups, although action-oriented, are in practice a combination of action and support. (p.7 *op cit*)

### **The Third Term: 1987-1990**

Thatcher's re-election in 1987 strengthened and developed the New Right project. Fundamental changes in service delivery were introduced which saw the state retaining the role of purchasing on behalf of the 'consumer' but from providers either already outside the public sector proper or consigned there (NHS Trusts, grant-maintained schools). Direct service delivery was no longer to be the responsibility of public bureaucracies and services were either to be hived off altogether into the private sector (extending privatisation of nationalised industries) or to be delivered via quasi-markets. With this expansion of the 'mixed economy of welfare', however, came the continuing theme of centralised control over the direction of policy and provision and an increase in (semi-) independent scrutiny of outcomes by regulatory agencies and inspectorates.

In this climate the formal voluntary sector equipped with new management skills (and the new managerialism that went with it, including mission statements, pursuit of excellence, goals and tasks) entered a 'contract culture'. The sector moved from collaboration with its one-time partners local government (except in community care) to receiving substantial increases in direct funding from central government and the opportunity to compete for new service delivery tasks. This was, as Deakin (1995) noted, harsh on 'generic groups' operating at community level and many women's and minority ethnic



groups, the latter being predominantly self-help/mutual aid groups. For pressure groups, advocacy and campaigning was deliberately excluded. The Co-operative Development Agency, which had had to rid itself of any hint of 'socialist' values in order to survive under Thatcherism, was given the death knell in 1989 and closed in 1991 (Hall, 1999).

Outside these restrictions however, the User Movement continued to flourish, raising fundamental questions about the nature and form of welfare service delivery and the conceptual frameworks that informed them. Groups also formed new alliances with professionals sympathetic to their views.

### ***The Carers' Movement***

Following in the wake of the Users' Movement, the late 1980s saw growing pressure from and recognition of the Carers' Movement. In fact this movement had its roots in an initiative by a single carer, Mary Webster, in 1963 but it was only from the late 1980s that carers began to be actively discussed by policy makers, predominantly because of the central significance of informal care in the development of the community care policy at both national and local level. These community care initiatives (predominantly the closure of large-scale institutional care for people with mental health problems and people with learning disabilities) combined with the promotion of 'active citizenship' and the rolling back of the state led to increased demands on informal carers, most of whom were women. The feminist movement and the increased growth of a Carers' Movement challenged the assumptions behind taken for granted and privatised caring relationships and this began to lead to challenges at the conceptual level. As Barnes (1997) noted, although self-identification with the professional term gave a source of collective strength, one of the key concepts challenged was the way in which services constructed the carer/cared-for relationship as one of dependency and burden, failing to acknowledge the reciprocity which may exist in caring relationships and the nature of relationships which existed prior to the start of care. The objective of the Carers' Movement has not been restricted to service improvement and ensuring that the needs of carers themselves are acknowledged and responded to. In seeking recognition as experts in caring they are

challenging the right of professionals to define the nature of their problems and to determine the appropriate response to them.

Carers share with the User Movement the aim of asserting the authority of experiential knowledge alongside and sometimes in preference to, that of professional knowledge. However, users' and carers' priorities and concerns may often conflict and there has been opposition from within the disability movement to the introduction of legislation aimed at carers because the demands of disabled people are based on the notion of rights rather than care. Nevertheless, we see in all of these movements wider objectives or processes relating to civil rights and citizenship – an enhanced notion of citizenship that includes private as well as public lives. We will return to this theme in Chapters Seven and Eight.

### ***Policy Developments related to single-issue groups in health and social care***

The late 1980s saw a raised profile for self-help/mutual aid groups at both a local and a national level. In 1986 the Manchester Self Help Resource Centre opened with a similar remit to that of Self Help Nottingham. Wann (1995) outlined their role as being there 'to enable and empower; to show people that they can do things' (p.76) and assisting groups in making the transition to formal voluntary organisations, if it is something groups desire. Interestingly, the Centre staff viewed their intermediary role as particularly important since they were more aware of the issues for self-helpers than professionals would be.

At a national level, self-help/mutual aid groups began during this era to be represented by bodies that specialised in the subject matter of the group such as Cancerlink and Body Positive. The National Council for Voluntary Organisations (NCVO) at this time provided general assistance and support for self-help/mutual aid. At a central level however, there was no strategic response to self-help as such until in 1986 the Government funded a three million pound project to look into the support needs of self-help groups. The project related specifically to self-help groups in health and social care rather than self-help/mutual aid *per se* and complemented two independent initiatives that pre-dated the central response.

There were three key components: firstly, The Self-help Alliance was a pilot scheme run by the Department of Health starting in 1986, under an initiative called 'Helping the Community to Care' (part of the wider Community Care reforms), which set up 18 projects to support self-help in different parts of the country. The funding was for three years only and none of the projects survived intact (see below). Humble (1989) identified eight categories of self-help that the Alliance operated in: physical conditions, positive health and well being, mental health, life crisis, behavioural disorders, lifestyle and social status issues, caring for carers, community and welfare activities. Responsibility for overseeing the development of the projects and providing central support was delegated to a consortium of national voluntary organisations, known as the Self-help Alliance. Secondly, the National Self-help Support Centre was set up in January 1986 with funding from charitable sources. It was an independent initiative sponsored by the Volunteer Centre and the NCVO, both respectively representing national volunteer services and the voluntary sector. It acted as an umbrella for self-help support organisations and workers and had a promotional role in raising awareness about self-help. It provided support and information to local workers engaged in self-help and administered the Self-help National Network. A significant related activity was the facilitation of a network of black workers. The third component, the Self-help Workers National Network was founded by practitioners in the self-help field, in 1984 and continued whilst the Self-help Support Centre was operative.

To date, the Self-help Alliance has been the only national state-funded social policy intervention specifically related to single-issue self-help groups. This development may be seen through the lens of Thatcher's ideology: whilst she endorsed this initiative she simultaneously closed down the support structures for the co-operative movement – the CDA was abolished in 1991. This period of government saw a general rise in the country's standard of living but deepening social divisions. It is perhaps not surprising then that we see the rise of financial self-help/mutual aid again in the shape of credit unions and also such self-help activities as squatting and the anti-poll tax movement, the latter being explicitly anti-capitalist in ideology and action. Backwith (1996) noted how

the state legitimises some forms of self-help/mutual aid and classes others as 'deviant' (p.3). In this era Thatcher appears to legitimise what was perceived as individual 'self-help', whilst attempting to control the excesses of the mutual aid/collective action component.

By the end of 1990 the political and economic situation was unstable. The Poll Tax was increasingly unpopular but Thatcher refused to back-down on this policy. Major divisions were erupting within the Conservative Party over membership of the European Union (then the European Economic Community) and this issue finally forced her to resign in November 1990.

## **CONCLUSION**

This chapter has discussed the ways in which different forms of self-help/mutual aid can be linked to the economic, social and political circumstances from which they emerge. With the founding of the welfare state we have seen that, at least for a while, financial forms of self-help/mutual aid begin to diminish, although not to disappear. This historical period saw the emergence of new types of self-help/mutual aid groups related both to structural and cultural issues, a post-modern form of self-help/mutual aid. Alongside these main movements we have also seen the evolution of the groups that are the focus of this thesis, the single-issue groups in health and social care. These groups were the wellspring for, and form a continuing part of, the user and carer movements, but as I have suggested they also have a distinct identity and a predominant concern with the well-being of their membership. As we shall see in Chapter Four, the absence of recognition of this distinction has contributed to the lack of policy-making to support them.

In common with the self-help/mutual aid groups described in Chapter Two, these single-issue groups offer their active membership the potential to develop new and different ways to cope with the problems and issues they face. Their social relations based on peer reciprocity distinguishes them once again from the formal voluntary sector. In relation to

**the visible single-issue movements such as feminism and disability it is clear that the sharing of common experiences enabled a radical re-framing of an existing attributed role and identity. This implies that the processes in self-help/mutual aid groups hold the potential for people to question and challenge their situation even if not all groups do so.**

**The ambivalence of the UK state towards self-help/mutual aid groups can be seen as unfolding over time. This appears to be because of the duality of self-reliance and collective action embodied in the groups. This means that whilst both the Left and the Right may embrace aspects of this activity as part of their ideology, there is no sustained commitment by either to supporting it. Whilst the state may be forced to respond to visible (and noisy) forms of self-help/mutual aid such as the feminist movement, it is easy to ignore the grassroots health and social care groups which only become visible through their relationship to service user and carer movements and therefore become equated with it. Grassroots self-help/mutual aid groups have lacked a distinct identity in relation to social policy which needs addressing.**

## **Chapter Four**

### **Contemporary Developments in Social Policy response to self-help/mutual aid: Major to Blair (1990-)**

#### **INTRODUCTION**

This chapter concludes the analysis of the New Right era by detailing John Major's particular perspective on state-voluntary action relations. During his administration we see a consolidation of a form of partnership between the state, the formal voluntary sector, and a rise in consumerism in services. Whilst the latter offers opportunities for the user and carer movements the policy initiatives are individualistic in nature and fall short of the democratisation of services. Concurrently we see the withdrawal of national policy support for self-help/mutual aid groups. The responses of self-help activists are detailed, as are their policy recommendations (Hyatt and England, 1995; Wann, 1995), yet sadly we see this has no visible impact on national policy. This discussion is set against the backdrop of Major's notion of the active citizen, in which individuals take increasing responsibility for their own welfare.

The chapter concludes with an overview of the New Labour vision of the 'Third Way' which sees a resurrecting of the importance of voluntary action in civil society, the notion of the responsible citizen, particularly through the philosophy of communitarianism that underpins much of Tony Blair's policy. However, whilst this is seen to lead to enhanced relations with the formal voluntary sector, the response to self-help/mutual aid is once again fragmented and ad-hoc. Thus we see a renewed interest in financial forms of self-help/mutual aid and activities defined as community self-help but the single-issue groups in health and social care once again fall off the agenda. The Chapter concludes with a general discussion of the historical review, identifying recurrent themes and features in the relations between the state and self-help/mutual aid, many of which are revisited in the fieldwork.

## **THE MAJOR YEARS (1990-1997)**

### **The first and second terms (1990-1992/1992-1997)**

With Thatcher's resignation, Major inherited a country characterised by a strengthened centre, a diminished role for Local Government and effectively, a weakening of the trades unions. Although Major was apparently resistant to much of Thatcher's ideology in terms of his response to the formal voluntary sector much of her legacy lived on in the shape of 'contract culture' and new managerialism.

However, the late 1980s had seen a change in the economic circumstances of the country and a renewal of economic growth. Before Major's new term in office he produced *Individual and the Community* (1992) in which he explicitly recognised the importance of volunteering, charitable giving and business. Voluntary organisations (formal) were seen as often 'pursuing objectives that accord with or complement government goals in whole or in part'. Their particular contribution was to improve flexibility and choice.

### **Consumerist Policy**

In terms of self-help/mutual aid, Major's main response was to the user and carer movements whose 'demands' were understood through the lens of New Right ideology as 'consumers' of services in the (predominantly) statutory sectors. Major's main achievement was to place more emphasis on the 'empowerment' of the individual, codified in the subsequently much derided 'Citizen's Charter'. This was designed to provide the individual with a full account of claims on the public sector as a consumer of public services and ways in which satisfaction could be gained if claims were not met (Deakin, 1996). Nevertheless, it was a response to the growing user movement (outlined in previous chapter) and in a partial sense recognised the relevance of experiential knowledge. A thoroughly individualistic philosophy underpinned the spate of policies that followed - the most significant of which were the NHS and Community Care Act (1990) and the Carers Recognition Act (1995)<sup>1</sup>.

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<sup>1</sup> These were targeted in the first instance at Social Services Departments (SSDs) as they took the lead in co-ordinating community care. The involvement of users and carers in the Health Service has been much slower to evolve and only really begun in the late 1990s.

The legislation promoted a 'consumerist' model of welfare – concerned mostly with involving users and carers in the assessments of their own need. Whilst the recognition of the importance of the service user's 'voice' in services is not to be underestimated, Beresford and Croft (1993) noted the tensions inherent in the rise of 'participation' in services that was being fuelled by very different ideologies and movements. The New Right's 'consumerist' notion of participation, in which people are framed as consumers and attention is given to treating their needs as commodities by creating a market of goods and services versus a democratic model arising from the user group movements whose primary concern was empowerment, the redistribution of power and people gaining more say and control over their lives. As they stated:

The politics of liberation do not sit comfortably with the politics of the supermarket (*ibid.* p56).

The reality, as opposed to the rhetoric, of participation has to be understood therefore within the context of conflict and tensions created by the different philosophies and aims of the two approaches. Nonetheless, as policy initiatives developed such as the creation of a Consumer Involvement group at the DoH, so too did user involvement initiatives develop at the local level, such as user involvement posts in Social Services Departments, users' involvement in the training of professionals within Departments and Higher Education establishments and user inputs to planning Committees. User-led organisations also emerged such as the Wiltshire User Involvement Network, who registered as charities and thus formed a new type of self-help organisation. However, nearly all involved users in learning how to input their views via established bureaucratic mechanisms, that is to say, it was done on the state agencies' 'terms'. Interestingly, Taylor (1996) noted that during this period formal voluntary organisations were much slower than statutory agencies to involve service users – perhaps a left-over from their 'benevolent' past.

However, none of the central initiatives showed any understanding or strategy about the specific role or knowledge that grassroots self-help/mutual aid groups in health and social care may have, nor of the processes that professionals might need to go



through to collect their views sensitively. Without a central steer, self-help/mutual aid groups were potentially either ignored or treated as ready made 'focus groups'.

Critically, the predominant concern of grassroots self-help/mutual aid groups in health and social care is to provide mutual support through shared experience. Any diversion from this activity therefore may dissipate precious and limited energies. In contrast to the groups that see themselves as part of the service user's movement, many self-help activists at Self Help Nottingham's 1995 conference were actually warning of the dangers of diverting energies into statutory bodies' consultation and participatory exercises. Similarly in Wilson's (1995) study, self-helpers rarely mentioned formal ways of commenting on services as being of value to them, they were more concerned with the benefits to them as individuals that came through taking part in the group. Wilson found that self-helpers in the study were influencing service delivery in a quiet and informal way, outside formal patterns of consultation. Groups were more likely to be geared to improving the quality of service at a field level than influencing strategy (not that these are necessarily mutually exclusive). None of the groups saw changing services as a primary aim - indeed many viewed this as a diversion.

This is not to imply that self-helpers see involvement in service design and delivery as irrelevant, but their hesitancy about engaging with service-led consultations continues to distinguish them from user groups whose primary aim is now to campaign and involve themselves in changing mainstream services.

With the emphasis on user involvement and the stress on individual users, the grassroots self-help/mutual aid groups were effectively ignored. The Manchester Resource Centre closed in 1993 due to lack of continued funding and in 1994 the Self-Help initiatives (outlined above) were closed down. Wann (1995) saw the closures as critically related to funding issues and central/local relations. The projects were funded for three years with an explicit statement by central government that it would not continue its support and a hope that local authorities would fund those projects that proved 'valuable'. The local agencies where the projects were based would have preferred five years funding and felt central government pump-priming

would not be productive unless more work was put into building relations with local funders. The demise of the projects in no way reflected their evaluations -rather the opposite. The main reason was that local authority funding had run dry. With the Centre's demise, responsibility for the Self-Help National Network fell back to the local practitioners.

This withdrawal of support understandably bothered activists in the area. In 1995 following the demise of the Self Help Initiatives, NCVO published *Investing in the Heart of change: The Case for Resourcing the Support and Development of Self-Help Activities* a document co-written by Hyatt and England. A statement in the introduction by the then Director of NCVO, Naomi Eisenstadt, reads:

We believe that self-help is the bedrock of the voluntary sector, incorporating basic principles of user involvement, advocacy, campaigning and community development (*ibid.* p.v)

The key purpose of the report was stated as establishing NCVO's continued support for self-help, establishing the particular needs of self-help groups as distinctive from generic technical advice needed by (formal) voluntary organisations and ensuring that self-help was on the agenda for the forthcoming Committee on the Future of the Voluntary Sector and the Labour Party Review of the sector.

The report was based on a comprehensive review of existing literature and highlighted the diverse forms that self-help/mutual aid could take but emphasised the common elements between them. This was the first time in the available UK 'policy' literature that self-help/mutual aid groups in health and social care were viewed as part of community activities and linked (conceptually) to the other forms of self-help/mutual aid that occur in communities. It also highlighted the beneficial impact that self-help/mutual aid activities were likely to have on communities and professions and the role that support and development activities played in maintaining self-help/mutual aid. The report emphasised that self-help/mutual aid was not a substitute for an effective network of essential service provision.

Hyatt and England concluded by suggesting some 'proposals for the future'. These included: the need to establish a coherent national understanding, strategy, and profile

of self-help to inform resource allocation; the need to market self-help activities and their impact to ensure they are on the agendas of national policy makers; and to recognise 'self-help as a primary vehicle for social and economic innovation and change' (p.14). Four functions were identified as needing investment: direct, low level resourcing of self-help activities through the creation of a 'risk fund'; the consolidation and expansion of effective local support and development systems; the co-ordination of local and national support systems; and the creation of a national liaison and promotion systems. It was recommended that these and other activities could be locally and nationally co-ordinated through intermediaries (such as NCVO, NACVS, Sia). The paper ended by calling on NCVO to determine its role in self-help support and development.

This report was shortly followed by Wann's<sup>2</sup> Institute of Public Policy Research (IPPR) publication *Building Social Capital: Self-help in the Twenty-First Century Welfare State* (1995). Joseph Rowntree funded the study, which was an exploration of the benefits that self-help/mutual aid activities can bring to individuals and communities, and the part they could play in a 21<sup>st</sup> Century welfare system. In this document Wann argued that new thinking about welfare should recognise self-help as a core activity, viewing it as one of the most important sources of support to individuals and communities, next only to family and friends.

The first step would be to acknowledge the existence and scale of self-help activities, to recognise that they have a vital and legitimate role in defending and extending the well being of the people. This recognition would come from national and local government, but it would have to be endorsed by professionals in health and social care (*ibid.* p.103)

Wann's remarks recognised that the 'power' struggles are as much located in relations with professionals as with local and national policy makers. Similarly to Hyatt and England she stated that supporting self-help/mutual aid groups was not about justifying cuts in state services but about recognising the strengths and limitations of self-help/mutual aid and considering how best to sustain it (p.104).

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<sup>2</sup> Wann set up the Self Help Centre at NCVO in 1986 and co-ordinated it until 1990.

The report recommended that a national strategy for self-help should be developed alongside the formal voluntary sector; acknowledging the differences between the two but attempting to build a constructive relationship (p114). Recognising that self-help/mutual aid groups are by their very nature autonomous and may or may not require or seek support, she recommends that 'modest' public funds should be invested in local organisations which offer support to self-help groups – one support agency in each locality and one or more national umbrella organisations for self-help support. Wann also calls for UK research and evaluation to explore the effects that self-help/mutual aid has on individuals and communities. There is no public written account of the impact or otherwise of these two documents and there is no evidence of any action being taken at a national level. By 1996 NCVO literature began to focus almost exclusively on the formal voluntary sector and self-help/mutual aid had dropped off their agenda.

Major's administration came to an end in 1997 with no further policy related to self-help/mutual aid. Overall, the New Right's administration saw a continuance of the 'partnership' theme with the formal voluntary sector that had started in the 1970s but, as Kendall and Knapp (1996) noted, the general ideological climate had changed. Central Government had pulled power back to the centre and fundamentally affected the relationships that the formal voluntary sector had with local government. 'Contract culture' was well established and the voluntary sector was newly-professionalised, with dominant concerns such as management and economics. This contrasted with the state response to self-help/mutual aid and a gulf between the two had emerged, crystallising both their similarities and - crucially - their differences. self-help/mutual aid had gone from the heart of the matter to the margins, despite its continued increase. Wann (1995) identified this as an essential paradox at the heart of self-help in the 1990s: while the groups were blossoming in new areas as well as old, central support was waning.

But in a sense the formal voluntary sector had 'come of age', taking a prominent place both locally and nationally alongside the central government. This was reflected in three significant analytic reviews of voluntary action in the 1990s that focused on state/formal voluntary sector relations (Pollit, 1990; Knight, 1993; Deakin

Commission, 1996), which reflected many of the themes identified in the previous chapter. An understandable consequence of the profile being given to the formal voluntary sector was the sudden interest by academics and policy theorists about the role, composition and activities of the 'third sector' and this led to the launch of a major influential research project led by the Johns Hopkins University. The project (JHCNSP<sup>3</sup>) was a multi-country comparative study of the non-profit sector which excluded self-help/mutual aid groups from its definition of the third sector in both a historical (Morris, 2000) and contemporary sense (Munn-Giddings, 1998; Borkman and Munn-Giddings, 2000). This definition was adopted in the UK component of the study and was largely reflected in the new histories of 'the voluntary sector' (Kendall and Knapp, 1996) that selectively acknowledged the relevance of self-help/mutual aid (Davis Smith, 1995), but did not distinguish it adequately from the philanthropic movement nor explore their differential relationship to the state.

As a result, despite the recommendations of Hyatt and England (1995) and Wann (1995) self-help/mutual aid generally, and single-issue groups in health and social care specifically failed to make it onto social policy agendas (both governmental and academic) despite the recurrent theme that their activities were influencing welfare relations both directly (for individuals) and indirectly (via their obscured links with the user and carer movements). By the mid 1990s NCVO, formerly the national body that had promoted self-help/mutual aid and deemed it the 'bedrock' of the voluntary sector, relegated it to the margins. This is evident from their research, publication and conference agendas (Bradburn and Munn-Giddings, 1997).

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### 3. 'New Constructions of the Third Sector'

This project has been widely acknowledged as the most comprehensive attempt by social scientists to define and map the non-profit sector i.e. that distinctive space outside the market and the state (Morris 2000). Salamon and Anheier as part of this comparative study have constructed a structural-operational definition (see below) and used this to map 12 countries (1992) and have extended it to a further 33 (Salamon and Anheier, 1999) and are now using data gathered through this project to explore civil society. Self-help/mutual aid is excluded from this definition. This exclusion matters because of the relevance of the (JHCNSP) study to constructing the new history and contemporary understanding of both voluntary action and the voluntary sector in UK. As Morris stated by lumping mutual aid activities in with the excluded categories of fee-for service, private practice and commercial contracts it 'blurs all distinctions between the market and the non-market and between individualistic and collective behaviour' (p35). In the UK volume of this study Kendall and Knapp (1996) although noting the importance of self-help/mutual aid to voluntary action explicitly exclude friendly societies, co-ops and building societies because of their supposed quasi-commercial nature. Self-help/mutual aid groups in health and social care fall outside of this definition altogether.

JHCNSP structural-operational definition of the non-profit sector

- Organised – institutionalised to some degree in terms of their organizational form or system of operation
- Private – institutionally separate from government
- Non-profit-distributing – not returning any profits generated to their owners or directors but ploughing them back into the basic mission of the agency
- Self-governing – equipped with their own internal apparatus for governance and
- Voluntary – involving some meaningful degree of voluntary participation, either in the operation or management of the organisation's affairs

## **THE BLAIR YEARS (1997- )**

The New Labour government, headed by Tony Blair was elected in May 1997. Reform of the welfare state was one of its major tasks. This was to be achieved in a new and distinctive way – the third way, which claimed to be different from the old left and the Conservative right. In his Green Paper ‘*A new contract for welfare: New ambitions for our country*’ (DSS, 1998a, p v) Blair outlined this route for achieving a welfare state for the 21st century. This was not to be about dismantling welfare, leaving it only as a low grade safety net for the destitute, nor about keeping it unreformed and under-performing, but about reforming it on the basis of a new contract between citizen and state (Powell, 2001). The third way claimed to promote opportunity and empowerment instead of dependence. Based on the principle that work is the best route out of poverty it offered work for those who are able to and dignity and security to those who are unable to work. The model combined public and private provision in a new partnership and also places renewed emphasis on voluntary and community action as an integral component of social and economic development.

The social theorist Giddens (a major advisor on policy to the Blair administration) viewed the Third Way as an :

...investment in human capital wherever possible, rather than the direct provision of economic maintenance. In place of the welfare state we should put the social investment state, operating in the context of a positive welfare society (Giddens, 1998 p.117 as quoted in Powell *op cit*).

Powell sums up the key concerns of the Third Way as an ‘investor’s welfare state’ which may be seen in four areas: an active preventative welfare state; the centrality of work; the distribution of opportunities rather than income; and the balancing of rights and responsibilities. Policies to support these ideas were quick to follow such as Our Healthier Nation (DoH, 1998 c); New Deal(s) for the unemployed, lone parents and disabled (1997-); and the establishment of the Social Exclusion Unit (1997) as part of the Cabinet Office with its remit to research into specific aspects of social exclusion such as teenage pregnancy, school exclusion and truancy and neighbourhood renewal.

**The emphasis was on paid work (underpinned by a minimum wage) and education as the mechanisms of social inclusion.**

**Lister (1998) noted a paradigm shift from Old Labour concerns with equality to a New Labour focus on social inclusion and equality of opportunity, together with an emphasis on social obligations rather than social rights. She views this as imported from the U.S ‘despite the deployment of continental language’ (p.215), although Hutton thinks it derives from continental notions of ‘stakeholding’ (1997). Diversity and difference, the third way argues, is better dealt with by ‘inclusion’ than by traditional notions of ‘equality’.**

**The emphasis on both social inclusion and social obligation has also impacted on New Labour’s notion of citizenship. According to the new Clause 4 of the Labour Party constitution ‘the rights we enjoy reflect the duties we owe’. The Third Way of citizenship moves from ‘dutiless rights’ towards ‘conditional welfare’. Lister summarises a view that sees a ‘decent’ society being not based on rights but on our duty to one another (p.217). The modernising of the welfare state is then about an ‘active’ welfare state that promotes personal responsibility and individual opportunity as opposed to a ‘passive’ welfare state that encourages dependency and lack of initiative. Although the main way in which this ‘rights’ and ‘responsibilities’ approach manifests itself is in relation to work it also has implications for the way in which state – voluntary action relations are conceived.**

**For the first time in Labour’s administration since the war we see the return of the language of both the importance of civil society, voluntary action and, explicitly, ‘self-help/mutual aid’. Policy initiatives have followed that purport to both recognise the intrinsic value of such activities and their role in welfare provision. But how has the sector been interpreted and involved? Certainly one shift has been to explicitly acknowledge both philanthropy and self-help/mutual aid as an important part of civil society and to make the links between these different forms of voluntary action – seeing both as integral to community development.**

## **New Labour and The Third Sector**

When Frank Field was appointed Minister of Welfare Reform, at the beginning of the New Labour administration, he argued that we needed to break out of the 'welfare = state' mentality. The key was seen in seeking new, not state, forms of collective provision and the example used was the Friendly Societies (Powell, 2001). This type of activity was seen as a useful adjunct to the 'state-private partnerships' which New Labour saw as needing to work together in the 'interests of the citizen'.

...the re-drawing of the boundaries between state and individual responsibility is not simply an exercise in downsizing state responsibility (but) crucial to the recreation of a civil society based on a partnership between individuals, organisations and governments'.  
(Field, 1997 a)

Giddens saw that the fostering of an active civil society was a basic part of the Third Way. Government can and must play a major part in renewing civic culture. For Giddens (1998 p.9), the new mixed economy involved government in partnerships with agencies in civil society to foster community renewal and development. Similarly Hargreaves (1998 p.76) argued that the government must find a way of bringing the third sector into its reforms of the welfare state. These views are reflected in Blair's major policy objectives which Powell (2001) sees as underpinned by a vision of a 'strong civil society enshrining rights and responsibilities..where the government is a partner to strong communities' (p.21). Blair constantly emphasised 'community', which he claimed was the basis of socialism (Johnson, 2000).

However, Blair's thinking around 'community' is strongly influenced by the ideology of communitarianism of which Etzioni (1995) was a major proponent (Johnson, 2000). Communitarianism not only emphasises the importance of duties and responsibilities and civic duty but also encompasses within it a strong 'moralist' view about, for example, the return to family values; it can be seen to have a broad appeal exposing the shortcomings of the stark individualism associated with Thatcher's era and consumerist society more generally but as Driver and Martell (1998) have noted, it holds conservative seeds within its liberal philosophy. There is a strong prescriptive and ethical or moral element in New Labour which frames and assumes that



**'communities' are distinguished by their shared moral values – community initiatives in this light can be seen as a way of restoring social cohesion.**

**The emphasis on strong communities and community accountability can be seen in a range of policy initiatives such as Surestart, co-operatives in health and in involving community groups in 'partnership' with local government and health authorities such as Health Action Zones. The emphasis on involving 'communities' themselves is fed by and leads into New Labour's renewed interest in voluntary action and state-voluntary action relations.**

### **New Labour and the formal voluntary sector**

**In 1998 New Labour introduced a 'compact' between the government and the community sector in England. The policy was drawn up through consultation with the voluntary sector and government departments and made explicit reference to the Deakin report (1996) and New Labour's own pre-election document *Building the Future Together* (Labour Party, 1997). It was not a legally binding document but was 'intended as a general framework and an enabling mechanism to enhance the relationship between the Government and the sector' (para 1). The document described its underlying philosophy in terms of 'voluntary and community activity' being 'fundamental to the development of a democratic, socially inclusive society' (para.5). It noted the different accountability that the voluntary sector has and stressed the importance of consultation and partnership.**

**Lewis (1999) noted two particularly important points. First, the term 'partnership' was not new, but its use in the context of proposals for the public sector more generally was new. There was a stress on 'collaboration' rather than competition. This echoed the 'closing' of the internal markets by New Labour in the public sectors whilst retaining the purchaser-provider split. Secondly, and most importantly in the context of debates about what constitutes the 'voluntary sector', it referred to the 'voluntary and community sector' – this recognition owing much to the adoption of communitarian thinking outlined above. Including community groups in the**

definition of the voluntary sector is significant since self-help/mutual aid groups, as has been suggested above, could be viewed as an important part of the community.

Although there is this broader recognition of civil society that the compact echoes, Lewis cautioned against assuming that the voluntary sector was being appreciated in and of itself; rather she suggested a cautious welcome. As we have seen in Chapter Two, historically, the notion of partnership between the statutory and voluntary sector is fraught with difficulty. As Lewis stated :

...For there to be a true partnership between sectors, government has to respect voluntary sector difference, but the voluntary sector has to find a more effective voice in the policy-making process (*ibid.* p.267)

What does the partnership mean in terms of the government's agenda? It appears that the state is once again looking for pointers and models of working differently. Mo Mowlam, (1999) speaking to the NCVO Voluntary Sector Lobby Conference in Westminster stated:

...I'm relying on you to teach us a thing or two about 'joined up working'. You've been doing it with each other and with the communities you serve for years – years when the government were ploughing their own furrow in isolation. (Mowlam, 1999)

In recognising both the skills and the networks of voluntary organisations, there has been a drive to increase the number of people involved in the interchange. In 1998 there were over 230 secondments or attachments between the civil service and the voluntary sector. Mowlam stated that benefits were flexibility, the building of better relationships and the development of people's skills.

Certainly renewed interest in volunteering has been seen as part and parcel of the communitarian philosophy. In January 2001, Brown announced a major package that was heralded as the 'start of a transformation in the relationship between the state and the voluntary sector'. Announcing the allocations from the 2001-2004 Spending Review, in the UN Year of the Volunteer, the government claimed to have doubled its support to the sector and launched a £300 million package related to mentoring, modernising the infrastructure in voluntary and community organisations, the

Children's Fund, community groups in deprived areas, volunteering in the public services and a National Experience Corp for the over 50s to pass on their skills and experience.

Chancellor Gordon Brown stated:

The next five years will witness the biggest transformation in the relationships between the state and voluntary action for a century. Just as the era of no such thing as society (Thatcher) is at an end, so too the era of centralising government and 'Whitehall knows best' is over, and a new era – an age of active citizenship and an enabling state – is within our grasp. (Brown, CAB 006/1)

Certainly the re-engagement with voluntary action and the broadening definition of the voluntary sector to include community groups holds the potential for a re-assessment and acknowledgement of the relevance of self-help/mutual aid groups. In the UK the exclusion of non-formalised community groups from an agreed definition of 'the voluntary sector' might be something UK academics so keen to give a professionalised image to voluntary action might live to regret. However, in terms of self-help/mutual aid the response has been selective rather than consistent and has not, as yet, located single-issue self-help/mutual aid groups in health and social care within their broader community tradition and networks.

### **New Labour and Self-Help/Mutual aid**

New Labour's major initiative has come from the Social Exclusion Unit's work on neighbourhood renewal. In *Bringing Britain together: a national strategy for neighbourhood renewal* (1998) a report that examined Britain's 'worst estates' (defined in terms of poor housing, unemployment, street crime and drugs) a strategy to address the key causes of social exclusion was proposed to offer 'joined-up' solutions to 'joined-up problems' (ARVAC, 2000). A key part of the strategy was the setting up of 18 Policy Action Teams (PATs) that included a team (PAT 9) that looked specifically at community self-help. In this document community self-help

was defined in a number of ways<sup>4</sup> but self-help/mutual aid groups in health and social care were *not* cited.

Significantly, in keeping with the analysis of communitarianism above, the frame that community self-help was given was one of its potential both to combat social exclusion *and* to promote social cohesion:

The absence of strong communities makes it difficult to enforce laws about anti-social behaviour, vandalism or keeping the streets clean, leading to degradation of the environment... community self-help is one of the key ways to deal with this vicious circle (*ibid.* p.2, 2000).

As Johnson (2000) stated, according to communitarians, economic success depends on social cohesion, which in turn implies the moderation of competitive individuals by principles of mutualism, fellowship and social responsibility (*ibid.* p.9).

When the PAT9 reported in the summer of 2000, emphasis was given to supporting self-help/mutual aid as part of community development. Amongst its key recommendations was that the government should commit itself in policy and practice to support community self-help which included not placing 'undue burdens' on groups in terms of accountability and financial reporting. Nowhere in the PAT report is there mention of the contribution that self-help/mutual aid groups in health and social care could have to community development, reinforcing the earlier point that Hyatt and England (1995) and Wann's (1995) reports are not considered in national policy deliberations. It is clear, therefore, that currently the New Labour definition of community self-help does not include the groups in health and social care.

This omission is replicated in two influential Joseph Rowntree Foundation (JRF) - funded studies that make a strong case for the role of 'community self-help/mutual aid' in addressing social exclusion. Whilst both studies are highly supportive of the contribution and role that self-help/mutual aid activities in relation to social exclusion, similarly to the PAT report they do not make the links with health and social care groups. The first of these reports— *Harnessing Self-Help to Combat Social Exclusion*

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4. Community activity (such as organising a holiday play scheme); community self-help with a mutual or economic basis (credit unions, LETS); activity based around shared interests (such as faith groups and self-help groups for

(Williams and Windebank, 1999) was a study of 400 households in deprived neighbourhoods of Sheffield and Southampton, the research looked specifically at self-help/mutual aid as 'an additional tool' in tackling social exclusion to complement job creation. Their conclusions were that policies were needed to support 'bottom-up initiatives' such as LETs, Employee Mutuals and Mutual Aid contracts as well as 'top-down' initiatives including the reform of the voluntary sector of New Deal for Communities and the introduction of an Active Citizen's Credit Scheme.

In the second study *Mutual Aid and Self-Help: Coping Strategies for Excluded Communities* Burns and Taylor (1998) drew heavily on the literature pertaining to health and social care groups such as Wann, (1995) and Wilson, (1995). However, the typology they used distinguishes self-help/mutual aid from the community sector.<sup>5</sup> Interestingly, health and social care groups were located between the community sector and other forms of self-help/mutual aid. Whilst Burns and Taylor were at pains to point out that their classification was a 'spectrum' and the intention was to demonstrate difference, the exclusion of health and social care groups from their study unintentionally places them outside the discussion and conclusions for policy-makers. This is a shame since many of their conclusions would have relevance for or be pertinent to, health and social care groups.

Burns and Taylor noted, for example, that self-help/mutual aid could provide a direct and practical solution to immediate need, therefore, this 'sector' (*sic*) is a vital response to social exclusion. Importantly they noted that mutual aid can be destroyed by attempts to incorporate and therefore suggested, as do Hyatt and England (1995) and Wann (1995) that an intermediary organisation in the community would be useful. They also recognised the tension inherent in working with such a volatile resource and stated that policy-makers would need to be tolerant of the differences in organisational structure, ideology and form of accountability that characterises mutual aid.

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refugees); involvement in formal voluntary organisations active within communities (such as victim support). (PAT report, 1999).

<sup>5</sup> Self-help/mutual aid was defined as a 'sector' which was characterised by the absence of paid staff, informal rules, direct forms of decision-making and a network of structure of organisation which they defined as such things as community support, shared childcare and soup kitchens (p.7). The community sector was shown to include tenants' associations, neighbourhood watch.

**A delicate balancing act is needed if mutuality is to be encouraged without being incorporated or suppressed...in resolving this tension it is important to understand that mutual aid networks operate within larger communities' (*ibid.* p.27)**

**This is important as Burns and Taylor are at least acknowledging that self-help/mutual aid consists of multiple small-scale activities which 'combine to form a huge-web of social and economic activities which exist outside of state regulation and form the bedrock of society'. They argued that a community development approach that facilitates self-help/mutual aid (through intermediaries) can actively encourage the formation of a diverse range of mutual aid networks, so as to make the pattern of mutual aid more inclusive and link people across informal networks. In this sense, any policy related to self-help/mutual aid can be viewed as part of a community development approach. Given the earlier discussion and the recommendations of Hyatt and England (1995) and Wann (1995) this would have been an ideal opportunity to promote health and social care groups as part of that 'community' debate.**

**The reasons why health and social care groups keep slipping off the research and policy agenda appears to be linked to their lack of distinct identity. Perhaps one of the difficulties lies in the fact that self-help/mutual aid groups in health and social care are largely invisible, informal and operating outside recognised structures. Additionally, as has been suggested from the earlier discussion, they appear to be part of two communities (at least). Firstly, most groups founded by self-helpers themselves are part of a geographic community, their activities are thus in a broader network of local community relations – as will be further illuminated in Part Two of the thesis. Secondly, groups are potentially part of an 'identity community' (partly induced by professional boundaries) that transcends geographical communities. Arguably, it is important to see them as both. Different groups prioritise these different identities at different times. Perri 6 (1997) has argued that the kinds of community policy the voluntary sector should seek to encourage are those that are based on broad networks of loose ties rather than the more conventional understandings of communities as a tight network of strong ties based on family and kinship. This type of understanding currently lacking in policy would lend itself to encompassing the health and social care groups.**

Consequently, New Labour which is now engaging selectively with self-help/mutual aid activities have as yet still not given a central policy steer regarding single-issue groups in health and social care. However, activists in the area are seeking to put this on the government's agenda. Thus Self Help and Mutual Aid Research Network (SHAMARN)<sup>6</sup> at its Conference in 2000 with the Self Help Practitioners Network (SHP) and Self Help Nottingham (SHN) is in the process of drawing up proposals to expand its work into the national arena. Lord Michael Young was also before his death lobbying via the Community Development Foundation (CDF) for a national body to promote and represent self-help/mutual aid groups.

In terms of New Labour's response to the User and Carers Movement, in rhetoric at least there has been a constant emphasis on the importance of the 'empowerment' of users and carers. This marks a move away from the traditional labour pre-occupation with the service providers and may well be related to the very strong elements of anti-professionalism held within communitarianism philosophy (Johnson, 2000). The government has continued to strengthen the legislation and policy related to involving user and carers in service design and delivery, for example the National Framework programme in Health that now makes it mandatory for users and carers to be involved in service development and delivery. However, there appears to be little central steer as to whether this should be achieved through groups or individual users/carers. Nevertheless the movement now has its own momentum and this has seen further developments in user-led organisations and user-led research (such as Faulkner, 1997; *Strategies for Living*, 2001) which is particularly significant in terms of framing studies from direct experience. These will bring interesting tensions because, as Borkman (1999) noted, the values, approaches, styles of organisation and practice of user-led organisations that have evolved from self-help groups are drastically different from the government's. New forms of voluntary organisations are also evolving which specifically promote the relevance of experiential knowledge and lead developments on user-led self-help strategies, for example The Long-Term Medical Care Alliance whose first Director, Judy Wilson, was previously head of Self Help Nottingham.

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<sup>6</sup> Based at Self Help Nottingham SHAMARN is a national network of researchers, self-helpers and practitioners.

We enter the 21st century then, with renewed support for voluntary action in civic society. Johnson stated that New Labour sees the voluntary sector (defined as both formal sector and self-help/mutual aid) as an essential element of a civil society encouraging active citizenship. A communitarian philosophy, which emphasises duty, responsibility and civic obligation, pushes the voluntary sector further to the centre of the stage as the 'mixed economy of care' develops. Mikosz (1998, p.13) discussing the 'third way', writes of the rediscovery of the 'civic sphere'- that is, of voluntary and mutual organisations which are neither state nor private and whose existence strengthens the 'fabric of society', the idea of social capital. Self-help/mutual aid groups in health and social care should clearly be on the agenda.

## **DISCUSSIONS AND CONCLUSIONS**

To understand the modern manifestation of self-help/mutual aid, it has been useful to locate it in historical perspective. This has been important because it places self-help/mutual aid as both a philosophy and an activity which has taken shape in a variety of forms in response to differing political and historical contexts. Tracing the historical 'roots' of modern-day single-issue groups has therefore assisted us in understanding the relationship this activity has with the state and welfare interventions. It has identified themes that have re-occurred over time and also illuminated the legacies that have arisen over time from the activities of such groups (such as contributory schemes) that are frequently an unacknowledged part of Social Policy's history and development. It has given a much clearer understanding of the links that contemporary single-issue groups in health and social care have with both historical forms of self-help/mutual aid and other contemporary expressions, for example the service user and carer movements.

Overall, critical analysis in Chapters Two, Three and Four has provided an insight into the way that the state has understood, made assumptions about and consequently viewed and responded to, voluntary action. Chapters Two (pre the welfare state) and Three and Four (post-foundation of the welfare state) have compared and contrasted the relations between the state and the two arms of voluntary action – philanthropy



and self-help/mutual aid. Whilst both aim to provide voluntary support to those in need, each has developed with different characteristics and traditions. Whilst a critical literature on the history of the relationship of the voluntary sector to the state over time already existed, this held only a partial and unrepresentative account of self-help/mutual aid activities. This analysis has therefore been drawn from disparate sources<sup>7</sup> in an attempt to understand the relationship of self-help/mutual aid to social welfare. Broadening an understanding of the relationships between self-help/mutual aid, philanthropy and the state is not just a matter of adding self-help/mutual aid – it fundamentally changes our understanding of the state to voluntary action and the impact of voluntary action on social relations.

We have seen how voluntary action has been conceptualised in a variety of ways according to the ideology of the government; it may be treated as an adjunct, complement, indicator of need for statutory service, replacement for a service or a threat. Whether it is believed to have any intrinsic value in and of itself varies according to the ideology of the Party in power. We have seen that there have been quite different understandings of and relationships to the formal voluntary sector and self-help/mutual aid. Since the foundations of the welfare state, the state has sought a partnership with the formal voluntary sector, the form of which may have varied over time but is ultimately dependent on the more powerful partner – the state. The more formal and instituted the organisation, the more the state is able to determine the space and role it can occupy. Self-help/mutual aid on the other hand can:

ensure innovation and diversity precisely because it operates outside the uniformity which results from state regulation and on a democratic system which only legitimates majority decisions (Burns & Taylor, 1998)

Understanding self-help/mutual aid's differences and points of intersection with the formal voluntary sector is also therefore important in terms of understanding the contribution/impact that self-help/mutual aid makes to people's lives and on social policy. In the UK as in most other European countries, the voluntary sector is enjoying a resurgence in popularity and due to the reduction of directly provided

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<sup>7</sup> The analysis has drawn on three main sources: labour histories that document working class movements, literature that appears in an *ad hoc* way in the current documentation of the formal voluntary sector, and national research and policy documents produced during this period that have had specific reference to self-help/mutual aid.

services by the state since the late 1970s is becoming a key player in the provision of welfare services. One of the key difficulties facing the formal voluntary sector today is how to maintain its role as an innovator in social practice when it is directly funded under terms specified in a monitored contract. Contractual obligations have led the formal voluntary sector to a greater emphasis on professionalism and concern with organisational factors and financial support. This has been matched by an emphasis in theorising about the voluntary sector on macro issues - the relationship of the voluntary sector to the State and particularly the economic relationship between voluntary organisations, business and government (Munn-Giddings and Bradburn, 1997). Whilst these matters are important they are not the key concerns of grassroots self-help/mutual aid groups and a focus on such issues obscures the relationship the two forms of voluntary action could and should have.

Since the 1970s the overlap between these two forms of voluntary action (self-help/mutual aid and philanthropy) has become more complex and fluid. Pressure groups contain elements and roots of both. The newly emerging user-led organisations are a new form of formal voluntary organisation with close links to the self-help/mutual aid tradition. The effect of the service user and carer movements and user involvement in the development of policy is certainly redrawing the boundaries between all of the sectors. Weeks (1999), for example, describes the development of the Terence Higgins Trust 'as a mutually collective response' to a particular problem - AIDS. One aspect, then, of self-help activity is as a mechanism for the identification and response to unmet need in society. It is therefore a vital component in the initiation and work of voluntary organisations. However, whilst some self-help/mutual aid groups evolve into funded voluntary sector bodies most do not and need to be considered in their own right. Self-help groups are essentially a very local activity. They are generated by individuals coming together to help themselves and each other in their own communities. They neither need, nor are derived from, international or national policies for their development.

This has important implications for political support and social policy in this area. Wann (1995) pointed out that the development of self-help has taken place with little Government input but suggests that a supportive strategy which acknowledges the

relationship with the voluntary sector is necessary in order to foster self-help initiatives. Although self-help/mutual aid groups are by nature autonomous, their existence may depend on receiving or using resources. Activists in the area caution against any measures that may inhibit the character of self-help/mutual aid, but since the late 1970s as we have seen in Chapter Three, there have been recommendations that intermediary, co-ordinating bodies facilitate and support the activities of a range of self-help/mutual aid groups. The UK has been one of the few countries in the Western world not to have a central clearing-house supporting self-help activities<sup>8</sup>.

It is perhaps the ambiguity of self-help/mutual aid that results in governmental inertia. Both the Left and the Right can see the broad appeal of self-help/mutual aid from within their own ideology. If we return for a minute to the philosophies of Smiles and Kropotkin we can see that Smiles' notion of individuals who take the initiative and responsibility for developing their own lives is echoed in both Thatcher's Active Citizen and Blair's notion of Citizenship. Whilst Smiles' philosophy may have been embraced by both the Left and Right there has been an altogether more ambivalent response to Kropotkin's notion of mutual aid. Although Beveridge welcomed and supported self-help/mutual aid activities as an essential feature of civic society, a complement to the State, others on the Left have seen it as indicative of a need that the state should fill. Thatcher's policies clearly rejected the mutual or collective aspects of self-help, as is apparent in her dealings with the co-operative movement. Whilst Blair's concern with 'community' has resurrected the possibility of including self-help/mutual aid as part of the policy agenda, health and social care groups are currently excluded from the dominant definition of community self-help/mutual aid. Additionally, it is clear that the philosophy underlying support for self-help/mutual aid assumes that these activities promote social cohesion. As the review has suggested, not all self-help/mutual aid activities do so and in fact, may represent a challenge to the state. Johnson (2000) suggested that whilst communitarianism

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<sup>8</sup> In Germany, Belgium and Denmark, self-help groups are developing with support agencies, similar to those in Britain. Germany is one of the few countries to have a kind of self-help policy, as recommended to all EC member states by WHO. Government's were advised to organise national 'Kontaktstelle' (Clearing Houses) and stimulate the creation of local ones. Germany and Denmark have done so and similar moves are afoot in Belgium, Switzerland, Norway and Austria. An accompanying support network is developing. International meetings of self-help participants and support workers and researchers have been held in Frankfurt (1991), Canada (1992), Denmark (1993), Austria (1995), (1997), Israel (1999), Budapest (2001) where an international network of 'experts' has formed. At both the Danish conference in 1993 (op cit.) and the last British one (1995) there was a call for the European approach to be explored in the future and general agreement about the importance of expanding research and serious analysis in response to this growing area of activity (Hastie, 2000).

applauds the principle of self-help and mutual aid it is less enthusiastic about the advocacy role inherent in it.

However, Brankaerts and Richardson (1989) suggested that (Western) self-help groups are not good at being heard because they tend to be inward-looking, focusing on the interests of their members with little interest in linking with other similar organisations to apply political pressure. The lack of policy could therefore be regarded as due not only to the ambivalent attitude that the State has to self-help, but also resulting from the nature of self-help activity which would not welcome regulation or a planned approach. Indeed, groups may resent being used for engagement and participation purposes by professionals and statutory services, because their limited resources are focused on the immediate needs of members.

However, it is somewhat of a mystery why five years of a New Labour government has failed to recognise and engage with the fastest growing part of voluntary action – the single-issue health and social care groups. Their activities seem to have as much if not more to say about current notions of citizenship, social capital and participation than the formal voluntary sector. These links are revisited in the concluding chapter of the thesis.

A variety of expressions of self-help/mutual aid have been explored in the last two chapters. And this is by no means an exhaustive review. Katz has noted:

self-help embodies simultaneously a philosophy, methods that have a common base but vary a great deal, and a vast array of organisations that comprise a major and enduring social force.....self-help/mutual aid is constantly evolving and changing and therefore trying to encapsulate it in terms that were static, would quickly become obsolete (*ibid.* 1992, p.298-300).

Self-help/mutual aid like the formal voluntary sector varies according to the historical moment and socio-economic climate. We have seen in this review self-help/mutual aid that is clearly related to financial circumstances and clearly class related – the Friendly Societies, the origins of the Co-operative Movement and neighbourhood networks, in more recent years Credit Unions, LETS etc. These appear to be direct descendants of these early forms of self-help/mutual aid. These financial forms are

perhaps directly explicable in relation to levels of state provision. However, we have also seen forms of self-help/mutual aid that provide a means of support and an alternative conceptualisation of social/medical conditions and single-issue groups that are either directly related to perceived structural inequalities in society or stigmatised, marginalised social and health conditions. The membership of these groups is more diffuse in terms of class. Burns and Taylor (1998) noted that for middle-class communities, self-help and mutual aid may be seen as one strand in a web of choices, while for people who are socially excluded and on low incomes they may be the only way of coping where there is 'no alternative safety net' (p.29)<sup>9</sup>. Issues of gender, race and age are likely to criss-cross all of these and it is significant that once again gender appears relevant for these groups. All are related to forms of social exclusion whether this is material, structural, cultural or conceptual.

Whilst there are very different forms of self-help/mutual aid they do, however, originate from the same source – people's direct experience of a situation (social, economic or medical). Chapter Two showed that a very specific form of collective knowledge – 'experiential knowledge' – evolved within groups, which directly gave rise to new understandings about situations and ways of coping. This form of knowledge can be complementary to formal provision or it can be challenging. Certainly, however, the processes in these groups are common and hold the potential to challenge accepted orthodoxies whether professional, state or the wider society. Understanding the similarities and differences of dominant forms of self-help/mutual aid activities is important in recognising the particular contribution each type makes to individuals, groups and wider society.

For all the above reasons, it has been important to 'locate' self-help/mutual aid groups in health and social care in the greater web and tradition of self-help/mutual aid activities. Doing so assists in understanding the richness and multiple expressions of this form of voluntary action. It differentiates this form of voluntary action from philanthropy. It also highlights the importance of seeing self-help/mutual aid activity as a part of people's lives situated in a much broader web of 'community'

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<sup>9</sup> Whilst both early and later forms of financial self-help/mutual aid lend themselves to a Marxist analysis, the evolution of the single-issue groups is perhaps less explicable in these terms lending themselves to post-modern theorising, particularly in relation to a consideration of them as a 'new social movement' (Martin, 2001).

relationships. It assists in transcending the professional boundaries/categories within which single-issue health and social care groups are viewed and avoids a simplistic equation with the user and carer movements. The service user movement as Campbell has stated above, suffers from the confines of these boundaries. Tracing a history and locating different forms within a web of related activity is no less important for self-help/mutual aid than it is for the formal voluntary sector, of which Lewis has stated:

The idea that the differences within the voluntary sector make it impossible or difficult to treat as a sector, is reminiscent of the feminist movement's paralysis in the face of speaking for a category of women undifferentiated by class, race. Whilst there are obvious dangers inherent in identifying a voluntary sector and asserting it has intrinsic merits, there are dangers just as great in failing to recognise and analyse forms of collective action outside the state. (Lewis 1999, p.268)

Self-help/mutual aid activities, of which health and social care groups are a significant contemporary form are clearly a part of the third sector, a significant part of voluntary action and an integral component of civil society – their subordination to and exclusion from, the expanding 'reclaiming of the voluntary sector' such as the Johns Hopkins Project does them an injustice. Whether it is part of the 'voluntary sector' as earlier literature would say (see NCVO 'Heart of Change' above) depends on how this sector is defined, which has changed over time. This is not just a 'debate about semantics'. A lack of profile for self-help/mutual aid means a concurrent lack of research interest, funding, and corresponding lack of profile. Horton-Smith (1997) noted the same problem with funding and research related to other grassroots associations. He links directly the exclusion of grassroots associations from the 'flat earth' map being created by the Johns Hopkins project as leading to scholars and funders assuming they are therefore non-existent, unimportant or not part of the sector (p.120:a). This is particularly alarming in relation to self-help/mutual aid groups in health and social care which have been identified in chapter one as the 'fasting growing part of the voluntary sector' (Elsdon et al, 2000 p.5).

However, questions still remain as to whether voluntary action and specifically single-issue self-help/mutual aid groups in health and social care do or do not have any

**intrinsic value in the UK context. Why do these grassroots groups evolve? Do they exist only because state provision is lacking? Do those that join groups do so because they have less 'social support' than others? What do people feel they gain from membership that they can't get elsewhere? What goes on in these groups and what impact does this have on members' social relations?**

**These are not just questions for the politicians, the political activists, the practitioners and the academics. Fundamentally they are questions for group members themselves to answer. We will turn now to the narratives and interpretations of group members on all of these questions explored through case studies of two self-help/mutual aid groups for carers.**

## **PART TWO**

**A case study of contemporary self-help/mutual aid groups**



## **Chapter Five**

### **Methodology of the Fieldwork Research**

#### **INTRODUCTION**

This part of the thesis presents and discusses the findings from the fieldwork part of the study. Building on the discussion and issues raised through the deskwork analysis of the relationship of self-help to the state, this section revisits some of the key themes but this time from the perspective of those involved in contemporary self-help/mutual aid groups in health and social care. Chapter One gave a general outline of these groups. Although an initial literature review framed the focus for the following case study, it has also been informed by themes that emerged from discussions with the members of self-help/mutual aid groups and by themes that emerged from the desk research. The overall research process has therefore been an iterative one; issues that emerged via the fieldwork research informed the 'web' of links made in Chapters Two and Three between self-help/mutual aid groups and their broader community and political relationships. Similarly, as 'new' themes emerged through the analysis of state/self-help relations, they were introduced into the later stages of the fieldwork to be explored with group members. Figure 3 at the end of this chapter illustrates this dialectic relationship as a core component of the research process.

The aims and questions of the fieldwork research are outlined below in the context of the fuller study. This chapter explores the methodology employed to gain the views of the groups and includes a discussion of the methods and process of the research and an overview of the analysis of the data. Findings from the research are presented in Chapter Six. Chapter Seven then provides a discussion of the findings drawing on relevant literature and the 'findings' from Chapters Two-Four. This leads into the penultimate chapter of the thesis, which draws on both the desk and field research to re-evaluate the relationship of self-help/mutual aid to social policy.

## **FIELDWORK RESEARCH QUESTIONS**

The overall aim of the study was to explore the relationship of self-help/mutual aid groups to social policy – with a focus on contemporary single-issue groups in health and social care.

By:

1. Desk research that explored the historical relationship of the state to self-help/mutual aid and situates self-help/mutual aid in relation to philanthropic traditions of voluntary action
2. Fieldwork research that explored, from the perspectives of members of two self-help/mutual aid groups, the significance and impact of group membership on them, their personal, professional and ‘political’ relationships. The key research questions were:
  - (i) Why they join and stay in groups
  - (ii) What they feel they gain from being in a group (that is not available elsewhere)
  - (iii) The impact/consequences of membership in terms of personal and ‘political’ relations (with professionals, community)
  - (iv) The dominant concerns of the group
  - (v) The key processes involved

## **PHILOSOPHICAL AND POLITICAL ISSUES**

The questions that emerged for exploration with the self-help groups lent themselves to qualitative research. As Bryman (1996) noted a number of synonymous terms have emerged as alternative labels for the qualitative approach, but they all fundamentally mean the same thing; that is, ‘an approach to the study of the social world which seeks to describe and analyse the culture and behaviour of humans and their groups from the point(s) of view of those being studied’ (p.61). Whilst qualitative research is underpinned by a variety of theoretical approaches, for example, symbolic interactionism, phenomenology and verstehen, the most fundamental characteristics of qualitative research is its express commitment to viewing events, actions, norms and values from the

perspectives of those being studied. It is therefore concerned with the meanings that individuals and groups attach to things, events and situations: that is, the way in which individuals and groups construct their world. This can be applied to individuals, professions and groups (for example, self-help groups), organisations and societies. In this sense, researchers committed to the philosophy of qualitative research share a fundamental assumption that humans and human groups construct 'realities' and therefore that multiple understandings and 'multiple realities' may co-exist within a human society. This demarks it from the positivist philosophy that underpins quantitative research, which takes as its starting point a belief/assumption that there exists a 'truth' that can be uncovered with the correct research techniques. The different conceptions about the nature of 'reality' are the concern of ontology. How we get to know about reality /theories about reality are the concern of epistemology.

Qualitative research is often branded as 'anti-positivistic' in the sense that it rejects the belief central to the philosophy underlying quantitative research, that human beings can be studied in a manner similar to the natural sciences. Positivism can be defined as an approach to the creation of knowledge through research which emphasises the natural science model, with the scientist taking the role of the objective researcher who, through deductive processes, collects 'facts' about the social world which are then arranged in a chain of causality with the aim that this will indicate general laws about how the society works. The philosophies underlying qualitative research are anti-positivist in the sense outlined above that they claim 'a different way of knowing' as Rist (1984) puts it, one based on involvement, empathy and experience. In looking for 'meanings' rather than 'causes' qualitative research rejects the natural science model and sees the task of social research as resting on the meaning of social events and processes, based on the lived experience of human society, from the actor's point of view. Inductive reasoning<sup>1</sup> is claimed as the processes for qualitative research. Bryman (1996) used the term

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<sup>1</sup> Many critical theorists take issue with the claims by qualitative researchers that they enter the field 'void' of assumptions, propositions for their research. With the exception of strict adherence to the philosophy of phenomenology which advocates entering the field without a literature review, most qualitative research begins with a literature review/consultation with key stakeholders. In this sense the 'hunches' that inform research, whilst not forming traditional hypotheses can be seen to be a form of deductive reasoning (i.e. observations are not carried out in the absence of informed context).

interpretivist<sup>2</sup> to describe the underlying epistemology of this kind of work. Qualitative researchers rarely frame their studies in terms of hypotheses; rather they define a number of research questions for exploration, as is the case with this study.

A number of methods have evolved from these two broad philosophies (positivist and interpretivist) that reflect the underlying philosophies of the two approaches. Qualitative methods enable the researcher to capture the meanings and constructs people give to their world. Examples of methods that have arisen within the qualitative tradition are semi-structured and unstructured interviews, focus groups and participant observation. By contrast quantitative researchers use structured methods such as experimental research characterised by Randomised Controlled Trials (RCTs), survey and structured interviews and observation. Fig 4 at the end of the chapter gives a fuller overview.

However, since the 1980s it has been common practice both within and outside of academia to be pragmatic about the use of methods. Most studies now combine a number of methods (both quantitative and qualitative) which are most relevant to the subject matter and questions of the study. In relation to this study, the underlying epistemology of this project is qualitative (interpretivist) taking at its heart commitment to self-help group members' own views on their engagement and gains from being in a self-help group. However, a number of methods can and have been used to capture this commitment (see below). Denzin (1978) termed this 'methodological triangulation' where a plurality of methods is used to explore the research questions. Sarantakos (1993) noted that this can be inter-method, where two or more methods from different methodological origins are used and/or intra-method where two or more techniques of the same methodological origin are used.

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<sup>2</sup> The term interpretivist is sometimes used as a catchall phrase to denote non-positivistic methodologies (Bryman 1996). However, it also used by some writers to denote a very particular methodology based on a very literal interpretation of phenomenology.

## **Values**

In 1967 Becker famously posed the question – whose side are we on in research? In the introduction I have provided a personal reflection on my motivation for doing this research. The questions that formed the basis of this study arose out of a complex mix of personal and political values and involvement in ‘social action’ groups and my practice as a social researcher undertaking research, which sought service-user views on their situation and experience of service delivery. I did not therefore start from the perspective of a detached bystander but with a particular history and perspective at heart and with a personal and political commitment to self-help/mutual aid groups.

The initial idea for this Ph.D. study was my own and the questions that arose for study were in the first instance developed by me. Because I began the study from my own questions, I did not ever intend it as an exemplar of participatory research<sup>3</sup>. However, at various stages of the research (see process below) members from the self-help group were involved in contributing to the design and interpretation of research data. As the study unfolded I attempted to work with self-help groups to meet both my own questions and those that arose for them as the study progressed. In this sense the study attempts some form of participation in various stages of the research process.

Because I began the study with a commitment to self-help/mutual aid groups, I cannot and do not wish to claim that the starting point for the study was ‘objective’. Rather, my concern was with the validity of the study (see below). Quantitative and qualitative philosophies in research also differ about ‘objectivity’. In keeping with traditional notions of the natural sciences, positivists attach significant importance to the notion of objectivity in the social sciences. This means that during every stage of the research

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<sup>3</sup> ‘Participatory research recognises that most research serves the powerful: government over the governed; management over the workers. So its goal is democratic as well as collaborative inquiry. This means that the core issue is empowerment: not only people’s involvement but also their control. It challenges inequality by supporting people in the creation of their own knowledge; strengthening their abilities and resources. Its rationale is their right to participate actively in processes affecting their lives’. (p.332, Stanton, 1989). Participatory research incorporates a number of different methods, models and perspectives including Action Research (Winter and Munn-Giddings, 2001); Co-operative Inquiry (Reason and Reason, 1991), Feminist Research (Roberts, 1981) and User-led research (Faulkner and Nicholls, 2001; Ramon, 2002). At the core of its value base is the centrality of those with direct experience participating in processes to effect change in their lives, communities and service provision.

processes explicit steps are taken to minimise personal prejudice and bias, with a belief that social reality will be presented as it is rather than as it is interpreted by an investigator (Haralambos and Holborn, 1990). As Sarantakos (1993) stated, this comes from a view that sees social scientists as technicians rather than reformers, neutral observers and analysts rather than philosophers or moralists (p.28). Qualitative researchers, on the other hand, in rejecting the notion of 'value-free' research, propose that from the moment a researcher decides to 'frame' a study in a particular way, they bring to a study their own personal and political values, attitudes and assumptions. In this sense, value neutrality is not only unattainable but also unnecessary and undesirable. Rather than deny these inherent features a researcher brings to a project, it is argued, it is better to make them explicit and reflect upon them and their impact during the course of the study. In this view, with which I fully concur, it is acknowledged that researchers are not mere 'neutral vessels' through which uncontaminated data flows, rather they are active 'constructors' of knowledge themselves.

## **METHODOLOGY**

### **A case study of two self-help/mutual aid groups for carers**

The study involved the detailed examination of two groups through a variety of methods therefore the overall methodology would fit with the definition of a case study. Denscombe (1999) defines a case-study as 'a focus on a particular phenomenon with a view to providing an in-depth account of events, relationships, experiences or processes occurring in that particular instance' (p 137). The choice of case study methodology was based on two main factors. Firstly, the methodology was appropriate to the research questions. In order to explore in depth the views of group members and particularly the processes involved in groups an extended period of time and a number of complementary methods were needed. Secondly, in relation to the overall study, the case study approach complemented the macro level analysis of self-help/mutual aid groups to the state, providing a further dimension to the study based on the perspective of group members. Case-studies make no claims to be representative. Rather as Becker stated, they attempt

to arrive at a comprehensive understanding of the group in question (as quoted in Haralambos and Holborn (1990 *op cit*). Becker claims that they can also be used to develop more general theoretical statements about social structure and process. Case studies therefore can lead to the generation of new hypotheses to be examined and explored against other data or in future studies.

A number of methods were used to gain the insights required and these are explained in more detail below. The main methods were in-depth semi-structured interviewing, postal questionnaire of non-active members and taped group sessions. In addition, comments made by self-help group members during feedback sessions to the groups were used to develop themes. Reflective notes made after sessions in a 'research diary' were also used to inform the study. All research tools are reproduced in Appendix 2.

The many types of self-help/mutual aid group are illustrated in the typology in Chapter One. Carers groups were chosen as the case-study for the research for several reasons. Firstly, 'informal caring' is something that everyone at some point in their lives is likely to be involved in – whether for children, siblings, partners or parents. The 'official' definition of a carer is someone who cares for a relative, partner or friend or for a child with a disability. They care, unpaid<sup>4</sup>, for people who cannot manage without help because of disability, illness or frailty (GHS, 1998). Under this definition there are 5.7 million informal carers in the UK today. This equates to one in eight adults. Men are almost as likely to care as women are (42% and 58% respectively). Most carers are aged between 45-65 years, and half of all carers look after someone over the age of 75. Almost one million care for over 50 hours a week. It is estimated that 65% of carers suffer from ill health or injury, 59% having deteriorating health as a result of caring.

A variety of studies have shown that carers suffer from emotional stress, financial worries, physical demands, isolation and loneliness, lack of information and support

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<sup>4</sup> Whilst health care is free in the UK for both carers and the people they care for, there are a number of social care costs which are not adequately covered by existing structures. In terms of income, depending on the level of dependency of the person being cared for, carers are entitled to welfare benefits such as attendance allowance. In addition, partly as a result by the carers' lobby every carer is now entitled to a full assessment of their needs via the social services department. However, there is little emotional support available via statutory services.

(Ungerson, C, 1987; Twigg, J, et al, 1990; Finch, J, 1989). The plight and extent of young carers' activities (those under 18) is also being increasingly recognised (Becker, 2000).

The rationale for taking a specific self-help/mutual aid group is strong both in terms of feasibility and focussing it on caring seems to be particularly pertinent to the arguments being constructed and explored in the Ph.D. Caring is both a personal and private activity but also a public and political issue. Carers self-help/mutual aid groups are growing (Barnes 1997). Some carers groups are affiliated to national bodies (such as Alzheimer's and National Carers Association) which also have a growing international network and presence. There is also a growing awareness of the pressures on carers and the personal and health consequences of providing long-term care (GHS, 1998). The Carers Lobby, mentioned in Chapter Three, has moved 'caring' from a private/hidden activity into public politics nationally and internationally. In response to this growing movement by carers there have been in recent years a number of policy initiatives in this area – Carers (Recognition & Services) Act (1995), The National Carers Strategy (1999), Carers and Disabled Children's Act (2000). Given then, that caring is both an expected and privatised activity and a public issue, it is an interesting area to explore in terms of why some people join self-help/mutual aid groups and what they hope to get out of membership.

## **PROCESS**

### **Sampling**

Since the purpose of qualitative research is to understand and explore meaning in given situations, sampling in qualitative research is approached quite differently to that in quantitative research. Rather than the techniques adopted in the latter of representative sampling,<sup>5</sup> sampling in qualitative research tends to be either *purposive* i.e. the sample

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<sup>5</sup> Representative sampling used in quantitative research is based on mathematical probability theory and attempts to ensure that each 'sample unit' has an equal chance of being chosen to take part in the study. Random sampling adheres strictly to this principle; other examples are systematic sampling (taking, for example, every 10<sup>th</sup> house or every xth person



being selected on the basis of a particular variable that is being studied, or *theoretical* in which the sample selection is driven by the theoretical basis of the study (Jack, 2000). For this study the sample chosen would fit into either of these two types – the carers self-help groups are an indicative (but not necessarily representative) type of self-help group in health and social care.

### **Access**

At the start of the project a 'list' of self-help groups did not exist in the South East region where the study was conducted. As explained in Chapter Three the South East does not have self-help clearing groups that exist in the Midlands and North of the country. Even the local Council for Voluntary Services (CVS) did not have a comprehensive list, only an *ad hoc* list based on groups that had self-publicised to the CVS. Access therefore was via the local Social Services Department's Carers Support Worker who referred me to a new organisation that had just been established to co-ordinate representation of carers' views in the vicinity. This group held a partial list of groups that defined themselves as self-help groups. No other details were documented. Ten groups were approached and four groups replied. It seemed feasible to study only two groups in depth. Given the debates in Chapters One-Four, it was felt useful to compare a group based in a local community with one that was geographically dispersed and based solely on the 'issues' being faced. Eventually it was possible to negotiate the study with one group that had been founded by carers themselves and that was based in a local vicinity and another that had been formed initially as a support group facilitated by a Carers Officer (joint funded by Health and SSD) but that was now identified as running itself. A profile of both groups is provided at the beginning of the next chapter (Findings). The fieldwork was conducted during 1998 and 1999.

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on the electoral register) and stratified sampling (sampling first on relevant variable data, for example, to reflect gender,

## **The First Stage: Semi-structured interviews with active members**

The study began with a semi-structured interview with the founding members of both groups so as to gain a profile of the group and its main activities. The interview explored the origins of the group, its organisation and membership.

Because of the value base expressed above, I was conscious of the tension between 'presenting' a project and yet trying within that broad framework to facilitate participation and respond to the concerns and issues within the group. I therefore spent two sessions with each of the groups getting a 'feel' for the issues and processes within the groups. At the first session I outlined my intended research and handed out a written copy of the proposed project. I felt it important to outline my personal motivation (in relation both to self-help/mutual aid and caring) for the study and to make two things very clear:

- a. that the study was for a Ph.D. and therefore long-term, so as to ensure that there was no expectation that 'quick' results were likely to surface or be used for local objectives; and
- b. that the focus of the study was about self-help/mutual aid groups rather than on carers groups and the 'results' were therefore going to be related to understanding of matters relating to self-help/mutual aid rather than carers issues *per se*. Although the group was appreciative of this, their concern was understandably with caring issues rather than self-help and this remained a tension throughout the project (see ethics). I left the meetings early to enable the group members to decide whether they wanted to take part.

Getting group consent is an issue that is considered under ethics below. After getting approval from both groups via their chairs I then attended a second session to answer any queries that members may have had and to acquaint myself better with their concerns. I made some reflective notes after each of these sessions to inform the semi-structured interview schedule. A semi-structured interview contains a number of themed areas to

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age or ethnic profile of an area and then applying random sampling techniques).

explore pre-determined key issues with respondents. However, the interview is conducted in a 'conversational' mode, which means that the sequence of questioning may vary from interview to interview although the same themes will be addressed. In addition the semi-structure enables the respondent to introduce new issues in relation to the themes, which may then inform future interviews. An example of this, is the issue raised in the first interview of the importance of previous experience in groups that was then raised in all further interviews. This is known as an 'iterative' process common in qualitative research that enables respondents or findings to shape subsequent stages in the research study. Sarantakos (1993) describes the benefits of this method as its practicality and flexibility, providing a way in which issues, concepts and words can be explored in greater depth. This method therefore seemed an appropriate way to explore in depth the self-help group members' understandings of their reasons for joining the group, the meanings they attached to their membership and the gains they felt they derived from joining the group. It also afforded the chance to explore what the members felt the group offered them that was unavailable from services (statutory or voluntary) and whether or not membership of the group had, in their view, affected their broader relationships. The semi-structured schedule of questions was piloted with two carers who attended another self-help group to check that the questions asked were relevant, clear and unambiguous. As a result of the pilot some minor amendments were made.

I then wrote to all the members of both groups to seek their permission for an in-depth interview with them in a location of their choosing. All core members agreed to be interviewed and all chose their own home as the desired location for interview. The interview covered baseline data such as gender, age, length of caring etc and explored with respondents their reasons for joining groups and the gains they felt they could attribute to active group membership. All the interviews were taped and transcribed. All participants were offered the opportunity/right to see, amend and agree their transcript but no one chose to do so. Two members expressed perhaps a common view that they were 'already too busy' to add this to their chores, but most seemed rather surprised that a researcher would be ready to do this – this is indicative of the stereotypes and roles held about researcher/researched roles.

## **The Second Stage: Postal questionnaire**

After this stage of the research I fed back the preliminary findings (in terms of themes) to group members at a group meeting, where we discussed the results. Again, whilst I was more than ready to be challenged the response was somewhat 'passive'; group members expressed an interest in the results and expressed identification with the results but did not challenge or add to them. However, the discussion with both groups led to a broader concern with how to keep their groups viable and, given the obvious benefits of group membership, a concern as to why their 'sleeping members' did not attend. Since this could add an interesting dimension to the study we agreed to jointly design a short survey (structured questionnaire) which would be sent out (via chairs) to the rest of the membership. Both self-help groups were keen to establish the primary reasons why people did not attend and to ask non-active members how they might develop their meetings to attract more attendance. Additionally, they wished to explore how they might be able to offer support to those unable to come to meetings.

As a result of consultations with both groups I drafted a structured questionnaire and sent it out to both groups for comment. This was an interesting experience -- both groups added additional questions and one group rewrote my covering note so that it would be more accessible and relevant for carers. Since the postal questionnaire was designed with the self-help groups, the groups themselves acted as the internal-check for phrasing of questions, ambiguity and relevance. In addition, similarly to the schedule for the semi-structured questionnaire, the postal questionnaire was also sent to my Ph.D. supervisor for comment and additions.

The questionnaire was then mailed out to all non-active or 'sleeping' members; that is, all those people who were on the mailing list of both groups but who did not attend at all or had attended less than twice in the past two years. The letters were sent via the chair of both groups to assist in anonymity. In total 31 questionnaires were sent, 13 for Group 1 and 18 for Group 2. Six were returned from Group 1 and seven from Group 2. Of these,

five people agreed to a further in-depth interview. The follow up interviews were conducted in respondents' homes and followed a schedule that covered issues such as previous experience of groups, reasons underlying non-attendance, other forms of support and changes that could be made to groups to encourage more members to attend (see Appendix 2). The results from this stage of the study were then fed back in verbal and written format to groups.

### **The Third Stage: Taping the meetings**

To gain an understanding of the key issues in group meetings and the processes by which these were discussed it was agreed with groups to tape two meetings in each group in full (two hours per meeting). This process combined with the reflective notes made after sessions assisted in illuminating both the key content and processes in both groups. I was present during both of these meetings but by now had a long established relationship with the groups. The tapes were transcribed in full.

### **Analysis**

Because of the multi-method approach there were two distinct phases to the data analysis. In the first phase the data from each stage of the project was analysed through thematic analysis. In the second phase the analysis achieved greater depth by looking across the results of the different stages of research to identify key themes and issues that occurred across the range of data. In addition 'tensions' were identified in the data, for example, where the results from one method appeared in tension with the results from another area. During both phases, I cross-referenced the data with key variables to see if any patterns emerged, for example in relation to differences between the two groups, active vis-à-vis non-active membership and other variables such as gender, length of time caring etc. Each finding was checked for inter and intra-group comparisons. The key issues that arose from the desk research (Chapters Two-Four) informed the final structuring of data into four key areas: motivation and gains in group membership (individual gain); peer relations compared with professional relations; processes in groups; and the wider impact

of group membership. The findings chapter that follows discusses the results under these headings.

In the first phase all the data from the semi-structured interviews (with both active and non-active members) were fully transcribed<sup>6</sup> and then analysed by thematic analysis. Thematic analysis focuses on identifiable themes and patterns that emerge from the data (Aronson, 1990). The themes are identified as units derived from patterns such as recurring issues, activities, meanings or feelings or conversation topics (Taylor and Bogdan, 1981, Lofland and Lofland, 1984). Aronson (1990) summarises the processes of thematic analysis as one where codes are assigned to various themes. Coding links different segments of the data together to create categories which then enables the researcher to explore different concepts and to put the data back together in new ways so that theories can be developed (Strauss and Corbin, 1990). The important analytical work lies in identifying the relevant concepts and establishing and thinking about the linkages in the data, not the process of coding. Coffey (1996) stresses that coding need not be viewed as simply reducing data to pre-existing categories – it can also be used to expand, transform and re-conceptualise data, opening up more diverse analytical possibilities. An example in this study is the impact and relevance that emerged from the findings regarding the importance one of the groups attributed to their part in local community activities (see Chapters Six, Seven and Eight).

As described in the methods and process section above, each stage of the results was fed back to the self-help groups for their response and comments. The tapes of the four group meetings were also fully transcribed and in addition to thematic analysis were analysed to decipher the main ‘topics’ of discussion. This revealed some interesting similarities and differences between the two groups. Following Borkman *et al* (2000) the flow and ‘dynamics’ of the conversation were analysed to discern the nature of interaction between group members (was it supportive, challenging, emotional, practical).

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<sup>6</sup> To fully transcribe or not to fully transcribe – that is the question and of endless debate in the social Sciences. Some researchers advocate only partial transcription once the main themes have been discerned (Strauss and Corbin, 1990) However, I tend to favour (where feasible) full transcription as I subscribe to the perspective that qualitative research should be an ‘iterative’ process and ‘new finds’ in the data could and should inform re-evaluation of the original analytic framework. Additionally, all respondents were offered the opportunity to assess their transcripts and for this reason alone full transcription is necessary.

This stage of the research was 'double-checked' by another researcher (Lesley Smith) with whom I have worked for many years, who took the transcripts independently to discern for herself the recurrent themes, key issues and processes. We then discussed our individual responses (which had a high level of congruency) before I made the final decisions on the data to be included as part of the study.

The postal questionnaire was analysed by simple aggregation of responses and themed analysis of data from open questions. The results were cross-tabulated to discern any patterns based on key variables. Alongside this primary data, as secondary sources of data, I considered the issues raised both in my reflective diary/notes of the various stages of the research and the material sent to me (unsolicited) by carers (see Appendix 4, Carers Testimonies). As these sources of data did not form part of the main methodology I used them to supplement, strengthen or illustrate the points discerned through the analysis of the primary data.

Whilst I am aware of qualitative data packages that may have assisted in the analysis of the data (such as Ethnograph, N\*DIST, NVIVO ) I undertook the analysis manually. This was a pragmatic decision, since access to relevant packages was not available until the latter stages of the study, by which point the time involved in entering the data onto computer-assisted packages was not justifiable in the overall schema.

The final phase of analysis consisted of looking across the key themes identified in the different stages of the project and considering the key issues arising across the spectrum of methods and data. As the project progressed and I was concurrently developing the desk research stage of the project, emerging themes arose that assisted in developing a useful framework for exploring the findings from the fieldwork.

## **VALIDITY ISSUES**

Qualitative researchers have no single stance or consensus on addressing traditional topics such as validity and reliability in qualitative studies (Cresswell, 1994). Early

qualitative researchers felt compelled to relate traditional notions of validity and reliability to the procedures in qualitative research. Conventionally, validity and reliability are the 'accepted' criteria by which all research is judged. Validity refers to the accuracy and truth of the data and the findings that are produced, i.e. is the study capturing what it intended to? It refers to the concepts that are being investigated, the people or objects being studied, the methods by which data is collected and the findings that are produced. Reliability is concerned with consistency and replicability i.e. that the research methods being used will give the same answers over time, across groups, irrespective of who administers them. The two are not necessarily compatible as Plummer (2000) noted in relation to attitudinal scales:

They may test well for consistency but bear a highly tentative relationship to attitudes. Validity should come first, reliability second. There is no point in being very precise about nothing. (*ibid.* p.102)

The questions of validity and reliability therefore have to be considered at a philosophical level as well. According to Leininger (1995) since the goals of qualitative research are not to measure something but rather to understand fully the meaning of the phenomena under study, the criteria for judging the research must be different to that of quantitative research. Silverman (1993) suggested that it is 'authenticity' rather than 'reliability' that is often the issue in qualitative research, as the aim is to gain as authentic an understanding of people's experience as is possible. Lincoln and Guba (1985) and Stevens and Hall (1997) also offered a different way of defining validity and reliability. The alternative concept suggested is 'trustworthiness' – a way of judging whether the research has been done in such a way as to give readers confidence in the findings. Three criteria define this. The first criterion is credibility and refers to the internal validity of the research, rather like authenticity above where participants recognise their own experience in the findings. The second criterion is dependability, which is evaluated according to whether the research fulfils the criterion of auditability, that is, that the research process is sufficiently transparent and clear to enable readers to understand how the results have been reached. Finally, transferability refers (rather like external



reliability in positivist research) to whether the study results or processes can be transferred to other contexts outside the study setting.

Applying the concept of 'trustworthiness' to this study, every attempt has been made to verify my own interpretation of the findings with that of the participants. For example, each interviewee was offered the opportunity to comment on transcripts and each stage of the research was fed back into groups for comment and verification. Whilst few suggestions were made to amend or enlarge on my own interpretations this could be viewed in two distinct ways. One, the more positive, that I had indeed put into words the key issues for people or secondly that despite building a relationship over time members felt unable to challenge the 'expert' 'outsider' researcher. In terms of the latter it is for this reason that advocates of participatory inquiry suggest that all stages of the research process are led by those affected by the inquiry (in this case the self-help groups).

Interviewer bias and the effect of my presence on the self-help group's sessions need also to be taken into account. In keeping with the values and politics that informed and motivated the study (outlined above) in both the group sessions and personal interviews I answered questions when put to me by group members about my views, personal family experience of caring etc. Whilst in traditional terms this 'subjectivity' would be seen to bias the results of the study, there is a strong tradition in qualitative research of rejecting this notion, as outlined above (in philosophy and politics section). I have already acknowledged that my own gender, motivations about studying self-help/mutual aid and choosing 'caring' as the focus, will have affected the framing of the interviews. In the interviews however, I was careful (as far as is possible in a 'conversation'), not to lead the interviewee but rather to respond to the issues raised by them. My presence in the groups is also likely to have impacted on the processes. I addressed this by building a relationship with groups over many months before attempting to tape sessions so that my presence was not unusual. The act of taping as an 'inhibitor' in and of itself may also be questioned. The only evidence I had of this was the 'saving' of a conversation about the use of cannabis to alleviate some symptoms of Multiple Sclerosis until after the tape was off!

Finally, the double-checking of interpretations of transcripts with another researcher ('critical friend') was also a useful verification. Denzin would have termed this 'researcher triangulation', a complement to 'methodological triangulation' where more than one researcher's interpretations are sought to bear on the findings (Denzin, 1978)<sup>7</sup>.

## **ETHICAL ISSUES**

This research was carried out in accordance with ARVAC and APU guidelines and therefore covered key principles such as informed consent, confidentiality and anonymity. Informed consent was derived as a principle from the Nuremberg Trials (Prendergast, 1999). This requires that each person participating in the research is fully conversant with the aims of the study and aware of their part in participating in it. To this end as well as outlining the study at a full group meeting, each person was sent an outline of the study and a consent form (see Appendix 3). The consent form assured participants of the confidentiality of the data and anonymity on the write up of the study. Each respondent was offered the opportunity to withdraw at any time. Anonymity<sup>8</sup> is traditionally difficult to guarantee in qualitative studies because of the relatively small size of studies and numbers involved. All respondents and the people they mentioned in interviews have been given pseudonyms and the locations of groups have been obscured.

However, ethics is as much about social relations of research as it is about abstract principles. Plummer (1983) identified two broad positions in relation to ethics: the ethical absolutist and the situational relativist (Denzin, 1978). He noted that those advocating the first view seek to establish firm principles which should guide all social research, for example, informed consent – these are embodied by 'professional

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<sup>7</sup> A third area of triangulation is theoretical triangulation. Where, as is the case in this study, more than one theory informs the design or discussion of research findings.

<sup>8</sup> This traditional principle in research is increasingly being questioned through alternative traditions of research such as participative inquiry, where many users and in particular user-researchers are arguing for the right to identification in research studies (Kemshall & Littlechild, 2000, Grinyer, 2002). The claim is being made that anonymity can and has been used to further researcher careers and gives no identified credit to the people who provide the data for the study. This argument is related to the successful lobby for payment for respondents in funded research projects, where the researcher is being paid but the not respondents (on whom the success of the study rests).

Nationally the trend is towards professional guidelines the recent Research Governance framework introduced by the DoH (2001) widening the remit of the Local Research Ethics Committees (LRECS).

guidelines'<sup>9</sup>. The second view in contrast suggests that ethical dilemmas of the researcher are not extraordinary but part of day-to-day life and therefore there can be no absolute guidelines. Attempts to impose such guidelines amount to trying to 'legislate morality' which could result in mindless rigidity or something that perpetuates privileges and elites, that is, by assuming researchers have a higher morality than others could. Interestingly, during the course of the research it became possible to compare the 'ethical guidelines' produced by professional bodies, voluntary organisation and those produced by self-helpers to guide a researcher employed by them to undertake some research on their behalf. It was striking that whilst the professional guidance was predominantly focused on concerns about litigation, the ethical guidance for self-helpers was concerned almost entirely with the social relations of the study, for example, how to treat the person being interviewed. Guidance produced by the voluntary organisation ARVAC falls somewhere between the two.

Ethical considerations are involved in the whole of the research process, but can be conceived of on two main levels:

- a) the macro ethical concerns of research, that is, the relationship of the research/researcher to the sponsors of the work, including the general politics of the research; and
- b) the micro level, considering the ethical dilemmas that may arise within the research relationship. These are illustrated in the diagram below. It is difficult to separate out the macro from the micro since the former will undoubtedly dominate the latter.

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<sup>9</sup> For example, Social Research Association (SRA), British Sociological Association (BSA), Association of Researchers in the Voluntary and Community Services (ARVAC).

**Table 7: Macro and Micro Ethical Issues**

<b>Macro</b>	<b>Micro</b>
Organisation of the research	Relationship of researcher to researched
Funding Sponsorship Involvement in the research process Definition of the problem Choice of methodology/methods How results are disseminated	Informed consent Confidentiality Anonymity Honesty/deception Betrayal

A commitment to taking the self-helpers' view as central to the research implied that a particular emotional and political commitment was taken. This both led to and informed the many ethical 'dilemmas' that arose during the course of the research. Many of these were raised and discussed in the validity section above. However, some additional ethical issues arose from the choice of methodology and analysis of the data that relate to the researcher-researched relationship. Whilst the semi-structured interviews were a useful way in which to understand the issues that were of most relevance to the self-helpers, the 'conversational' nature of semi-structured interviews (that are going well) inevitably leads to a form of rapport that may cause its own ethical dilemmas. For example, Finch and Oakley (in Roberts, 1981) have noted how warmth and empathy in semi-structured interviewing may lead to the interviewee disclosing more than they may have wished and on reflection wishing to retract some disclosure – hence the importance of offering respondents the opportunity to read transcripts and to withdraw at any time. The interviews were also of a sensitive nature and I felt an ethical duty to ensure that I reciprocated in some way, by for example supplying information or contacts regarding questions raised by interviewees in the course of interviews.

A particular issue in this study was gaining and retaining group consent. In research with groups, collective as well as individual interests are at stake and this is an area where traditional guidelines are left wanting. Individual interests may be relatively easily secured with assurances of confidentiality, anonymity and codes of ethics but it is more difficult to ensure that information will not be used against the collective. Equally, the consideration of the impact of a study may cause dissension in a group if some of the group members wish to participate and others do not. This was partially addressed by

presenting the research in the first instance to the whole group and waiting for group approval before arranging the semi-structured interviews. However, because the research was undertaken alongside a full-time job it was spread over a period of time and during this time there were inevitable changes in the group composition. This meant renegotiating consent, for example, to tape the group meetings. In the original methodology I had intended some more formal observation of group meetings but some members of groups were unhappy with this suggestion and it felt inappropriate in the context of the relationship being built with members. I therefore abandoned this method as an 'ethical choice'.

A constant tension in the research that was not ever resolved was that I was interested in 'self-help/mutual aid groups' and the groups were interested in carers' issues. This became apparent for example when discussing whether a national organisation to represent self-help might be useful. From my findings in part one, I can see the relevance, if not the necessity for this form of co-ordination, whereas the self-help groups were more concerned with national bodies that represented carers' interests.

Finally, the main method of analysis could in retrospect be seen to be less than adequate to give due weight to the processes within self-help groups. According to Mauther and Doucet (1998) acknowledging the power relations between the researcher and researched is particularly evident at the data analysis stage where researchers reduce, cut-up and distil their accounts, thereby losing much of the complexity, subtleties and depth of their subjects' narratives. Researchers categorise their words into over-arching themes and, as we do so, the discrete, separate and different individual interviewees are lost (Thurlow, 1999). Thematic analysis was a pragmatic approach – relevant to understanding the issues as I had constructed them. However, it can be claimed that such an approach 'fractures narratives' with quotations often being taken out of context of the overall story of which they form a part. In fact, as outlined in the next chapter, the key process of the groups was the sharing of stories in group settings. Narrative analysis would be ideally suited to understanding this in the future (Reissman, 1993). The main themes to arise from the analysis of the fieldwork data are shown in Fig 5 at the end of this chapter.

## **LIMITATIONS**

All studies have their limitations related to the focus, methodology and analysis of the study. In addition we can add the relevance of the study in the first place. If we start with the latter point, my long-standing interest in this area and its limited exploration in the UK whilst providing a strong rationale for the study also lay at the core of its limitations. In framing the original focus for the study I was largely reliant on US studies which cannot be easily 'transplanted or translated' into the UK which has a significantly different culture and welfare system. Additionally, much of the US literature relates to 12-step groups which are governed by a set of group rules present in only some UK grassroots groups. This led to the necessity to have a much clearer picture of the relationship of self-help/mutual aid to social policy in this country. But here again the literature is wanting, so although I have provided a novel re-analysis of existing historical literature, there is still much more that could be done in this area, which I have suggested towards the end of the thesis.

In terms of the 'case-study' of contemporary self-help groups it is questionable as to how far the carers' groups are representative of other carers' groups or of other self-help groups. Particularly with regards to the latter, carers do not belong to a 'stigmatised' group and thus aspects may be missed that would be provided in a study, say, of mental health groups. Given what has emerged about the differentiation of support for self-help in the Midlands and North of the country vis-à-vis the South East, it is also possible that views may have varied on some of the issues because of geographical location. Another significant limitation was that all of the group members were white. In the particular region this was perhaps reflective of the local demography but as the literature review claimed that self-help groups have been particularly important to people from minority ethnic populations it is an omission, to be addressed in the future.

Comparing the views of active and non-active members formed an important part of the study. However, as the non-response rate to the postal questionnaire (42%) was quite

high and the semi-structured interviews were conducted with an even smaller group of people, the results do not necessarily reflect the views and perspectives of other non-active members.

However, as discussed in the sampling section, small-scale in-depth studies do not ever attempt to be representative, rather they provide an exploration and illustration of the issues. Returning to the 'transferability' criteria discussed in the section on validity above, I would suggest that this case-study confirms some existing research findings, provides leads for new areas and exemplifies a process that could be used in case-studies with other self-help groups.

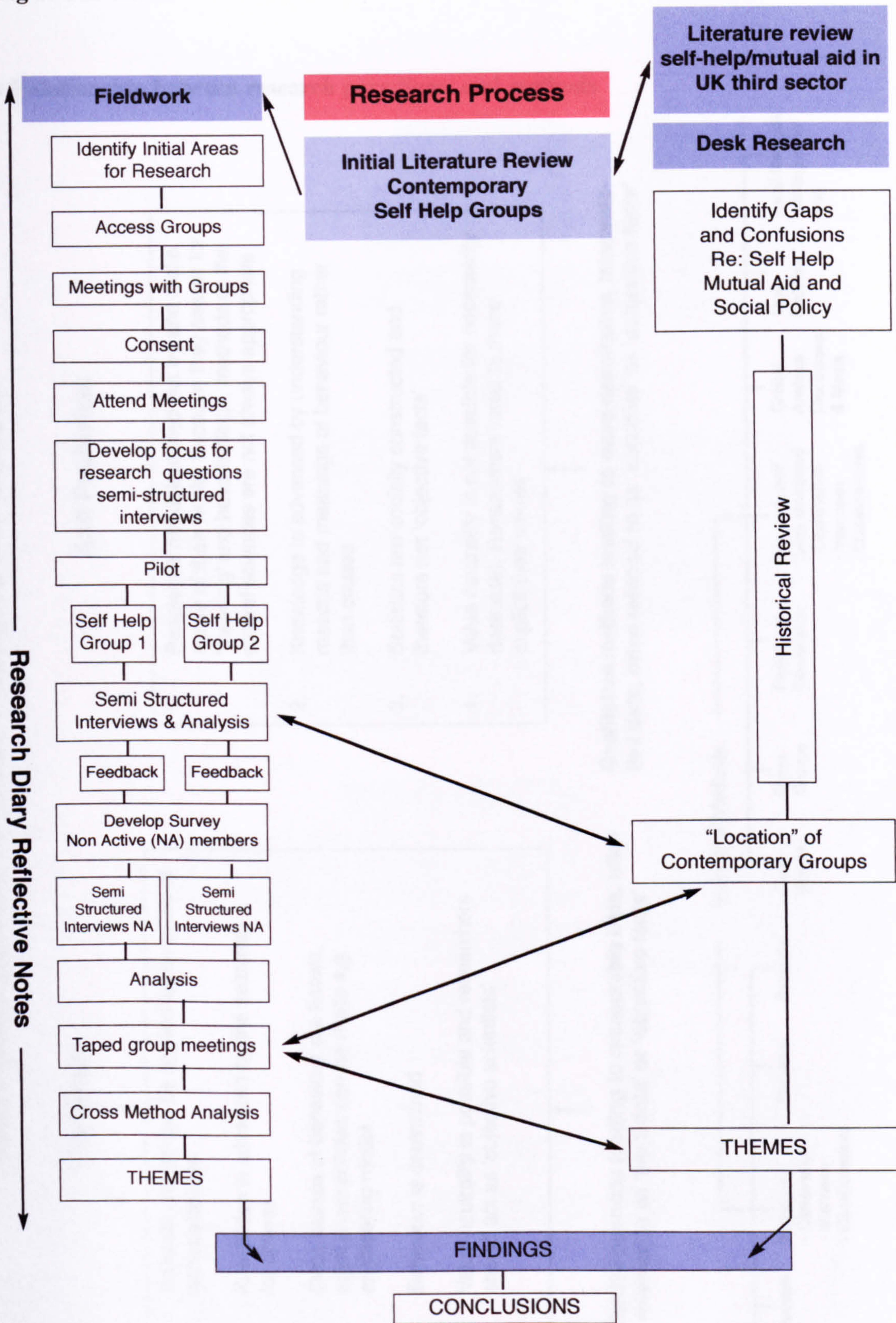
Each method inevitably contains its own limitations. For example, semi-structured interviews whilst enabling flexibility also hold the danger of losing any focus to the interview. Additionally, respondents according to Sarantakos (1993) may not be truthful, forget or lack the information required. Ultimately, as with most qualitative methods, the success of semi-structured interviews depends on the rapport with the researcher. The choice of multi-method methodology was therefore important for an in-depth study of the two groups.

Finally, a broader research issue arose through the method of analysis: 'thematic analysis' looks for consensus as a way of discerning key issues, when in fact some of the more interesting findings may lie in the points of dispute/conflict in the data<sup>10</sup>. Therefore thematic analysis disregards points made by 'individuals' alone and may make it difficult for challenge to the consensual view. This is perhaps particularly exaggerated in analysis of individual semi-structured interviews, which are then aggregated to form analytic categories.

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<sup>10</sup> Looking for conflict in data is considered important by contemporary grounded theorists (Strauss and Corbin, 1990) and action researchers such as Dilemma Analysis (Winter and Munn-Giddings, 2001)

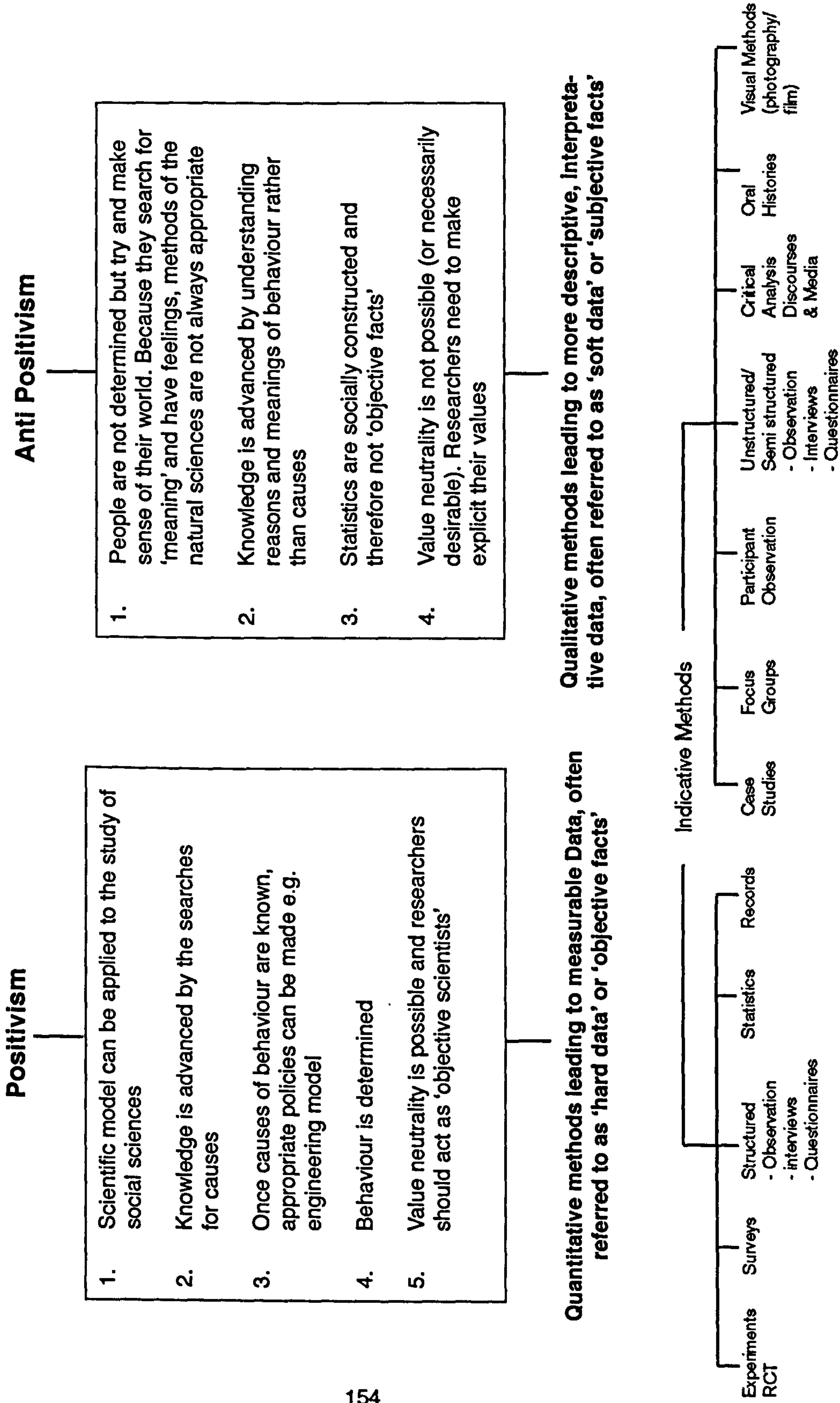
**Fig 2: The Research Process**



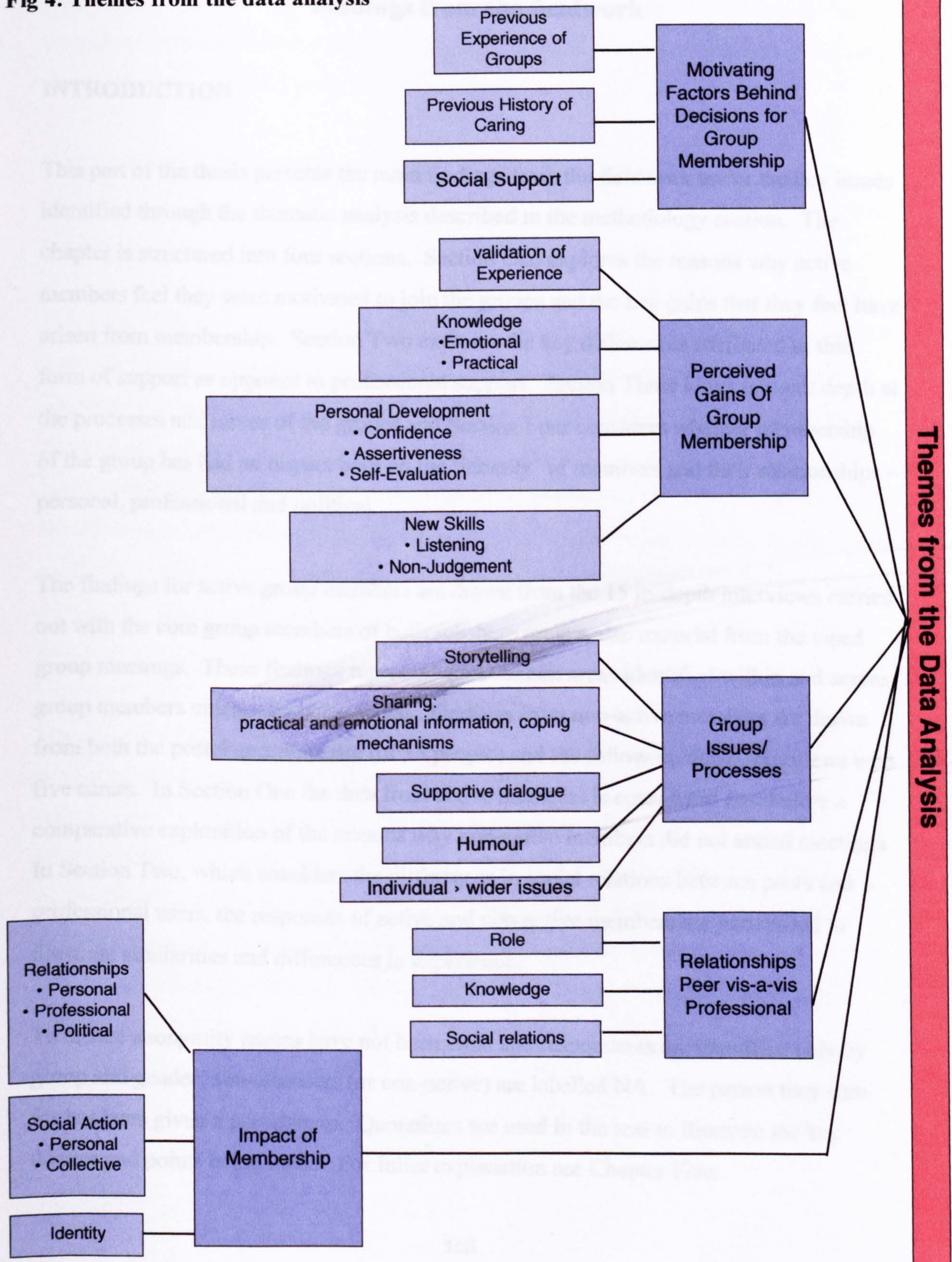


**Fig 3: Relationship between research paradigms and methods**

## Relationship Between Research Paradigms and Methods



**Fig 4: Themes from the data analysis**



## **Chapter Six**

### **Findings from the fieldwork**

#### **INTRODUCTION**

**This part of the thesis presents the main findings from the fieldwork under the key issues identified through the thematic analysis described in the methodology section. The chapter is structured into four sections. Section One explores the reasons why active members feel they were motivated to join the groups and the key gains that they feel have arisen from membership. Section Two explores the key differences attributed to this form of support as opposed to professional support. Section Three looks in more depth at the processes and issues of the groups and Section Four considers whether membership of the group has had an impact both on the ‘identity’ of members and their relationships – personal, professional and political.**

**The findings for active group members are drawn from the 15 in-depth interviews carried out with the core group members of both self-help groups also material from the taped group meetings. These findings represent the common areas identified within and across group members unless otherwise stated. Findings from non-active members are drawn from both the postal questionnaire (of 13 people) and the follow-up depth interviews with five carers. In Section One the data from active members is considered first before a comparative exploration of the reasons why non-active members did not attend meetings. In Section Two, which considers the differences in social relations between peers and professional users, the responses of active and non-active members are juxtaposed to illustrate similarities and differences in experience.**

**To ensure anonymity names have not been cited and respondents are identified only by group and gender; non-attenders (or non-active) are labelled NA. The person they care for has been given a pseudonym. Quotations are used in the text to illustrate the key themes and points being made. For fuller explanation see Chapter Five.**

Profiles of the groups and tables of members' characteristics are presented in a short introduction overleaf. The baseline descriptive data was collected during face-to-face interviews with the members who attended meetings and similar information was elicited from non-active members in the postal questionnaire.

## **OVERVIEW OF THE TWO SELF-HELP/MUTUAL AID GROUPS**

### **Group 1**

This group for carers was started in 1992 by two carers who lived in the same geographic area. The group operated in a small town (c 10,000 population) in the South East of England. It is an 'organic' group in the sense that it was established as a result of two people finding themselves in a similar situation. One was a man with a background of voluntary work, based around his experience as a father of a child with severe autism. He also found himself in later life caring for his wife. As a churchgoer he was struck by the similarity in experience between himself and of the female minister who mentioned in a sermon that she was also caring for her husband (who suffered from motor neurone disease).

The group operated in a locality and was open to any carer of any age. The group was comparatively formal in structure, having roles for each member such as chair, secretary and treasurer. It had no formal funding but members ran raffles, stalls etc. to raise money to cover costs. The venue was provided free (originally they met in a church, and later moved to a day-centre; they now meet in a village hall). The group held monthly meetings, occasionally with invited speakers. They took part in three or four 'events' a year as part of local community activities, such as summer cream teas and village fetes. They held a Christmas Party each year to which all local carers and the person they care for were invited.

At the beginning of the research, Group 1 had a core membership of six (two men and four women), they currently have a core membership of five women and one man. Both founding members left during the course of the study. After the termination of the fieldwork was completed the group expanded its activities to include a 'drop-in' health and information service that is run with a local professional.

## **Group 2**

This group was for carers of people with a disability. The group was initiated by a carers' liaison officer in 1994; the professional was jointly funded by health and social services. The group members identified themselves as a self-help/mutual aid group as from the outset the professional had planned her eventual withdrawal. The group was advertised to all known carers of service users in the local social services area.

During the study the group met once a month in the premises of a Social Services Department (SSD) daycentre, for two hours. The time coincided for some with the use of the centre by the person they cared for. In keeping with SSD restrictions the centre and carers group was open only to those deemed to be in the 'adult services' provision made for people aged 18-65. This upper age limit was problematic for carers who were often older than the person they cared for.

There was a core membership of between seven and nine carers (three or four men and four or five women). There was no formal funding but the premises were provided free. Once a year the group met independently for a summer party. Group 2 had no formal roles as such; the professional continued to attend meetings and produced a newsletter for non-active members/carers. The professional had also, on the group's request, organised external speakers and a training event. By the end of the study the professional had moved post and the premises were no longer available. The group had decided to continue but to meet in members' homes.

**Table 8: Profile of active members**

Variables	Self -Help Group 1 N=8	Self-Help Group 2 N=7	Total
Male	2	4	6
Female	6	3	9
Ethnicity: White English	8	7	15
Age (years): Range Mean Mode	53-91 55 62	50-67 51 65	
Socio-Economic Status	Professional 4 Skilled manual 2 Manual 1 Other 1	3 4	7 6 1 1
Employed	0	0	0
Given Up Employment To Care	3	3	6
Length of Time Caring: Range Mean Mode	6 months-10 years 4 years 5 years	2 years-36 years 11 6	
Length of Self-Help Group Membership Range Mean Mode	5 months-5 years 3.5 years 5 years	6 months-5 years 3 years 5 years	
Caring for: Spouse/Partner Son/Daughter Other	4  4	5 2	9 2 4
Involvement in Other Voluntary Sector Activities: Self-Help Group Voluntary/Charity Church Other	3 7 3	4 5 1	7 13 4
Regular Support: Family Friends Professionals Other None	1 1 3 3	1 1 5 0	2 2 8 3

**Table 9: Profile of non-active members**

Variables	Self -Help Group 1 N=6	Self-Help Group 2 N=7	Total
Male	2	2	4
Female	4	5	9
Ethnicity: White English	6	7	13
Age: Range Mean Mode	38-82 67 70	48-73 63 62	
Socio-Economic Status	Professional 2 Skilled manual 1 Manual 2 Other 1 (not stated)	2 1 3 1 (housewife)	
Employed	0	1	1
Given Up Employment To Care	2	1	
Length of Time Caring: 1-5 years= 5-10 years= 10+ years=	4 2 2	3 1 3	
Length of Self-Help Group Membership: Range Mean Mode	N/A	N/A	
Caring for: Spouse/Partner Son/Daughter Other	6	3 5	9 5 * (nb includes a respondent caring for 2)
Involvement in Other Voluntary Sector Activities: Self-Help Group Voluntary/Charity Church Other	2 1 2	0 1 3	2 2 5
Regular Support: Family Friends Professionals Other None	1 1 1 3	1 1 4 1	2 2 5 4

\* Five follow-up in-depth interviews with non-active members composed of two men and three women, their ages ranged from 62–83, the length of time caring ranged from four years to 47 years. All lived with the person they cared for (all spouses), one was still in employment.

## **SECTION ONE: ON BEING A MEMBER...**

In this section I explore people's motivations for joining self-help/mutual aid groups. Some contrasts are made between active and non-active members exploring why some choose to attend the group and others do not.

The primary reason given for joining the self-help groups by active members was related to the loneliness stemming from the perceived diminishing support available via usual social networks. They were also motivated by the need to meet people who were in very similar circumstances. The majority of carers were looking after someone with a degenerative condition, which had started late in their lives. The view was consistently expressed that their 'usual' support network of close friends and family had not been able to cope or did not know how to offer assistance to them. This was coupled with a feeling that it was not possible for people who did not share their experience to understand fully the nature of their caring responsibilities. However, it appears from the findings that a previous positive experience and expectation of gain from the group was important and differences in experiences of previous groups (not necessarily self-help) differentiated active from non-active members. Other major differences related to active members' willingness to consider the future degeneration of the person they cared for and to learn coping skills and an openness that they could learn coping skills from people already in that position.

### **MOTIVATION FOR ACTIVE AND NON-ACTIVE MEMBERSHIP OF SELF-HELP/MUTUAL AID GROUPS**

#### **Social Support**

As can be seen from the profiles of active and non-active members there was little difference among them in relation to the level of support received. The motivating factor



for active members was the type of support offered in the group based on an empathy that derives from experiencing the same or similar situation.

For example:

You lose all your friends and people who used to ring you up don't any more and, all of a sudden, you realise that you are alone with a big problem. (Female, Group 1)

I think the main thing I went there for was support ... with my family being in Asia, half the trouble is I can't go to my parents and discuss my problems and I find the group gives support. I go to moan about something or other, but the group sit and listen - you can let a bit of stress off and ... - I look forward to it to wait 4 or 5 weeks it is so long in between. (Male, Group 2)

Well I think the companionship bit and understanding from someone who has problems themselves...it doesn't matter what the problem was but outsiders [those not directly experiencing caring] think you are managing because you put up a front to preserve your partner's dignity. I was hoping to have someone to talk to occasionally and with whom I wouldn't have to go through all the preliminaries...they would know. (Female, Group 1)

Meeting people who have the same lived experience was therefore seen as very important. All of the carers interviewed mentioned this at some point during their interviews.

... because there is mutual understanding, people know how it feels and the problems you are facing. (Female, Group 1)

The main reason I wanted to go mainly was to give me a break, to get out the house to a different environment, possibly doing something without Sandra, meeting with other like minded people, they were the main reasons for going. (Male, Group 2)

## **Previous positive experience of groups**

The majority (11 of 15) people who attended the group had some previous experience of being active in and enjoying group membership. As can be seen from the profile this varied between membership of other self-help groups (7/15), church groups (4/15) or voluntary work/activity (13/15). Previous experiences of the benefits derived from groups also appeared to be a major motivating factor for membership.

We have always been actively involved, always, and that was a way of knowing what was going on. Unless you joined a group like that you were in the wilderness. (Male & Female co-carers, Group 2 – talking about membership of a voluntary organisation)

I've been involved in and run groups for many years ... so it wasn't difficult. I didn't mind opening up or saying anything about myself... it's difficult to explain, I don't mind sharing my experiences. I'm not a very private person in that respect. I am in others, but not that. (Male, Group 2 – talking about the church plus talking newspapers)

I thought I had better get involved before I needed someone. (Female, Group 1)

However, joining a group (especially an established group) for those without previous experience appeared to be a very difficult step:

Yes, going through the door is the first hurdle sometimes. It took two or three sessions before I was able to see that the others were just like me and having the same problems, expectations and so on... For the first two I sat outside the room and just went in for the last 15 minutes... (Male, Group 2)

For a long time we were always very wary. We never said an awful lot, but gradually you realise that you were coming out and saying what you thought and communicating in such a way that you were shedding your troubles. Other people did listen. It took quite a long while for that to happen from what I can remember. (Female, Group 2)

However, although previous experience of being in a group made joining one easier, the social roles in self-help groups are based on reciprocity and therefore unique. Borkman (1999) refers to these relations as peer-volunteering, which are quite different to those adopted in a traditional volunteer setting, where one person is dependent on the help of another. For some members their previous experience of volunteer work made the transition difficult.

***(Res) So you've got no history of self-help groups in your life before?***  
**(Self-helper):** No, because I'm not, I mean I was a member of the Red Cross for years, so I helped people. Yes. And that I suppose is why I thought when my husband got Alzheimer's and became very ill very quickly, that I could cope. And went on coping because I'm an efficient kind of person anyway. Thinking to myself, well I'm coping with this because I've had the background of looking after people who have had problems. But in the end I'm afraid it got to me. Yes, it is very different caring for somebody who you know. It's the emotional side. (Female, Group 1).

However, not all respondents felt the same:

No, it has not been a problem, because logic and commonsense prevail. It has not been a problem – the problem is caring every day for my husband ... having to give all of myself, every minute of the day. (Female, Group 1)

In terms of previous experience of groups, there were no apparent inter- or intra-group differences on any of the key variables (see profile). However, comparing these findings to those of non-active members revealed some interesting differences.

### **Why some members chose not to attend meetings**

The active members in the two groups shared my desire to find out why people who knew of the groups' existence and were on their mailing lists (and therefore 'members') did not attend. Our common-sense assumptions at the time were that non-attendance was likely to be due primarily to practical reasons such as limited access to the group because of lack of transport, and secondly that the support networks of non-active members (good

family, friendship circles of support etc) might be fulfilling the role provided to active members by the self-help/mutual aid groups. However, there were no major differences in the support networks of active and non-active members as can be seen from Tables 7 and 8. Although in the responses to the postal questionnaire five people who did not attend the group stated that they saw access as an issue, and three mentioned transport issues, in the follow-up depth interviews the reasons given by people for their non-attendance were related to other factors. The factors concerned 'presumptions' about the nature of groups, past experience of groups, and their narratives on their caring 'careers' and therefore their construction of what they expected of themselves as carers.

### **Lack of interest/poor past experience of groups**

A common theme in the interviews with non-active members was that attending a group was not for them. Group attendance was not perceived as something that would offer support:

I am not that type of person. I am a quiet sort of person. (Female, NA, Group 2)

Probably people who like going to meetings... they don't do the other things I do, you see. Also there are different situations in life. (Female, NA, Group 1)

Arthur is the sort of person who likes to be on a committee – I don't. (Female, NA, group 1)

Some referred to previous negative experiences in groups or volunteering:

I have met people who have been in going to groups who have latched onto me who have not been very nice people... 'lame ducks'. I had a nervous breakdown. It has made me wary of joining groups. It is also like when I volunteered and I was given a young chap - well he wasn't that young - he was mentally disabled and latched on to me. You are giving the support but not getting any. (Female, NA, Group 2)

No it is just not for us. It is not that I disapprove of them or dislike them. The thing is we have only been to one meeting and that was not a carers' meeting. That was a general meeting at [daycentre]. I think it made me realise it was not the place for me. I just don't like meetings. You were just basically pronounced to. You said anything out of line there was no discussion at a later date. I am just not a meetings type of person. I am just lazy I suppose, I can't be bothered. I am lazy in that direction - it is not in my interests. (Female, NA, Group 2)

I heard it said some years ago 'is your husband ill again?' and this was from a staunch pillar of the church. I think this commonly happens. He wasn't supposed to be ill again. I went to church and was told your husband has had a lot of prayers. I was more or less told I shouldn't have been asking for more - I wasn't at the time. I am afraid I don't go to church now - I still believe in God. A lot of people high up in the church seem to dictate to you. I do not like being dictated to. (Female, NA, Group 1)

There was also scepticism about whether attending the self-help group would make things better, along with fears that it might in fact make them feel worse. One aspect of this was a resistance to consider (or fear) the future and a conscious decision to cope on a day-to-day basis. This is a direct contrast in attitude to those who join and do attend groups (see below).

I think in some ways if you speak to other people, it can be a bad thing

*(Res) mmmm, why do you think that?*

Well they might think, well, how do they cope? I've got to be honest, I mean, your life is not your own. You're always... you think I can't do this because. You're always feeling responsible. Somebody's dependent on ... I find the best thing to do is to be very confident. I never let anybody knock me, no, because I'd turn round and say if you can do better yes, sure I'd stand back. I always feel that, that gives me confidence and gets it done.

*(Res) And you don't feel necessarily sharing it with somebody who is doing the same thing would make you feel better?*

In fact it could make you feel worse. Yeah, well I think, yeah you could feel sorry for a person, because they may be worse than you, probably they are, but ... they may be further advanced. And you may see things or know things that you don't really want to know yet. The situation is not going to get better, I know that, but you can condition your mind to say well I'm doing alright at the moment but I don't want to know what it's like... That's how you have to deal with this, that's how I've learnt to deal with this. Yes, yes. You cannot plan (Male, NA, Group 2)

***(Res) Are there people you know in a similar situation to you?***

Yeah, my lad will listen, but I can't, I don't want to burden him, these people like to be happy ... you can't burden someone else can you? But if I come to the meeting, the first thing I would do, is look at the bloke who is 10 years older than I am and would go up to him and say 'how are you coping?' And it might knock me for six. (Male, NA, Group 2)

... If I hear about things that might happen to us I start worrying and I don't want to worry about things that might happen. I worry as they happen. (Female, NA, Group 1)

...But, it's no good when you try to advise somebody, everybody is different ... it's no good saying what is the problem and saying, well I managed to do it, you don't, that's not the way at all. You've got to understand what the person's feeling inside and then be diplomatic and approach it in that way ... (Male, NA, Group 1)

This negative view of the experience of attending group meetings was coupled for some carers with assumptions that attendance of self-help/mutual aid groups required personal disclosures. This stereotype of the nature of self-help groups seemed to emanate from the media portrayal of US self-help groups (such as Alcoholics Anonymous, AA) and popular daytime television 'disclosure shows' (such as Oprah and Kilroy).

Well...I hate all that 'I'm Jack and I'm a drug addict' stuff. I don't want to talk about it unless I want to talk about it ... (Male, NA, Group 2)

All that sitting around in a circle ... no, it's not for me. I'm practical (Female, Group 1)

In the postal questionnaire there was an interesting gender difference that emerged regarding expectations of a self-help group. When asked what they would look for in a group the men stated either advice or arranged help/assistance; whereas the women stated they would be looking for friendship, fellowship, encouragement and understanding.

## **Identity as 'Giver'**

Amongst the responses given, there was a strong sense that all of those who did not attend meetings cast themselves as 'copers' and found it difficult to accept help from others. When asked whether they knew of others in a similar situation they framed their answers in a way that suggested they were in the position to give assistance but not to ask for it in return.

***(Res) You have a lot of experience caring, is there anyone, family or friends who have had similar experiences and you can talk things through with?***

Well my cousin because her mother was taken ill and in bed. My cousin got so she could not cope with it. When her mother was rushed up to London for a brain operation, my cousin could not go and visit her, so I went twice instead. But umm I was giving my cousin advice then and to get all the help she could then.

(Female, NA, Group 2)

***(Res) Is there anyone you can talk about caring with?***

No, not really. There is a couple of people up the road. A brother and sister. She was poorly last year broke her wrist and hip, she couldn't do much - carers went in the morning and then dinner. They didn't cook anything, only tinned things; she has meals on wheels Tuesday and Thursday but they don't eat them, they throw them away. When I went shopping I got them a couple of dinners. The carers put them in the microwave for them (Female, Group 1)

***(Res) What about your friends? There is no one close by?***

No not really. That's why I go and see the old girl up there. I say old, she is the same age as me, but I am better off health-wise. It is pathetic to see. (Female, NA, Group 2)

It is notable that in addition to the themes above the female carers who did not attend meetings also said that not wanting to leave the person they cared for was another important reason for non-attendance.

I could have pushed myself and perhaps I would have enjoyed it. We have just had so many problems over the years they have come and gone (Female, NA, Group 2)

We went to the summer tea and there was a do at Christmas time. He has only been twice. It is just the bother of going down with him and I wouldn't go without him (Female, NA, Group 1)

In addition, the person they cared for did not like the idea of attending themselves or the carer going on their own:

We will be selling tickets soon. He said he didn't want people to come around watching him! (Female, NA, Group 1)

I haven't heard anything since before Christmas - about the dinner - we didn't go. A lot of strangers - he didn't want to. I don't think many do go. (Female, NA, Group 1)

When asked if anything would induce them to attend meetings, apart from one man who said he would never be interested in going (but later went!) the other four stated that they would consider going with their partner for 'events' such as the summer fete or if a professional speaker came to give a relevant talk

I don't think so really, unless they have a real, a professional person, then that's another thing. A professional person at a meeting then you can have a very good meeting. Someone who gives real useful advice (Male, NA, Group 2)

None of the respondents thought that the venue was a significant issue, however the timing of meetings was an understandable issue for the one carer who also had a job.

### **Previous history of 'caring'**

In addition to the views held about groups, a significant finding from the in-depth interviews with non-active members was that all of them had a previous history of caring for someone else in their family, usually without support. They felt they had acquired skills and ways of coping as a result of this previous experience that led them to conclude that they would have little to gain from attending a self-help group.



Oh, it just goes back a long way ... I was very independent but I lost my mother when I was 10 years old ... so I had to learn to cook, and do the fire and things at night, and funnily enough, my auntie said, you must learn to cook these substantial meals, because one day you might need it. And do you know ... this made me independent, self-sufficient, yes, and I've always sort of done this and when this happened it didn't come too hard ... I think, well I can cook, I can clean the place up you know, let people come in and do the washing (Male, NA, Group 2)

Yes, I started caring for people when I was 15 years [old]. I have been caring for Arthur for 41 years now. That is why I am not over interested in going to meetings, because I just have to get on with things (Female, NA, Group 2)

This group of people gave the impression that 'coping' was something you learnt to do yourself, turning to others only in extreme situations.

***(Res) Does it help you to think that other people are in a similar situation?***

Yes, it does help, it does help me knowing I'm not the only one But... you've gotta carry on on your own, or try to. See it's made me very hard, very very hard person... so they [other carers] don't get any sympathy from me. See, I will put up with things and perhaps you should go down to the doctors to sort it out, but you don't ... you have to be very strong in yourself otherwise you wouldn't accomplish it ... And I set myself these little targets and get on with it and that gives you another added strength really. You do this and you surprise yourself cos you can do things that you never thought you could do. Perversely I'm not very sympathetic towards myself. (Male, NA, Group 2 )

The emphasis on coping was, however, related to the practical tasks of caring.

Respondents gave revealing answers when asked whether they felt they were able to cope emotionally with caring (a particular support identified by self-help group members who attended meetings).

***(Res) Do you feel you've learnt emotionally to cope with the caring?***

No you don't, no. I don't care what anybody says, I've become hard and that's, that. You cannot live with it really, I mean, I think I'm emotionally easy to stress up ... But then, I say sometimes I think nobody cares, nobody comes to help. Yes, and I just say that, that's another way of getting it out of you, if you had help, you might be more reluctant to work it out. The only thing that does stick in my mind for

the future is as I get older, how the hell am I going to cope, that's the bit that worries me. (Male, NA, Group 1)

That is another side of a carer that people don't really understand, how it affects them mentally. Yes, yes. I mean I laugh, but inside there is this sort of thing, you are responsible, more responsible and you think to yourself, that you're never free, you've never got this nice easy feel, I used to have a nice easy feel. You're always there and it's ready to tighten. It's the little things ... having the discomfort of finding a disabled toilet and what can I say, finding the shop with no steps. (Female, NA, Group 2)

As has been mentioned, there was no significant variation between active and non-active members in the social or professional support available. The only additional source of support available to one carer was through his work. He found that although 'juggling' paid work and caring for his wife was difficult, the work itself offered him an outlet. In addition a work group, a business club that met once a week, gave him the opportunity to talk about his personal situation with (female) colleagues.

I like work, really do like me work, it's a thing you can get into and ... you can lose yourself, so that's another outlet for me, yes. Which is another way [of] letting off steam. I mean it's nice to talk to other people - don't get me wrong, but I belong to a business club, and I speak [about caring] to other females, who are more understanding than males. I say that because they've been left with a burden of having to look after their mother's or their father's or perhaps partner is ill and they understand the problem.

Being able to be seen in the first instance as a professional who was also caring for his wife seemed an important aspect for this carer:

They are on a similar scale to me and they are in business, so we can hide it ... they always come up and talk to you and say how are you ... one of them who is looking after her mother, she's in the stress business, which is Stress in Business, which makes you ill. It's stress all the same, she sort of says, how are you coping, and I say, well I just get on with it. The more you think about it, the worse it will become, so...

*(Res) What is so important about the support from your business club?*

I'm on the same level you see, you know. A morale boost really to me. (Male, NA, Group 2)

This last dialogue was very revealing and related to the perceived need to be on 'equal terms' with those you confided in. This, of course, is precisely what self-help groups potentially offer and something of key value to members who attend.

Another interesting finding emerged when non-active members were asked how they coped when caring became stressful: all referred to individual and private activities such as gardening, knitting and painting.

## **Summary**

Although there were no differences in the level of support available to active and non-active members, there were clearly two main factors that affected the motivation of carers when deciding whether or not to join a self-help/mutual aid group. Firstly, previous positive experience of group membership seemed important and led to an expectation that there was something positive to be gained from joining the group. It is of interest that many of the active members had a history of participation in other voluntary action activities, which suggests that there may be some previously unexplored links across the voluntary action sector. The primary motivating factor was, however, a belief and expectation that there was something particular, something unique, to gain from being with others in the same situation. This uniqueness manifests itself in the reciprocal peer relations developed in the group which we will see as central to the findings in section two. Secondly, the way in which non-active members viewed themselves as 'copers' focused on the 'day-to-day' differentiates the way in which they construct their narrative about their caring identity from active members. This will be further explored in section four.

## **PERSONAL GAINS FROM ATTENDING THE GROUP**

A major part of the semi-structured interview with active members was exploring what they saw as potential gains from attending the group. The answers ranged from information and emotional and practical support to the role the group had in validating

their personal experiences. Active membership of the group was also seen as leading to the gain of new skills and attributes.

## **Empathy**

Overwhelmingly, the key factor that people who attended meetings said that they had gained from being part of the group was meeting others who could do more than sympathise with their situation and who could empathise from their own experience. For example:

They know what it is like ... They have been there and survived.  
(Female, Group 1)

I definitely feel I come away happier and contented knowing you are not alone and there are thousands out there doing the same sort of thing with the same sort of burdens and, basically it gives you a little more energy to carry on with everything in life knowing there are others doing the same thing (Male, Group 2)

It's like being part of a special tribe, you are one of the gang ... it gives you a natural link ... let your hair down, play and giggle ... you belong to an exclusive club (Female, Group 2)

They are like a club, a club to which you don't really want to be a member, but you go to because you have been through a similar experience ... and it is that what unites you (Female, Group 1)

... Let's face it, the last thing people want is other people's problems. And so, even when I go there you know, I feel as if I am being a burden sort of thing, let's face it, I don't think you want to turn round to people and say too much; at the end of the day they might say 'oh no not him again!' Well this is how I feel. I wouldn't like to have to sit down and keep listening to other people's problems, you don't want it. But, yes, it is the only way, nothing else competes, I don't go there, moan and come away feeling relaxed, it doesn't do that. It just helps to know other people are in the same situation (Male, Group 1)

Respondents said that attending the group gave them practical and emotional support and information. As self-helpers swapped their personal stories, they were able to identify

and recommend specific local services (such as welfare rights entitlements and dentists who were willing to make home visits) and suggest coping strategies to each other that helped them build, as one carer put it '*a unique map of information*' that would never have been possible via one agency/source.

### **Practical information**

Sharing information about their own experience in the group gave active members a much broader knowledge base about practical sources of help than they had hitherto been aware of.

I think being in a group like this as you listen to the different people, you realise and you learn who you can approach, yes, where maybe you didn't know that avenue was there and you just find out, all sorts of things from the group (Male, Group 2)

I was on the point of paying the plumber to come and change all my taps, when someone at the group said you should have an assessment done on your mother, they would not only be able to provide you with some equipment, but they will also be able to advise you what would be the best...And as a result of the first visit from someone from Social Services, I was supplied with levers to go on the taps, so that mum can turn them on and off easily ... amongst other things, another handrail for the stairs and a little handrail for the steps down into the garden, yeah, and since then I've had things like raised toilet seats and grab rails outside some of the doors ... all of which has made it a lot easier for mum to get around the house.

*(Res) and was it only due to other people saying that in the group?*

Yes I didn't realise that I could get an assessment and get this sort of thing through Social Services. (Female, Group 1)

Definitely the practical tips, other people's experience of what to expect of Janet's illness, how to go about helping her as much as possible. (Male, Group 2)

I think it is more practical help, how to cope with everyday life given the situation. So rather than let the illness be a burden, how to manage it. It is less of a burden, that is the biggest thing. You can get information; Sally gets various people here to chat to talk about various aspects. So, I suppose you learn ... small bits, ideas perhaps what you are entitled to

and what you are not entitled to and things that are going on and perhaps if you didn't go then you wouldn't hear them. (Male, Group 1)

These responses can be compared with the situation of non-active members. In the latter group only one person interviewed (the male who worked) had any other source of information about caring to draw on. It was noticeable (from the questions asked of me) that non-active members' knowledge of welfare rights was very hazy. In fact, the newsletter sent by Group 2 seemed to be the only source of information about carers' rights for non-active members. The newsletter was valued by non-active members, as both a source of information on welfare rights and as an insight into other carers' lives.

*(Res) What is useful to you in the newsletter?*

... it's looking at other people's similar situations to yourself, and also about things like welfare rather than not finding out. (Male, NA, Group2)

*(Res) Have you found it useful being on the mailing list at all?*

Yeah, it is very informed. Sort of reading on [about] other people, some of their problems they've had and the information that they bring out about carers' rates and all (Male, Group 2)

### **Emotional information**

The sharing of stories in groups also enabled self-helpers to discuss and pass on ways of coping that they have found useful. The regular monthly meetings also offered a forum in which members 'monitored' one another's problems and progress. The impact of hearing how others coped was particularly powerful because members felt they could personally identify with the situation. For example:

I learnt a lot from Sonia and Rob... because they'd been caring for so long (30 years for a son with disabilities) that for them it had become 'normal', it was their lives. I learned how to make things seem more 'normal' ... by not making everything into an event, rather making it part of our day's routine. (Female, Group 2)

This type of support stood in contrast to the support available outside the group, even from family members who did not have direct experience of caring.

It is incredible, the family still find it difficult to take... they don't know how to handle it... they've worked it out intellectually, they are the first to tell you about dementia but that's their sum knowledge... no emotional knowledge... completely missing (Female, Group 1)

A particularly pertinent issue was raised by an ex-carer who still attended Group 1. She had learnt through her experience of caring that it was incredibly important to make time to share leisure and pleasure time with the person being cared-for.

Something I learnt after the event was that at the end of the day Jerry would say, 'are you coming to bed?' and I wouldn't because I needed time for myself. Even if I watched rubbish on TV – I wanted 'me' time. I think he was trying to say I want to talk to you... you have been rushing about all day... thinking back I would have done it differently. To be aware of their personal needs because you can be so overwhelmed by their [physical] difficulties... it's a hairy, difficult subject (Female, Group 1).

I feel strongly that you can get all leaflets on incontinence or whatever but the real thing no-one has produced, is the relations between the carer and the sufferer: that is crucial and it makes the situation heaven or hell. You don't get advice how to maintain that relationship... when they have gone you regret it.

*(Res) Is that a function of the group?*

well... not advice... directly but it is somewhere... maybe the only place you can talk about it (Male, Group 2)

Something that differentiated active members of the group from non-active members was the formers' willingness and active concern to try and understand what they may have to face in the future. People who attended meetings thought that having this knowledge was useful in enabling them to learn to cope, whereas non-active members (see above) actively sought to avoid engaging with the future and said that they coped better by dealing with things on a day-to-day basis.

Well, I like to listen to others' experiences, the social services, getting other types of help, the progression of the illness and others who have had the illness a lot longer, that sort of thing. It has been useful to me (Male, Group 2)

A key feature of the 'emotional support' carers gave each other seemed to be sharing ways of finding space for themselves and not feeling guilty about it.

I think we all get a lot from feeling okay about wanting a bit of life ourselves... which I think you must have, you must be able to go out. I remember one lady she was tied [to the person she cared for] but some people won't come out, won't allow themselves to come to the group... I feel sorry for them because they are missing out on the very things that might help them do the job better (Female, Group 1)

After our stress management course [arranged on request by social worker] we followed his advice and all went off to do something we wanted that week. At the next meeting we discussed it... someone saw someone they hadn't seen for 20 years, someone went out for dinner... (Male, Group 2)

This 'following up' of members intentions to 'help themselves' using techniques learnt through the group (either from group members or invited speakers) gave a 'monitoring' role for the group to assess whether members were coping, particularly during points of crisis.

Yes, you can talk over problems and after two hours you can come out feeling reasonably well. (Male, Group 2)

We worry about one another for sure, definitely. If there has been a real, real problem with someone, you know at that next meeting we have worried about that person, and if that person is not there, why aren't they there? (Male, Group 2)

Another important aspect mentioned was the trust built over time in the group. Active members were comforted to know that there were people 'who knew' about them and their situation and who could be contacted outside the group setting.

I suppose the real significance has been realising that there is someone else that I can turn to, at any time, for some help and some advice. To know what is available that will make life easier, that sort of thing. It is the main significance that it's had. (Male, Group 1)



It has made me feel that all is not hopeless, you feel as though you are not on your own. It is not a hopeless situation. There will be someone there if not to do something for you, but to see that something is done for you... I feel if I phone Judy [chair] to say look I am in a difficult situation, she would say leave it with me and do the contact... and if someone comes along with a similar problem you can help. One lady did want help; she lives not far from here. I didn't know her before and I asked her to come round for a chat and gave her literature on the subject that I had got. (Female, Group 1)

## **Experiential knowledge**

The type of knowledge that is exchanged in self-help groups has been defined as 'experiential knowledge' (Borkman, 1976) and is distinct from that offered by professionals and lay people. It also develops over time in groups and is based on collective as opposed to individual narratives. This distinct form of knowledge has a unique process of development and appears to offer self-helpers both practical and emotional support.

### ***(Res) Who or what would you say has offered you the most support?***

Being in the group... just talking about the situation. Others providing their experience, because experience is the way you learn and most of those have been caring a long time and have a wealth of knowledge to contribute. (Male, Group 2)

... James had fallen... and... he said himself, people have no idea what goes on behind the front door and this is the situation and sometimes those who are caring have this personal knowledge... (Female, Group 1)

Everyone that comes to the group says 'I have learnt more today', which is because it is a number of individuals who know. That is the way knowledge is passed around. (Male, Group 2)

Self-helpers identified the value of bringing knowledge and skills from other aspects of their lives (from past careers, for example) into the group to help both themselves and others cope with the various physical, mental and emotional aspects of caring and challenging the system:

We all look at it from different points of view... we all have something, different experiences, background and have done different jobs. (Male, Group 2)

That's another good thing. Albeit it a very small thing you can pass on, it can make a difference to another persons life. Passing on a little piece of knowledge. (Female, Group 1)

One of the most powerful things in the group, people understood what that man went through. They knew there is a process that the group share. (Female, Group 1)

### **Validation**

Isolation is a particular problem facing carers and given the rather 'rosy' stereotype and images associated with being a carer it is easy for those who feel stressed to doubt their own skills and feel that they are alone in not coping well with their situation. Attending the group offered the carers the chance to 'validate' their experiences and affirm what they were doing well and what they needed help with. It seemed that one function of the group was to 'normalise' the everyday experience of looking after someone who is dependent.

I feel, I suppose, I think I should do more for Sally - perhaps I should have a different attitude, so when you hear other people say that they do get down and annoyed, yes it makes you feel better in that respect, it's not just me. (Male, Group 2)

I think I was trying to say I felt guilty when Katie went away to give me a break, but being with the group they seem to get through to me that I am entitled to a good time myself. (Male, Group 2)

Well it's always nice to hear other people having a moan about something that you were going to moan about. And you think oh, it's not so bad after all, is it! (Female, Group 1)

You can feel you are not doing it right... I don't care enough... I could be a better carer... all these sorts of feelings... we can talk about here... go home and start again. (Female, Group 1)

## **PERSONAL ATTRIBUTES GAINED FROM ATTENDING THE GROUP**

As well as more general 'gains' expressed by members through their group membership, they were asked to identify any specific personal development that has arisen since joining the group. All of the interviewees felt that they had gained personal skills and knowledge that could be directly attributed to being a member of the group. The list of 'gains' concurs with previous research but adds new dimensions relating directly to skills learnt as a group member. Each of the areas on the list below was expressed by more than half the sample.

### **Confidence**

Interestingly people referred both to themselves and to observed changes in other group members:

Well I suppose yes, I did feel more confident about going to get an assessment, because I didn't even know there was such a thing beforehand and there are things that I didn't realise could be obtained, like for instance, the removable levers that go onto taps. (Female, Group 1)

You do learn, I have learnt to hold back and then I say something, and I hope in the way I have said it it hasn't come over as rude or forward or anything like that. You do learn to put your view better. (Female, Group 1)

### **Assertiveness**

It wasn't there when we started, we would sit around the table, hardly a word was said.. but that's not any more. That is evidenced in Thomas, suddenly that came, he wants to come. He hates it if he can't go - as we all do. Yes we all speak our mind as a group.

If you are with a planner that is a little bit different you have to be cautious and you need to know if you want to do anything. You need to know how to put that question, you can't bulldoze your way in. There are ways of putting over things and I think if you are more adaptable to

their ways and more able they will listen to you more rather than shouting. (Female, Group 2)

### **Broader vision**

It has made me realise that I can get out and do things on my own, and it is good to talk to other people, to keep contact with people outside the immediate family. I think the awareness that there is life outside the caring role and not to lose the contact with them otherwise you get so bogged down with the caring you can't see anything and there is a reason for life. (Male, Group 2)

### **Self-evaluation**

I know myself a lot better... we spend a lot of our lives escaping from things don't we, well you are up against it and at the end of the day you know yourself a lot better, you have been through a difficult situation which must have brought the good and bad out in both of you. (Female, Group 1)

You are a carer doing an amateur job compared to a professional ... it is an awful job and then at the end of it you have to evaluate yourself. (Male, Group 2)

## **SKILLS LEARNT THROUGH PARTICIPATION IN THE GROUP**

In terms of new skills learnt or developed in the group the self-helpers identified two main things: learning to listen without judgement and learning to appreciate others' experiences:

### **Appreciating others' experiences**

Looking at the different people that come here, they each have a different problem and I think that helps, because it makes you, I mean if you are just involved with Alzheimer's that's fine, but to know that there are so many other people who probably are as emotionally upset as myself, but for different reasons. (Female, Group 1)

## **Listening**

I would identify listening... you must be a good listener in a self-help group

*(Res) And has being in the group made any difference?*

Yes... not jumping in, which I used to... now I back off a little, I listen more and try to understand. (Female, Group 1)

In addition, the group that was initiated by a professional had particularly valued the course she arranged for them on stress-management, both for the techniques and the experience of 'being on a course':

You were taught how to relax yourself. How to take stress away. (Male, Group 2)

It was a giggle. We were like little kids really on the floor. (Female, Group 2)

## **SUMMARY**

Active members identified a wide range of personal skills and attributes which they saw as related to group membership. Predominantly these were gained from discussions with others in the same situation. The group clearly offered a 'space' to share concerns, seek information and advice from others and to know that, if necessary, the areas of particular concern would be returned to at the next meeting. The additional support that was offered from peers who could compare and contrast their experiences was viewed as particularly significant. This enabled both a validation and a challenge to the carers of their own view of their experience. It enabled them to broaden their view of the situation/issue and a collective knowledge to be developed. Also significantly it enabled them to recognise their own strengths and weaknesses. The impact of this is re-visited in Section Four. The asides made about the ability to laugh in the face of adversity and at times, 'giggle' and 'play' are themes that re-appear throughout the findings. The group seemed to offer a unique space for members to reclaim these dimensions to their life. This is because the group offered a place for them to be seen as 'whole persons' by other

people to value and have valued their other skills and attributes. This is explored in the next section through a comparison with their relationships to professionals.

## **SECTION TWO: MUTUALITY AND DEPENDENCY**

One of the major things identified by active group members as a benefit of self-help group membership was being seen as a 'person' rather than being cast and constrained in their role as a 'carer', the latter of which they felt typified their relationship with professionals. Moreover, in the self-help/mutual aid group the relations are based on peer support and on reciprocity/mutuality; in professional/client relationships the professional (however sympathetic) is in a power position to the client and the relationship is one of dependency. Dealings with professionals were felt to be characterised by unequal role relationships where, often, other aspects of the carers' life, their skills and knowledge, were felt to be either discounted or discredited. There is a contrast, therefore, between the social relationships that are present within the group as against those between a professional and their 'client'. As a consequence the self-help/mutual aid group was seen to offer a more honest exchange of situations and emotions than was generally available in a professional setting.

### **CAST IN 'ROLE'**

A consistent finding across and between the self-help groups was that respondents said that in their dealings with professionals it was hard to transcend the 'roles' in which they were cast. This extended both to their own experience of being seen as 'informal carers' and the person they cared for as 'client' or 'service user', with seemingly little regard for their broader persona. Whilst members were very (and perhaps surprisingly) sympathetic to the resource constraints facing professionals, concern was voiced at the general lack of appreciation of the scope and breadth of their caring responsibilities and of the importance of their relationship with and to the person they cared for. This was particularly the case in relation to those professionals with whom they did not have long-term contact.

I'm willing to answer their questions, but then, I think you'd find yourself in a vulnerable position when you are, you're caring for someone and what the Social Worker is looking for is to see whether you are emotionally capable perhaps of looking after that person also. And I think I would be very loath to be the helpless female who couldn't manage.

***(Res) And how is that different to being at the self-help group?***

you don't have to put on a front, you can just be as you are. (Female, Group 1)

and

Well it's Katie, she is the disabled person, really I feel most things are for her. It doesn't seem that there is much there to assist or help me. But in saying that our Social Worker at the moment is the best we have had. She's good but you still couldn't sit down, how can I say it, spill all your problems out. It's not that sort of relationship. (Male, Group 2)

These points are also graphically illustrated in the unsolicited 'testimonies' written by two carers and reproduced in Appendix 4.

Group members referred to the opportunities that the group afforded them to get to know others outside their caring role and to value both themselves and the person they cared for more holistically.

You revert back to what you did before...(Female, Group 1)

Yes, you are out of the house for a couple of hours. You are ordinary people for a couple of hours. (Male, Group 2)

If you are caring for someone with dementia, you have no, you get no, exchange of ideas, your ideas, personality is no longer of interest. You are in a situation in a carers' group where you can exchange ideas, not necessarily about yourself, about anything and you get a normal answer. That normality is nice. (Female, Group 1)



Although the focus of the group meetings and conversations was about caring, the meetings also provided an opportunity for members to relax for two hours. During that period people did not feel directly responsible for the person they cared for.

Yes it's somewhere I can get away with other people with the same things. I suppose it's still involved, but not involved. (Male, Group 2)

I think it's just going along and listening to what others have to say. It's nice to have something to look forward to, whilst it's about caring, it's not in the caring situation, it is something different. I haven't got Susie here, I haven't got to worry about her, when to take her to the toilet etc... it's a little bit of freedom... (Male, Group 2)

There was also a strong sense of being valued as a person rather than just a carer – one carer remarked on how she liked to dress up for the group as it was a rare social event in her life.

I feel valued as Mary, as me, people are interested in other parts of me like my painting; they are also interested in Ted [cared for] as a person, what he likes and dislikes. (Female, Group 2)

However, it is important to stress that members did not see the group as either an alternative or substitute for professional help but rather as a unique 'space' where they could discuss caring in the context of their fuller lives and relationships. This could not be replicated within the professional-user relationship, because the unique quality of the group was related to their peer-relations.

A good example of both the advantages and disadvantages of close relations with professionals is provided by Group 2. Members appreciated and sought advice and support from the social worker that had instigated and continued to support the group. Despite this appreciation however, it was apparent that in Group 2 meetings that there was a tendency to tacitly defer to the social worker and expect her to take action on issues raised by the group rather than take action themselves. (This is explored further in Sections Three and Four.)

## **POOR EXPERIENCE OF PROFESSIONAL-USER RELATIONSHIPS**

Despite a surprisingly high level of tolerance and understanding shown by the groups about the financial and other constraints facing caring agencies, many stories were relayed of the poor service they had received as carers. For some of the members in both groups, the self-help group held particular significance because they had lost their trust in the ability of services and professionals to meet either their needs or the needs of the person they cared for.<sup>1</sup> This is shown in the quotations below and again also graphically illustrated in the carers' testaments in Appendix 4.

But in the end it comes to the same thing. A common thing we don't have any trust, there is no trust. The harder you try the worse it becomes. You think you are there and then you are knocked back so much. You think there is nothing else that can go wrong, but of course it does.  
(Female, Group 2)

Despite increases in the number of initiatives to gain service users' and carers' views, the general impression was that consultations were dominated by professional agendas:

One of the area meetings of the management, the carers were outnumbered by Social Workers, 20 to 1. (Female, Group 2)

It would be nice to have a meeting some of the time with all the people, where the carers are actually asking the questions. It would be nice if it had been 50/50 or just a panel where we ask the questions. (Male, Group 2)

Interestingly, one carer mentioned the significance of receiving help from a social worker who was also disabled:

It helps, it helps to have someone who knows what it's like, because obviously you don't have to explain to them and the first person who came to see us from Social Services was herself slightly disabled and did know exactly what was needed to be of help. (Female, Group 1)

For one carer her poor experience of professional services was a motivating factor behind founding a self-help/mutual aid group:

You are flung into this, unaware of what there is... And when James' neck muscles went and I was in the doctor's surgery and said could they write me a prescription for a neck brace, they said that's occupational therapy. I rang them and they said it's not us it's either physiotherapy or the district nurses. I rang the physiotherapists and got an answer phone. I rang the district nurses and they said they would get the physios to bring a neck brace, well they didn't. Two days later after me being stropky and James with his head on his chest they finally brought it. You are faced with these challenges. You emerge wanting to help others... it is the life experience. (Female, Co-founder Group 1)

### **Inter/intra professional boundaries**

As the above quotation illustrates, because of the way in which service provision is delivered according to specialist agencies and professions it was felt that the concern shown by professionals was inevitably 'boundaried' by their specialism. Concern was also expressed by the seeming lack of knowledge of particular medical conditions exhibited by some general workers for example General Practitioners (GPs), although this example does also suggest that the GP was acknowledging the 'expertise' of the carer.

... and the doctors don't know anything about Alzheimer's. They don't. My doctor would say to me, he's lovely, he's a darling, and he [the doctor] has been so kind and will give me almost anything I ask for, but he says you are the professional, you are dealing with it... you tell me. And that is it, in a way, that unless a doctor works with Alzheimer's or has a lot of experience then they can't know it. Whereas these groups are far more useful, because it is dealing with the caring side, as this group is carers and the Alzheimer's group, which I go to which, is solely Alzheimer's. (Female, Group 1)

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<sup>1</sup> It is important to note that although the fieldwork was undertaken during the introduction of the Carers (Recognition and Services) Act 1997. The National Carers Strategy (1999) which has required every L.A. to introduce a local strategy to assess the needs of carers was implemented towards the end of the fieldwork.

Not only are dealings with individual professionals hampered by role distinctions. The intra and inter-professional boundaries are also often confusing to carers, who, despite the emphasis on care-management come into contact with a dizzying array of professionals each with their particular specialism, and with services that are bounded and categorised in ways that are difficult for them to understand. (See Appendix 4 reproduced at the end of this section, which shows the dramatic change in one carer's life after the onset of his wife's Alzheimer's).

A professional coming in... it's a different thing. See they are concerned with their service, it's as though they don't always want to know the real issue... I find they go off at tangents... we don't want that, we want to know what to do and what we can get... (Female, Group 1)

See that's another crazy thing... At 18 you belong to education, education doesn't want you at 19 you become an adult. At 65 you become an old person. (Female, Group 2)

The impact of professional service categories was graphically illustrated during the course of the research when Group 2 (which met on Social Services Department Daycare premises provided for disabled adults up to the age of 65) were informed that carers who had passed the age of 65 should not be on the premises! This was eventually resolved, but offered an insight into the lack of sensitivity and understanding being shown by some professionals about the nature of self-help/mutual aid groups.

Interestingly, non-active members also echoed these difficulties with services. Both active and non-active members, however, were at pains to point out *individual* practitioners that had been of assistance to them. Rather, 'blame' was attributed to the structures and systems within which people worked.

## **PEER SUPPORT/FRIENDSHIPS**

In contrast to the unequal relations they experienced with professionals, the relations built in the self-help/mutual aid groups afforded a kind of equal vulnerability, based on a trust

that seemingly cannot be replicated in professional/client relationships. It was not that assistance from professionals was not valued, rather its limitations became ever apparent. Relationships started in the group often transcend the group and some self-helpers used the term comradeship and friendships to describe the relationships that had been built via the group.

***(Res): If I were to ask you what you feel you've gained most from being in this group, what do you think you could pin-point for me?***

I would say a friendship that I was unaware of before, I do know now that I can contact anyone in this group should I need help. Should I need someone to talk to, and though I don't avail myself of that facility very often, well I've done it once. I feel that if I need to, I could pick up the telephone... There is someone there, should I feel desperate. Yes, someone you trust and someone who's close enough that when you go to these other groups, um, you don't know where these people live. ... Whereas people in this group, most of them I know they are in the vicinity at which I can travel, should I need to go to them. (Female, Group 1)

Each person's opinions and thoughts could help each other, yes friendship I think it is ... yes, communicating. (Female, Group 2)

It's only a friendship you see people once a month and you, they are friends at that time, and once you come away, then that's it, you don't hear about it until next time. (Male, Group 2)

The value seemed to lie in the comfort of knowing that others could be contacted at any time, even though few members actually met outside the group (probably because of their caring circumstances). The contact that had occurred had been female-female or male-female but not male-male, despite offers to one another in the group 'to go for a pint' etc.

If I felt bad I could phone someone and I have no doubt then that they would come over or shall we come to you, which is nice to know. (Female, Group 1)

The reciprocity of the relationship has been referred to several times above. It was apparent that the feeling of giving something back felt very important to all of those interviewed:

Well there is the comradeship, being one of the number hopefully, there is the emotional support and I have been able to contribute a little of my situation to the group, maybe not as much as the others because I haven't been caring for so long. (Male, Group 2)

This type of social relation led to an atmosphere and an environment which offered a 'safe place' where carers were able to express guilt and 'off-load' legitimately. Interestingly humour was identified as a major mechanism for this.

I remember going to CRUISE (a bereavement self-help group)... they were laughing, joking, getting on with things and yet able to say how awful it all was... but to see people laughing, having survived, it stayed with me... I thought yes, if they could survive, so could I. I think seeing them there, spoke more than any words could together and knowing that even though they were suffering underneath they carried on, that stayed with me all the time. That is the essence... knowing people are finding ways of surviving. You can be in a dire situation but if you know they know, it's okay, it's okay to laugh and joke... they know how you feel and it is still okay to laugh... this is how it is in this group. (Female, Group 1)

Humour about their situation, which would have seemed inappropriate in either a professional setting, or among people who did not share their experience, was legitimised in the self-help/mutual aid group as a way of coping and of having a good time.

I think it's a delicate need, you need humour. I would like to see a cartoon of the situation. At 10 o'clock there is the sufferer, neat, clean and there is the carer, hair all over the place, exhausted having done the job. I think I would love to see 'So you are a Carer' – a fun book to read together that will give information, awareness that might pass you by. (Female, Group 1)

When you are on the same [wavelength]... you know, you might be talking about clinical things that you wouldn't laugh about or talk about to anyone else... finding disabled toilets. Several times I have had to go to the Ladies because there wasn't one in the gents... so we tell humorous stories and if someone is sitting there kind of glum and stressed out it can lighten them. (Male, Group 2)

**I think in a way, people in my view, is that they for an hour or two they forget all about their problems, although they are talking about them, they generally have a bit of a laugh. (Male, Group 1)**

**I suppose if you realise that the two of you are facing the same situation. I'm not talking about life and death situations that's another matter. I mean I'm talking about things like Rob saying he spent an hour and a half at the shop with his mother, and then she went down again later on her own because she didn't get what she wanted. And you know, you can think we all put up with things like that sometimes and you sort of laugh together about it and it certainly lightens it. (Female, Group 1)**

## **SUMMARY**

**Overall this section illustrates the fundamental difference and consequence of relationship between peers in self-help/mutual aid groups and those they have with professionals. The former relations are characterised by reciprocity and the latter by inequality, if not dependency. For active members the self-help/mutual aid groups offered a 'safe place' where people could be open and honest about their vulnerabilities. A place where a particular level of trust could be developed because all members were in the same position. Moreover the group offered a place in which members' other skills and knowledge were acknowledged. A rare place, where humour could be used about and in relation to their caring responsibilities. All of this seemed possible because the group enabled active members to transcend their role as 'carer' which, it seemed, had not been possible in their dealings with professionals. We will now turn to Section Three to explore some of the dominant processes that occurred in the groups that led to the unique gains and benefits that active members have attributed to group membership.**

### **SECTION THREE:**

#### **LET ME TELL YOU MY STORY... CONTENT AND PROCESSES IN THE SELF-HELP/MUTUAL AID GROUP MEETINGS**

This section of the findings describes the format of the meetings in both self-help/mutual aid group meetings and outlines the main content of their meetings, in terms of the topics covered and the dominant concerns for groups. The processes of the meetings are described in relation to the type of exchanges (tone and style) that took place and the medium and mechanisms of the 'conversation'. The findings are drawn from four tapes of two, two-hour meetings with each group and are informed in addition by reflective notes made in a research diary throughout the course of the fieldwork (see methodology). One meeting from each of the groups is outlined below to give a flavour of the format and the type of discussions that took place. The meetings were, according to both my informants and my own experience, not untypical. Appendix 5(i) provides details of the topics and contents of all of the taped meetings.

#### **PORTRAIT OF A MEETING**

To illustrate the 'typical' format of the meetings, a picture is drawn from the transcript and reflective observations of one of the taped meetings from each group.

##### **Group 1**

Group 1 met for two hours on an afternoon in the middle of the week. Their meeting place changed during the course of the study but was always based in the locality from which their members were drawn. The change of venue was a deliberate attempt to try and increase membership, each time by finding a location that was easily accessible within the village and one that did not carry a perceived stigma. For example, at the beginning of the study the group met in a Church Hall (free use as one of the founder members was the Minister). This was felt to be a possible inhibitor to prospective members who might assume the group was religiously oriented. The group moved



therefore to a lounge in a local residential assisted care home (minimal charge from a 'sympathetic manager') and finally to the local village hall<sup>2</sup>.

The 'typical' meeting was held in the lounge of the residential home with eight people present. There were six regular members (five women and one man), plus one new member (a man) and the researcher. The room was a large one and chairs had been laid out in a circle around a coffee table. The 'Chair' positioned her seat so that it was slightly outside of the circle, which seemed to symbolise her role in the proceedings<sup>3</sup>.

Prior to the meeting beginning formally the two main 'leaders' of the group (the Chair and the treasurer) made coffee for everyone and there was a warm and informal exchange regarding people's circumstances, the health of the person they cared for and others that members knew in common. The meeting was opened by the Chair who started the meeting by displaying a picture that one of the other members had painted and was due to donate to a local hospital ward. Several people joined in the discussion congratulating the painter. The Chair and another member then described their recent visit to see one of the founding members of the group who had recently moved into residential care. The new member (male) was then welcomed. The Chair then instigated a discussion on the finances of the group, which led onto a more generalised discussion about the group's plans for a stall in the summer fete. This was a lengthy discussion concerned with the arrangements of people's roles in organising and attending the event. At this point the group resembled any other village meeting. This connection with local events can be seen later in the analysis as very important since it identified this local group as an integral part of local community activity.

There was then some general discussion and concern shown about a couple who had contacted the group but who had not yet attended. This led to a number of exchanges about the viability of the group and how to increase membership. A related discussion

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<sup>2</sup> The moves did not in fact increase membership, which in this case (see findings from non-attenders) did not seem to relate simply to access issues. The Group finally evolved into an information drop-in service run jointly with a local care professional. The self-help group continued as a part of this 'service' with predominately the same membership as before.

<sup>3</sup> This was a pattern in other meetings, where, for example, in the church hall both the chair and the treasurer sat behind a table facing other members who were in a circle.

about the isolation of carers took place. During this discussion a decision to change the time and venue of their meeting was made. Forty minutes after the meeting had started the Chair specifically asked: "Does anybody have any particular problems or anything?" and one woman from the group recounted a story about her difficulty in clarifying her financial entitlement following her husband's assessment for residential care. The story raised a number of issues related to the number of professionals within one organisation that the carer had to contact and the number of times she had been promised a return call. The other members remained silent during this story until another woman in the group suggested that she [the main narrator] needed to write to organisations, not phone them, so that something was formally on record. The emotional impact of her experience was acknowledged and other carers both sympathised and gave their own examples of similar situations. A number of other practical suggestions were given and another woman asked whether the woman's husband was happy in his new home.

This conversation went on for some while until the Chair directed a question to a male carer: "And how is your mother, Eric?" and a number of practical exchanges were made regarding the provision of equipment for his mother. During this conversation the main storyteller returned to the issue of her husband moving into care and the tone of the meeting became more emotional. A conversation then ensued which involved three of the carers about the problem of loss after a partner is taken into care. The main narrator during this discussion stated that at a recent meeting of another self-help/mutual aid group she attended a consultant who had presented her research on the impact of the transition to residential care had also concluded that professionals were underestimating the impact of the transition on carers.

Again at a certain point in this conversation the Chair specifically asked the new member how he was coping. The man answered in relation to his wife rather than himself, but moved it into an area where he expressed his concern about controlling his temper when he became frustrated about looking after her. All of the members of the group joined in by suggesting their own strategies for controlling temper. Included in this exchange were

questions asking him about his previous career<sup>4</sup>. Much sympathy was expressed and stories swapped about the 'emotional exhaustion caused through long term caring'. The issue of respite care was raised and concerns were expressed about the impact it had on the person being cared-for and the guilt felt by the carer. Suggestions were then swapped about recommended places for respite care. Two members offered to give their telephone numbers to the man who was worried about his ability to cope<sup>5</sup>.

The Chair drew the meeting to a close.

The meeting was generally informal and there were opportunities for everyone to contribute at some point although the focus of the meeting revolved around the situation of just two members in particular. The Chair's role was apparent; she not only conducted the formal business of the group but also raised and explored issues while others within the group responded to her direct questioning. Her interventions ensured the exchange of experiences, information and advice among members.

## **Group 2**

Group 2 met for two hours on a Monday morning. They met on the premises of a Social Services day centre and during a period when for some of the carers the people they cared for were attending the day centre.

In the meeting, there were nine people present including the social worker [who established the group] and the researcher. All were regular attenders and formed the core of the self-help group. There were five women and four men. The room used was medium sized and overlooked a garden at the back. The chairs were positioned in a circle and tea and coffee were available throughout the meeting. Although the social worker was not seen as leading the group, beyond informal chat, which occurred standing up by

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<sup>4</sup> This illustrates the point made in section one and two, that in self-help groups attenders are encouraged to give a full account of their life – to be seen 'holistically'.

<sup>5</sup> However, in many ways the seriousness of his concern was not addressed and in the meeting it is possible that a professional listening to his concerns may have felt obliged to intervene.

the coffee and tea facilities, the meeting proper did not begin until she was present. However, there was no real formal start to the meeting since there was not a formal Chair.

The meeting appeared to 'begin' when everyone turned their attention to one member. One woman began to talk about the difficulties of having assessments that were based on 'today's needs' when looking after someone with a degenerative condition. A number of stories were then swapped on people's experience of the assessment process, expressing concern about the lack of information exchanged between different agencies. People related both their own stories and those of others that they knew. At one point the conversation broadened into a general discussion around inequality in the system and confusion about governmental priorities in health care. This led to a discussion about a new multi-agency assessment called the 'gold standard' and the carers' experience of this (positive and negative). On three occasions, the social worker intervened to include quieter members of the group, asking them their views. One man described his practical problems in moving his disabled partner and two other men exchanged stories and practical tips about the best way to use a hoist. The conversation content was on practical difficulties, but the tone was very emotional and the main narrator was near to tears. One of the other men sat with his arm around him. At several points one of the women intervened to comment on the emotional side of assisting a degenerative partner and she then placed her self in the position of the dependent person, raising queries as to how they may have felt. This shifted some of the discussion for a while onto the physical and emotional difficulties of the people they cared for. The conversation then shifted back to their own experiences and feelings.

During this exchange there were many references to instances where carers had felt professionals had respected their views and other examples where there had been a blatant disrespect for their experiential knowledge. One man offered assistance outside the meeting to the main storyteller and suggested that he needed to take a break. This led on to a discussion about respite care and the difficulties in getting satisfactory arrangements. Underlying this conversation were comments that expressed sympathy

about the constraints professionals were under, coupled with frustration at the number of professionals they had to engage with. At times the social worker would give a summary of the suggestions people had made. The final part of the meeting was devoted to swapping coping strategies when feeling really frustrated. The meeting was not formally closed but one carer remarked on the time, which led to a general agreement that 'it was time to go'. One woman remained silent throughout the entire meeting but commented to the researcher at the end that the meetings did her "a world of good – just to know there are others in the same situation".

It is important to note that the social worker's interventions were subtle and appeared only to reinforce the natural process of the meeting. However, like the Chair in the other group she did ensure that everyone who wanted or needed to speak had the opportunity to do so and that each topic was debated/discussed fully. As before, experience, information and advice were exchanged.

## **CONTENT OF THE MEETINGS: TOPICS AND ISSUES**

A very wide range of topics and issues was covered in any one meeting. What was discussed was not prescribed *a priori* but rather arose from the substance of carers' stories as they relayed them to one another. Appendix 5(i) illustrates the full range of topics and issues covered in the taped group meetings. Across both groups, some dominant themes arose. These were related both to how members dealt as individuals with their caring responsibilities and to their dealings with agencies responsible for providing services. In the former, both groups discussed the isolation of caring, combined with the emotional exhaustion of feeling responsible for someone else. Both groups spoke of the feelings this evoked such as frustration and anger and the consequences in terms of insomnia and reduced tolerance, at times, to the person they cared for. The lack of understanding of family, friends and professionals peppered these conversations. During these exchanges, as will be illustrated below, other members offered useful 'tips' based on their own experience of dealing with the same situation. Practical tips on useful equipment and individual practitioners and services were also

swapped. These exchanges assisted in building the specific 'map of information' referred to in Section One.

Difficulties that members were experiencing in relation to assessments and respite care was another common feature across the groups. Much confusion was shown over the process of dealing with welfare benefits and assessment forms, particularly the newly-introduced Carers Assessment. This raised issues about carers confusion over professional roles and boundaries and annoyance at the lack of information exchanged between agencies. In relation to respite care both groups shared a concern over the standards of respite care, equity of access and the impact of respite on the person they cared for. Feelings of guilt and frustration were exchanged and members reassured one another that these feelings were 'normal' and that they were entitled to a 'break'. This can be seen as part of the 'validating' function of the group. Any challenges that occurred between members were very subtle and took the form of another member juxtaposing their story about a similar event that illustrated a difference in either the seriousness of their situation or their reaction to it. (This is explored below). In these discussions, in keeping with the findings in Sections One and Two, members both praised individual practitioners in their support and acknowledged the constraints within which they worked. However, multi-agency practices were the subject of concern for both groups and members were confused and frustrated by the lack of clarity regarding agency responsibilities and response times.

Two key differences arose. Group 1 spent a significant proportion of both their meetings planning their participation in local events such as the town summer fetes and church events, and an annual event for all local carers in their vicinity to which the people they cared for were also invited. Group 2, by comparison, focused only on their active membership and did not discuss the implications for other carers. This difference turned out to be a significant factor in terms of Group 1's activity outside the group in terms of their lobbying for change in their locality. Group 2 by contrast did not during the course of the study engage in any such activity but rather raised and then delegated 'macro issues' to the professional who attended the group. These differences are explored

further below. Paradoxically, it was Group 2 who devoted more time to a broader, 'political' discussion of some of the issues that individuals raised, such as inequalities in service provision and government spending priorities, but they did not move beyond the discussion to any action.

Across both groups it is interesting to note that inequalities, isolation, assessment, respite care, encounters with professionals (positive and negative) and coping strategies for stress were key. The differences were that Group 1 devoted much of their meeting to community issues and Group 2 tended to broaden their discussion from the individual to the 'political' level more often than Group 1. These differences are discussed in more detail below.

## **PROCESSES WITHIN THE GROUP**

The processes in groups were largely informal and therefore were quite distinct from the structure and formality in meetings within professional organisations. The following sub-sections describe both the ways in which attenders of self-help groups relayed their concerns to one another as stories, and the ways in which they provided support for each other. The final sub-section explores differences that were apparent within and between groups.

### **Storytelling**

Both groups used story telling<sup>6</sup> as the primary medium for sharing and exploring issues that were of concern to them. As was seen above, in the example meetings, this 'story-swapping' usually started before any formal start to the meeting had been declared and as one person relayed a story that encapsulated their main concerns, others would reply either by asking for more detail (see below) or by relaying their own story to illustrate either a similar situation or a suggested 'solution' to the problem.

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<sup>6</sup> Story-telling is a narrative account of a real or imagined event or events (National Storytelling Association, 2002).

As the extracts illustrate, matters that concerned carers were not framed as 'issues' as such but were embedded in their personal narratives. This point was boldly illustrated when, during the course of the research, a local agency asked Group 2 to 'frame their main concerns' for a forthcoming meeting on developing the local Carers Strategy. The group spent at least half a session struggling with this request, finally being able to list four main concerns. Given the multitude of issues discerned from transcripts of story-swapping (illustrated in Appendix 5(i)) it is apparent that professionals would be better advised to sit and really *listen* to group meetings rather than ask groups to contribute to service development in a way that suits professionals but is alien for the people concerned.

During these exchange of stories other group members would make a variety of practical and emotional suggestions. In the earlier findings (particularly section one) this was put forward as one of the most important attributes/gains from attendance at group meetings. The solutions offered were based on the direct experience of other group members and not therefore a resource that could be easily accessed by non-attenders.

An example of this process is given in the following extract<sup>7</sup> where the main narrator outlines her frustration in gaining a financial assessment. As she speaks, another member of the group subtly suggests ways in which she may get a 'better' result.

F1 Before I go any further I have to say that George has been in [residential home] four months and I haven't paid a penny.

M1 Oh don't worry about that.

F1 I filled in a form, a declaration of his income in December and they assessed me on that, for him, it's him they assessed and gave me a verbal account over the phone and that is the last I've heard from them. So, I tried County Hall on my own and was sent from this one to that one. I had about five people in County Hall who

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<sup>7</sup> In all of the following extracts from group meetings the gender of the speaker/narrator is indicated by the dialogue (F=female, M=male). Where the dialogue is between more than two people the speakers/narrators are indicated numerically. This numbering relates purely to the order of exchanges in the extract cited and is NOT related in any way to the identity of the speaker



then said and now your address, and I gave them my address and oh well, you're [section name], we'll put you through, so I went through all this again in [section name], not for the first time and each one kept passing me on and I finally, the penultimate one said "I know what you want, I know the number you want, I'll put you through, that'll sort you out." So she puts me through and the person who answers is my husband's social worker!

F2 Jean, you've made a lot of telephone calls and they haven't worked. Have you tried writing to them?

M1 Sometimes you get a better [response]

F2 It's only a suggestion but I mean at least if you wrote to them you might, and don't put your telephone number on the letter, get a written reply.

F1 Yes and they might know my phone number though, because it's on (their records?)

F2 Well, yes, but I mean don't make it easy for them, write to them so that they will expect to write back to you. You see you can't, you can't file a phone call. If that person just forgets what was said, the phone rings again and they go off for coffee or what have you and they've forgotten about it. There's nothing for anybody else to see, but if it's a letter it will get put into your file and then somebody might manage to pick up a pen and answer.

F1 ... yes I will do that.

(Group 1, Tape 1, p8a)

### **Sharing practical information**

In the following example, one male member is describing the difficulty he has of moving his wife in a hoist. Another man asks questions that clarify the technical details about the use of the equipment, before making a suggestion based on his own experience about how to use a hoist effectively. A female member also makes suggestions as to practical ways to dress the person who is in the hoist so that using the toilet is easier. Another female interjects twice to raise concerns about the emotional impact (of the use of the

hoist) on the person being cared for. The gendered nature of the exchange is explored in more detail below.

**M1** So I have got a hoist but no one has come up with a way of telling me how I can put the hoist on. And get the clothes down, onto the toilet, wash her whilst she has the hoist on and get the clothes back on. It is impossible.

**M2** Is it manual or an electric one?

**M1** Electric – you can push it but it is really just for transfer.

**M2** A ceiling one?

**M1** No it is not a ceiling one.

**M2** You have a chair that she can go into and then over the toilet?

**F1** This is going to sound really dreadful ... I went to a family once and they had ... they were so fed up with the transferring especially around the toileting aspect of the caring that they, the lady that had MS she had agreed that she would not wear underwear. She did not wear underwear and that is very common in the people who need this sort of care, awful though it is.

**F2** It's another erosion of a person's dignity.

**M1** Well the slit in the dress that is alright in your own home but when you are out ... that's the trouble.

**F2** How about an oval slit? Like a pinafore?

**M1** Velcro fastenings have been suggested.

**M2** I could probably tell you what we used to do. You get used to it really. You get them on the hoist – took them into the bedroom – get them out of the wheelchair on to the hoist – pull the wheelchair away while they are hanging there unfortunately and put the other chair in and just lift the skirt – it is better if you use one big flared skirt. And then there was a switch to bring them down. It used to be quite effective. We could do it in about 24 minutes in the end. You get used to it.

**F2** How does Sarah feel about it – does she feel safe?

M1 She doesn't seem to mind. At times there are problems.

**(Group 2, Tape 1, p5/6)**

Another common feature in both groups was the exchange of specific practical information that was thought to be of potential use to others in the group. In the following exchange one male member outlines the possible use of the Internet as a source of information and a female member adds another or alternative suggestion.

M1 [Discussing MS from the view of a 'sufferer'] They put their own web page on... Yeah, I think a lot of it is actually American, but you know, people have actually posted things on there about their experience of it and you know, what went well and what didn't and what to look out for and things. Quite useful really.

M2 I think you can find more or less anything on it. You can do. I mean sometimes you put a word in, I mean you might put health in there and you could 2,000 things it's found relating to health, so you've gotta go through all these different pages to find out if there's anything.

F1 Talking about health, I found quite useful, I sent away for the Carer's International Diary in 1999 and there's a whole section on that sort of thing, you just flick through it and look it up and it gives you the details. I thought was extremely good value for £4.99. Because you've not only got your diary, you've got all your, all the information, yeah it was good...I have the details.

**(CODS, Group 2, Tape 2, p13)**

### **Sharing Emotional Information**

We have seen in Section One of the findings that 'emotional information' was highly valued by the active members of self-help groups. The following example relates to the group's response to a new male member of the group. The extract illustrates the 'gentle' questioning about his situation and the attempt to assist him with his concern over his control of his temper.

A question is posed at the beginning by the female members so as to open up the possibility for the new male member to express a serious concern he has about the way he is coping with his caring responsibilities. Practical information is suggested alongside strategies for coping with the emotion of the situation. However it is also apparent in this exchange that the man's expression of concern is 'contained' rather than fully explored. However, in a later extract (below) a member does offer to talk to him in more depth outside of the meeting.

F1 How are you caring, how are you coping?

M1 She's very despondent. Very very low because she wants to do everything but she can't since the stroke. And she's frustrated and she can, she can make cakes that's her only therapy. And she's flaked out when she's done them. I mean that's her only therapy.

F2 Hmm she's given up on, she's not able to go to the art classes any more?

M1 No, nothing like that all at all.

F1 Have you had any um, help from people like the Stroke Association?

M1 No

F1 Any kind of advice or anything?

M1 No I suppose I'm at fault I don't apply or ask

F2 Yes, but there is one organisation called Way Finders, and this is mainly to help stroke victims, although I must say they did help me in some ways with my mother and they actually help you to get round things. You know, how to actually, how to help the person to actually do something.

M1 But.... I cannot handle myself... My temper is the cause of...I lose my temper at the... destroy it all of what's gone before... So I've got to learn to control my temper.

F1 The advice that I heard on that one is that if you feel yourself losing your temper, walk out of the room and slam the kitchen door or shout at the birds in the apple tree or something like that and then go back and start again.

- M1** That's it but the point being is that she is distressed then... and she said she's terrified of me because I lose my temper. That's only since the day she had the stroke.
- F2** But as I say with Way Finders they do actually help the person to do things for themselves. I mean my mother can cope with it now, but at one time she was finding it very difficult to write because she couldn't hold the pen and they gave me sort of a, like a sleeve to go over the pen that's made of soft foamy stuff which meant that she could grip the pen and write and...
- F** That's a good thing, that sounds wonderful.

**( Group 1, Tape 1, p13a)**

### **Sharing coping mechanisms**

The exchange of coping mechanisms, particularly around 'loss of control' and stress was featured regularly in both groups dialogue. In the extract below the suggested coping strategies were in-depth and all based on 'what worked' for other group members.

- M1** On that stress course they did say it was good for you to do something... completely different for yourself. That is a good thing, I think.
- F1** This [attendance at the self-help group] is your only time...
- M2** I look forward to this – I find I think I am very bad company actually at the moment.
- F2** Well you don't want to talk about it...
- F1** I go to T'ai Chi – that is good – you have to take your mind off it to concentrate to do it.
- F2** I feel like having a switch so I can go completely blank but my mind won't let me do that. I can't switch off – I try to lay down on the bed but I can't completely go away from it, I think of something totally different but within 5 minutes I am back again to what is happening.

- F1** We will have to get you some marijuana...
- F2** But have you thought when you go to bed... say to yourself I have a black dustbin bag by the door, to put all my worries in mentally use your hand to put them in the bag. It doesn't help straight away but try saying right, I will put it [a worry] in the bag ... and when you get so that you think it is full...
- F1** He would need two bags a night!
- F2** Well have two bags and say for argument's sake that someone is going to pick them up... It does not work straight away... it may help you overnight by actually working out your problems.
- M2** Trying to work out your problems that is the trouble... I can't sleep.
- F1** If you can't work it out shove it in a bag until tomorrow morning...
- F2** I write mine [worries] down on a piece of paper on the kitchen table and when I am fed up with them I put them to one side and go back to them later.
- F1** The other good thing is to put down the good and the bad you'll have a long list of all the rotten things especially those you want to have a go at with the authorities and on the good side you came here, had a cup of tea and the sun was shining. That does help in the end because you have wrote down.
- M1** I used to go and play tennis... if I was stressed out it helped.

**(Group 2, Tape 1, p31)**

Offers of assistance were sometimes quite practical and extended beyond the formal meeting. In the following example the carer is also encouraged to use the experience of others in their negotiations with the authorities.

- M1** Like I say at the end of the day if you get a proper lift put in there – it is far tidier, far easier and saves them money.
- F1** You could go for that, couldn't you? Say you have been to the group, talking to other carers.

**M2** Come round and have a look at mine. They have altered them these days – made them a lot better. Ours is 15 years old now but personally I think with a wheelchair involved especially with the circumstances of transfer becoming very difficult I think to use a stair lift is very dangerous. Very dangerous personally... but they don't listen to you.

**Group 2, Tape 1, p17**

And (following the conversation about the new attendee who has difficulties controlling his temper):

**F1** I'll expect you'll feel a bit annoyed with yourself because you can't handle it?

**M1** I can handle a lot of things, but you can't when you just, you know. You've got to.

**F2** I know, when you've got to keep holding on.

**F1** Do you want to ask anything? What's my telephone number? I know I gave it to you but it's ... on there [flyer for the group].

**(Group 1, Tape1, p16a)**

**Supportive dialogue**

Something quite striking about the dialogue in both groups was the general absence of challenge. The conversation within the groups was highly supportive and almost exclusively exhibited sympathy and concern. The questions to each other were aimed at gaining a greater understanding or clarification of the situation and the suggestions made were aimed at assisting the narrator in 'coping' better with their expressed concerns. Support was expressed in a variety of ways such as affirming the thoughts, decisions or actions of the narrator, empathising and describing similar experiences or occasionally gently reminding the narrator that things 'could be worse' through the use of personal experience. In the first example the main narrator telling his story about arranging respite care is asked exploratory questions. As he recounts how he challenged a decision

by the SSD his actions are re-affirmed by congratulations from the women and an admiring summary from another male.

M1 Do you remember I was telling you... about my problem, yes I was trying to arrange this long weekend. I spoke to [the social worker], and she said she couldn't help me because there were no beds available. Once they're gone, they're gone. All booked up.

F1 Well it states quite clearly in, the conversation that I had with [another social worker] she stated quite clearly that short term breaks, when you need to be planned with flexibility to cover special appointments or holidays or whatever. So I would, can only really ask you to challenge [the social worker] on that.

M1 Well, it's sorted. I spoke to the National Carers Association... he thought it was almost illegal...

F2 ... to leave you out.

M1 I wrote to her, do you want to see what I wrote?

F1 Oh well done.

M1 And eh, they've paid for it.

F2 Well done. Well, we'll have to get a medal for this man.

M2 You see, you used the system, not take what the Social Workers, ... you've got to challenge what they say all the time.

**(Group 2, Tape 2, p14)**

In the second example, the questioning is again very gentle but succeeds in drawing out and establishing that although the main narrator (F1) is not happy with having her husband in care she does at least feel he is cared for well.

F1 Now you asked me whether my husband was happy.

F2 Maybe happy was the wrong word; I was going to say perhaps comfortable would be better.

F1 No



- F2 He's not?
- F1 Nothing's right but then he has dementia and illusions.
- F2 How do you, yes, how do you feel about the way he is there. I mean do you feel he's being cared for?
- F1 Yes to the best of their ability.
- F2 You're happy with him there?
- F1 No I wouldn't be happy with him anywhere, he won't be happy, he can't be happy, he has delusions, he thinks there are thieves, he spends all day and all night searching for the thieves who he said they've got three duplicate sets of keys and [a] secret door in that wall.
- M1 Oh yes
- F2 Hmm, but what I really meant was you're not trying to get him moved to a different home.
- F1 No I'm not trying to, I wouldn't dream of it. They're doing their best but the point is I wouldn't be surprised if they can't cope with him much longer.

**(WIV, Group 1, Tape 1, p10a)**

In the final extract below, three of the women play different roles in empathising with the narrator (F1), summarising (F2), and pointing out (by virtue of their own situation) that things could be worse (F3).

- M1 I get so far and then blow my top.
- F1 I feel, I do feel for you.
- M1 It's so daft because I do walk out sometimes and then come back and say yes, okay, what do you want.
- F2 See I couldn't walk out like that, because my husband could set fire to the place. Not on purpose.
- M2 No, I know what you mean.

- M1 Well it's, you get so far you know, you can go so far and it's very hard to control.
- F1 And when you get to your age and my age, you haven't got the mental, emotional stamina, or physical stamina.
- F2 Emotional exhaustion as well.
- F3 Yes and you finish up not sleeping, that's what happened to me.
- F2 Yeah but you see people don't want to know. People don't want to know and people don't want to come and lend a hand, where they would lend a hand if you've got a relative who was perfectly normal, like a... and they can see... or somebody who's perhaps had a stroke or had arthritis, or just got something simple that they can, or had a heart attack. They'd come and sit... when you've got a combination of things and old age, all rolled into one, people don't want to come. They don't want to, they...
- M1 She gets very upset and... while I was away.
- F2 Does she watch the television?
- M1 Oh yes.
- F2 Thank God for that, my husband wouldn't, that was beyond... he wouldn't listen to the radio, and we couldn't have a newspaper, so I was deprived of all those three things, so I had a walkman which I used to put my earphones on in bed.

**WIV, Group 1, Tape 1, p15a)**

Although there was *little direct challenge*, the last exchange could be seen to exhibit subdued tension over who had it 'worse'. At no point during the fieldwork though, did this tension surface explicitly. All members had a vested interest in maintaining the group cohesion.

Although in exchanging stories the focus was on the 'caring' relationship and tasks, there were times when other concerns became the focus of discussion. This point relates to earlier findings that the people who are active and attending members of groups feel it is rare opportunity for them to be seen as a 'whole person'. In the extract below a long-

term member of Group 2 is discussing her recent cancer diagnosis<sup>8</sup> and the way in which the news was broken to her.

For example:

F1 I was in such a state, the way she gave it to me. And I said [consultant] has offered me chemo and as she walked away she said that's if they offer it you. So ... and I never had any visitors that day, it didn't matter, I didn't want them, you know, but I had, when Kev came in at night time, I was just absolutely devastated, I mean I hadn't got a hope in hell really and I'd really given up.

F2 And was she a nurse?

F1 No she was the House Doctor. I don't think it was over the holiday period, she was the house doctor then, I never drew the curtains because I was in such a state and then she came back with my notes. She said I thought I'd upset you. Well then the next morning she came in and she said I'm really sorry that I upset you she said, but a spade's a spade.

M1 She'd got told off!

F1 No, I mean if, I hadn't, I thought about it, I thought about reporting it. And then I couldn't be bothered, if you've got a case they take so long, don't they? But I reported it to my own doctor, when he came up a couple of days afterwards... he said you take no notice of that whatsoever, you take notice of what I'm saying to you. He said you get on up. He said we'll get those legs right, which touch wood, they are! He did. Yes. So whether he said anything, I don't know, I didn't care really. I reported to him, if I have to go back for this operation and she's there, I'll refuse, I won't have her.

F2 No I don't blame you.

F1 No, that set me back. Weeks, I should think, in my mind and my health.

**(Group 2, Tape 2, p1)**

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<sup>8</sup> Sadly this long-term member of the group died as a result of her cancer within the year. Group members were phoned on a round robin and as a group offered both practical and emotional support to her husband.

## **Humour**

As was noted in Section One, a very prominent 'mechanism' used by groups to either offload, lighten or deflect the seriousness of the issues with which they were struggling was humour. In other settings this humour would have appeared inappropriate but sharing humorous insights or interpretations of their own or others situations created a congenial atmosphere that contrasted with the substance of the discussion.

For example: (In relation to the earlier extract about using hoists)

M1 There is a funny story about 20 years ago we were at [hospital] I was told to come across and shown how to use a hoist. This hoist must have been nearly up that ceiling with chains. There were chains here and there – and I said sorry but she would have gone *(to the toilet)* by the time I get her in the hoist! It took about a quarter of an hour.

M2 Yeah, 20 minutes notice needed before it happens!

**(Group 2, Tape 1, p7)**

And (in relation to the problem expressed about controlling stress)

F1 Yes if there was something that you could sink yourself into at times – even if it was only smashing china plates against the garage wall...

F2 I have been to a back massage to stop my back getting worse and she has been giving me a going over massage and that – it is good.

M1 Sounds better than smashing plates..I'd need a lot of them [plates].

F1 The plates might be a bit cheaper if you got them from the charity shop!

M1 So might the massage!

**(Group 2, Tape 1, p33)**

## **Moving from the individual to the general**

In both groups the majority of the conversation centred on individual members' situations as illustrated above. However, stemming directly from individuals' own account of their situation, the conversation would at times move towards a more generalised discussion of the issue. That said, such generalised discussion seldom lasted long and conversations returned to members' particular circumstances.

For example:

**M1** Well that's ridiculous. Isn't it? So what happens if the person does live for another 20 years.

**F1** Well assessments can only be based on today's needs.

**M 1** When they assessed her two years ago, her needs were more than what they put in anyhow. That is what annoys me.

**F1** Well I am sure if [two members] had been here, well their child was born like that and everyone knew what their life was like. Each time they needed something it was a new assessment, a new grant.

**F2** Well that is what we were talking about earlier – they [the SSD] do not look ahead – it is a progressive condition. It would seem foolish to go to all the expense of putting in a stair lift when it is going to involve 4 extra transfers every time the person wants to go to the loo.

**(Group 2, Tape 1 p1)**

And:

**M1** ..the difference is, we were at an MS meeting and a lady had one on [a new body support] and you know Kate was quite annoyed 'how did she get one and I don't?' The one she has cuts into her, she won't wear it. It's ideal the other one but you have to pay yourself. Think of the money they are spending on Viagra – this is another thing-they seem more eager about this than helping people with MS. It's ridiculous really.

F1 Did reports say it would cost £10,000 per patient? They won't fund it. The most important aspect is that we have all donated money to MS for research, billions of pounds in donations a year, and when it's successful they say they can't afford it [a new drug reported that week] ..What's the point of spending all that money on research – billions of pounds? The moral aspects of these things are quite frightening.

M1 To get the drug now you have to be – not in a wheelchair but not walking too well. The areas are limited where you can have it...

**(Group 2, Tape 2, p.2)**

An interesting paradox was that overall (as Appendix 5(i) illustrates) Group 2 tended to debate the issues on a broader, more 'political' level than Group 1. However, when it came to any action on the issues outside of the group, only Group 1 lobbied on behalf of carers locally. This seems to be related to the importance attributed by Group 1 to their identity within their geographic community (see below).

## **INTRA AND INTER GROUP DIFFERENCES**

The next section explores some of the inter and intra group differences that emerged in the data. Three key differences were identified. Within groups *gender* appeared as the key variable determining the roles that members took within the group. However, there were discrepancies between the content of the discourse and the tone and body language in the conversation. Men tended to engage in mostly 'practical' exchanges about caring and women introduced the emotional content of both being a carer and being cared for. Yet men were often very emotional in tone and appearance, for example crying in discussions. Inter group differences were marked by the impact that having a professional in the group had on Group 2, in particular the way in which they deferred to her any action on group issues that needed to be taken. Finally, whilst both groups' main identity was as 'carers', Group 1 had an additional shared geographic identity and this also appeared important in their broader concern to effect some change for other carers in their locality.

## **Intra Group difference: gender**

Looking at the content of the discourse reveals some significant and stereotypical gender differences. As can be seen in the examples below, but also in the quotations earlier, men tend to concentrate on the “practical problems” of caring and practical solutions.

However, the tone of the interchange was revealing. For example, in relation to the extract given earlier about the hoist, the discussion included three men: one (the narrator) was near to tears and another sat with his arm around him throughout the course of the conversation. Therefore, while the exchange concentrated on the practical, both the tone and style were very emotional. This resonates with the findings in Section One, where men in response to a question to what they got out of self help groups spoke almost exclusively about information and practical tips and women identified emotional support and friendship.

There were however, distinct and gender differentiated roles played out within the groups where women were almost exclusively responsible for introducing comments that focussed the conversation not only on the perspective of the carer but also the person being cared for (as illustrated under ‘Sharing practical information’). Women tended to be the ones who introduced questions about the emotional impact of various situations for both the carer and the cared for. In the next example we can see the first women’s (F1) questioning is prompting the male to give more explanations and detail. The second woman (F2) is explicitly asking about Sarah’s (his wife’s) response to the situation.

F1 To go back to this meeting – when they said that you/she will get used to it [*shower, not bathing*] they said ‘you will have to get used to it’ to Sarah?

M1 Yes.

F1 And what did she say?

M1 She didn’t say anything.

F2 Did she discuss it with you afterwards? Was she very distressed about it?

**M1** No. Since she has been on anti-depressants she has changed, her outlook is different – she is more easygoing and accepts things more than she used to. She has lost her will if you like –

**F1** So do you think the showering – do you think it is going to be OK?

**M1** ... well this is only a suggestion at this stage – I will try and hold out for a bath type shower rather than just a straight shower because she doesn't like it.

**(Group 2, Tape 1, p14)**

In the example below a very forthright question by one woman is followed up by more subtle suggestions about places to visit that would be enjoyed by both the carer and his wife.

**F1** Are you coping alright?

**M1** Yes I'm coping alright with her, but... [very, very quietly spoken]... she gets depressed and... and she wants to do everything she can't so... frustration.

**F1** Yes. Do you get her out? I mean.

**M1** I do. I take her out to the ... in [town] and I take her round and we have a cup of tea.

**F1** So you can get her into the car alright?

**M1** ... in the car we use the wheelchair and wheel her around and she's got her zimmer frame and a walking frame..

**F2** She doesn't want to go shopping or anything?

**M1** I take her shopping in her wheelchair, but she wouldn't let anybody else.

**F2** I mean I've sort of got used to going to different places where a wheelchair is easy and one place that my mother likes to go is down to [town] to the [store].



- F2 ... and that's all very easy because all the shops are on one level there and no steps, no traffic and...
- M1 Yes you go and sit outside and have a cigarette but you can't have them indoors, because you're not allowed, so we go and sit outside.
- F2 Yeah, the other place my mother likes to go to and sort of look round the shop and have a cup of tea or lunch or something is the garden centre up at [location]. Because it's very spacious, they've got a big shop that sells all sorts of things. They do a nice lunch and you know, I just sort of find places where I can take a wheelchair... but if the weather is bad then you need to find somewhere...
- F2 Like [nursery name] or [nursery name] is another one that's quite good. I know it's a garden centre but they've got a shop and a lovely little restaurant and you can actually sit out, you're under cover but outside of the actual restaurant there. They've got tables and chairs. So you know, its best... Cos I've found this with mum. If she doesn't get out, she gets bored and then, she gets bored and there we're all, we're all miserable, so... (laughter).

**(Group 1, Tape 1, p1)**

**Inter Group difference: the role of the professional in Group 2**

There was little difference between the groups in terms of format and dialogue, even though one had a professional present. As an invited attendee it was clear that the professional was not leading the meeting, rather she seemed to subtly reinforce and summarise the general flow of the conversation. At times she would contribute her own particular skills and knowledge to the conversation. If anything she was less directive than the Chair of Group 1 who clearly felt obliged to start, progress and close the meeting. Role distinctions within groups therefore were not simplistically attributable to the professional divide, rather they seemed determined by the variety of roles that group members had evolved.

However, it was clear that professional/non professional roles re-emerged when action was suggested or required following issues raised in the group. Whilst Group 1 took up issues on their own behalf in Group 2 members tended to defer to the Social Worker for advice or ask her to take up actions on their behalf. She would also be the one to raise broader issues such as the part they could play in developing the local carers' strategy. She clearly accepted her role as advocate, although she would attempt to engage other members in any course of action required. For example:

**Professional:** I think it is very important that she feels you know as if she has finished the day like we all do and sit in the armchair for as long as she possibly can. I mean... the time might come when it may not be possible for her to sit in the armchair but while she can I would go for it. You mentioned she loves to sit on the sofa – that is a huge loss if someone can't. I had a bad back for only 3 months but to me it was a nightmare not being able to sit with the family in an armchair – it was just awful. So hold onto that for as long as you can. There may be chairs even if social services won't help there may be chairs available through the second hand or [store name] – I can't remember which – they send a newsletter here – it is on the notice board – on the back of the newsletter there is all chairs and cars and seats all sorts of things for the disabled at far more reasonable prices than buying new. I think you ought to definitely get that through social services because to be in a wheelchair all day... is just awful.

**M1** Well, I have the two OTs coming I think this Thursday so I will raise these issues with them.

**Prof** Do you feel quite confident to be assertive with them and to advocate for Susie and to stick to your guns, you need to.

**M1** Yes, I know what she wants – for instance these hoists in the house there has to be an easier way.

**Prof** Well call me if you need to.

**(Group 2, Tape 1, p16)**

**And:**

**Prof** Are we going to as a group, discuss how the [carers] strategy might affect us, draw up a plan of action. The [county] Carers'

Forum are working towards doing it and they do write to their local MP a lot.

**(Group 2, Tape 2, p12)**

### **Inter group differences: community orientation**

A major distinction that appeared in the content of the meetings in the two groups related to the emphasis that Group 1 placed on its local connections. Group 1 had evolved from and was based in a local town and spent a fair proportion of the meeting discussing their contribution to local events, such as church, town festivals and community fairs. At times, passages of the dialogue could have been attributed to any community meeting rather than self-help or carers issues. In the first instance I had interpreted this as a deviation from the main focus of the group but put in context of the other findings it can be seen as significant, since this community participation is a very strong and important feature of the group's identity. As Section Four will illustrate these connections were also important in terms of the group's profile, credibility and impact at a local level<sup>9</sup>. Because Group 2's membership was drawn from a wide geographical vicinity their shared identity was solely as carers and these types of discussions did not take place. The following extracts give a 'flavour' of the kinds of exchanges that took place in Group 1 regarding planning for community events and the integration of caring issues/realities with this planning.

- F1 I've got two tables, six foot long... and the Mayor is going to take them down for me. She can't get her airs and graces just cos she's the mayor, she can work as well. (*laughter*). She will take them down for me and I hope she will come and pick them up and take them back. If not, I think I've got somebody else.
- F2 Cos one's for us and one's for...?
- F1 One's for us for the Carers, and one's for the [locality] Society and they will be side by side and then I can be on both, you know, if I have to.

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<sup>9</sup> This interpretation was strongly endorsed during feedback sessions.

**M1** We'll have many helpers?

**F1** Yeah I think.

**F1** And I've got a couple of people who come and help on the [locality] Society stall or who are quite happy to come and help on the Carers' as well, if necessary, you know. You can't have these people being fussy about what they do.

**(Group 1, Tape 1, p4)**

And

**F1** Sheila gave us some books that were left over from the Cruise Fair and I have had a little market stall outside my front gate and I have taken £14.50 so we have actually got £49.17 plus that £14.50, but I thought I'd use that as a float for the June market stall and that brings us to the June market stall. What we need, what I really need is a few people to help on the stall during the day. Have we got any volunteers?

**F2** I might be able to, I don't know but I'm going on holiday and I'll be back that weekend before and I do plan to put one or two pictures on the railings.

**M1** Can you give us times?

**F1** The times in particular that I would like help is 12 till 2.

**M1** Well, I can do that.

**F** Right lovely. I believe I'm right in saying it starts at 10:00 a.m. I will have to be down there to sort of set it up, because I'll also be be sorting out the Willsdon Society stall at the same time, but if I can get sort of some of that 2 hours off at least, I can go home, get my mother, bring her back and feed her at the church.

**M** Yes, lunch is going to be there isn't it, some sort of lunch.

**(Group 1, Tape 1, p2a)**

However, the realities of caring crowd in:

**F2** Well if I'm here I'll do it.

**F3** I mean I will give a hand if I'm on duty, now that sounds odd, but if I'm on duty I'm not going away, if I'm off duty I go away. Because I have to get away from here. I mean if I don't my job and everything else is all here and I have no free time at all. So when my weekends are off, I do go away.

**(Group 1, Tape 1, p4a)**

## **SUMMARY**

This section has explored some of the common themes and processes that exist across the groups. As the outline of the meetings showed, both groups followed a very similar process where one story after another is relayed and is either validated or subtly challenged. Many of the features outlined in Sections One and Two are reiterated here – such as sharing practical and emotional information from direct personal experience. The frustrations with and limits to relations with professionals and statutory agencies are also apparent. Within the group we see offers of support that transcend the meeting (whether this is actioned or otherwise). The form of dialogue within the group is interesting in that it is non-confrontational and validating, yet the subtle challenges and examples of a different interpretation of the same experience could be seen to broaden individuals' perspectives on their own and others' experience.

The differences related to gender seem important, with women assuming the role of introducing emotion into the dialogue and the perspective of the person being cared for. The men's concentration in terms of dialogue on the practical aspects of caring reinforce the findings in Section One. The findings also cross-refer to the differences expressed in Section One over the role of the group for women and men, where women (even when they didn't attend) expected the group to offer friendship, emotional support and companionship and men were looking for practical advice and support. However, it is also clear that although these are the stated expectations, both genders gain both practical and emotional support from the group and the tone and body language of the men also revealed their use of the group as an emotional support.

**The difference in 'identity' of the groups has also been teased out. Whereas both groups share their identity as carers, Group 1 also have a common commitment to their locality – a shared geographic identity. This appears to lead them to devote more time and energy to participation in local events, giving them a local profile that they use in 'campaigns' to improve facilities locally.**

**The differences between a group that has 'evolved' organically in a locality and one started by a professional can have very important implications. Whilst the professional's role in Group 2 was facilitative and relatively unobtrusive, it was hard for either her or the group members to lose their 'role identities'. This had implications as we will see in the following section on the motivation and ability of the group to move from any personal action to collective action on an issue.**

## **SECTION FOUR: BROADER IMPACT OF BEING IN A GROUP**

It is clear from Sections One and Two that a long list of personal gains attributed directly to group membership was identified by active members. In addition, active members' responses implied that knowledge about their situation had built over time both individually and collectively. Both groups had been established for more than five years and nearly all of the core membership had been in the group for a minimum of three years. In these terms the groups and their memberships could be seen to have reached a 'mature' state. A key question then arose as to whether groups or individuals within groups used the knowledge they had acquired to effect change at a personal, local or wider level. The data analysis revealed some key differences in the findings between the two self-help/mutual aid groups and illuminated further distinctions between active and non-active members.

### **PERSONAL ACTION**

Some members felt that personal (individual) queries or challenges they had made to either individual practitioners or broader authorities could be directly attributed to their membership of the group (that is, they would not otherwise have felt able to make them). This derived either from the direct support of other group members or was attributed to the 'psychology' of being supported by the group, of knowing that others were aware of their situation and would support any course of action they took. Examples ranged from feeling able to question decisions made by individual practitioners to taking on organisations with the backing of the group.

What I think I've realised since I've been in the group is that there are so many people [in the broader community] who need help... who are scared to approach the authorities. Anyone in authority frightens the life out of them, and it's made me realise that when you talk in groups, as a carers' group... if one person says "but I said to my doctor, please explain this to me in words of three syllables" ....that means you're challenging your doctor, yes, and there are an awful lot of people who

wouldn't dream of doing that, would go out of the Surgery as lost as they were when they went in... (Female, Group 1)

The other important thing I think is the fact that we did seem to think that when we heard about others who had left the group, that they weren't able to fight as much as when they were in the group. (Male, Group 1)

One carer gave an example of something that began as her personal action but was then taken up by the collective.

When I was looking at Respite Care Convalescence, with our Royal Air Force Association, I'd found that when I asked if I could have Respite Care... they didn't do it. They would take any kind of illness and the carer, but they wouldn't take Alzheimer's. Now I was sort of horrified so that after raising this with them [personally] it was taken on my behalf [by Alzheimer's self-help group] and was taken up by Regional Areas and then taken to a Conference. Now the Royal Air Force Association is looking into having small units within their convalescent homes for Alzheimer's people or people with Dementia .(Female, Group 1)

All those interviewed in the self-help groups said that since joining the group they felt more confident in their dealings with professionals. This seemed to be due to the opportunities that the group offered them to talk through their situation and to gain different perspectives on it. Having their experience validated (or challenged) made them more confident about their knowledge, skills and abilities. Supporting one another at this personal level was common in both groups. This is also where the 'monitoring' role identified in Section Two was particularly important. Group members taking on a challenge had the opportunity to share, discuss and reflect on the issues and report back developments in later meetings.

However, there were some key differences between the two groups as illustrated in Section Three. In Group 1, members offered their views about each other's situation and the chair (an experienced community activist) offered particular strategies and information but none of the members attempted to advocate on another's behalf. Group 2 meetings offered similar opportunities for discussion with peers but it was clear from members' comments that they viewed their (ongoing) contact with the social worker as a place to 'put' their major concerns with services. The social worker also saw her role as



that of an advocate. This was particularly marked in relation to broader issues that arose that affected the whole group (see Collective Action below).

All but one of the non-active members felt able to raise issues with individual practitioners but did not have any support in doing this. Two non-activists said they would turn to their individual social worker if they needed assistance. One non-activist had tried to raise concerns about carers' issues at a broader level, through writing to his M.P. but again ended up referring it to his social worker (although at a personal level it did have a good outcome).

I wrote to that M.P. ... I think it's on DHSS files because it was a good letter. I sent it and I got a reply, I gave him a typical day, a carer's plight.

*(Res) What was the response?*

He really got out of it by saying it should go higher up, so we wrote another letter to them, saying I'd gladly exchange your job for a fortnight and I know who will come out the strongest. I didn't get a reply.

*(Res) What did you do?*

I passed it on to my social worker, she's far better than this last one, she had disabled children so she did understand.... She started to see that I needed a break...

## **COLLECTIVE ACTION**

Members in both self-help groups were adamant that their group membership and activities were not 'political' (by which they appeared to mean party political) yet members of both groups had been involved in challenging 'authorities'. As seen earlier, in the group initiated by the social worker (Group 2), challenges were still negotiated with and through her (even though she no longer officially led the group), whereas the local group (Group 1) initiated and led their own campaigns, generally through the formally elected chair and co-ordinator.

Group 1 had taken up a number of issues with their local council regarding access for people with disabilities in the community. One of these campaigns had been successful, the other had not.

A success we had was over the station at [name of local station], one side you can get off, the other side there is a flight of stairs [and therefore inaccessible to people with disabilities].

***(Res) How did you take that up as an issue?***

I remember that Penny got someone to carry her up and down. We showed a councillor how difficult it is in a place where the station was impossible [for people with disabilities] to use one platform.

***(Res) And did this have an impact?***

Yes. They have put in a footpath that now runs along the track to the high street.

***(Res.) Why do you think you had such an impact?***

I think frankly the sort of people in the group have enough savvy. Penny is a respected member of the community... the fact she ran one of the local amenities is tremendously in our favour... the future though depends on another generation.

and

***(Res) Having talked about things that you think should be available have you taken that further?***

Well mainly things like access to various places and unfortunately the one that we put ourselves out about most just didn't happen and that was access to the bottom Post Office... where you still cannot get a wheelchair and even someone with walking difficulties finds it difficult.

***(Res) Yes. So did you take that up as a group with the local Council?***

We did write letters yes, but to no avail. We were assured that the door would be moved from one end of the Post Office to the other, because of course it's on a hill<sup>10</sup>.

This raises an important issue and distinction between the groups – the group that took up issues and had the most impact locally was formed and embedded in their local community. Although they were a 'single issue' group their concerns reflected broader but bounded community concerns. The fact this group was co-founded by a female (vicar) who saw herself as a 'born campaigner' no doubt made a difference. The chair was also a known community activist. The co-founder described the group as 'symbolic' and 'a declaration' that this is 'an area of [town name] life we won't let drop'. She felt strongly about the need to 'educate' others about the experience, through church, schools, and friendships. From the beginning she had vision and networks that enabled the group members to turn their attentions outside the immediacy of their own situations. In the

individual interview she also talked about having used her own experience as a carer to inform her wider relationships

Relating to a person can break down the fear..it is like with Posy...when I introduce her, she has a speech impediment, people make assumptions, then I say she has 17 years banking experience and an MA... different, bingo, a different way of seeing her... it's the fear... people stop relating but if you can find ways for your boss, neighbours, family to understand about it, it can help them see how they can help. It makes a difference. I still remember a turning point in the reaction of my friend who said can we come to Sunday lunch and bring lunch? That was lovely... spot on, targeted help and friendship. (Female, Group 1)

Group 2 was different. Membership was drawn from different communities, across quite a wide geographical area. They met because of their common situation but found it difficult to effect change and when they attempted to do so (through the Social Worker) they did it through more formal channels and on a County rather than locality level. Although examples were given of issues raised with the local authority (such as anger over duplicate information being required by different professional groups over the same issue, and the length and inadequacy of assessment procedures) members could not identify (or were not aware of) any changes that had occurred as a direct result of their action.

## **IMPACT OF ACTIVE GROUP MEMBERSHIP ON CARING IDENTITY**

This raises an interesting issue about the way in which both individuals and groups conceived of their identities. Group 1 clearly viewed itself as belonging to and part of two quite distinctive communities – a community of carers and, as carers, part of their local geographic community. This point was affirmed during the feedback sessions. Group 2's main identity was as a group of carers and since they came from disparate geographical locations they did not attribute any importance to a shared geographic identity. This point was made in a different way in Section Three where the relevance of

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<sup>10</sup> After the termination of the fieldwork the group became active in a campaign to minimise local housing development, lobbying for social housing only for older people, and to ensure new housing was accessible for people with disabilities.

community activities for Group 1 was apparent from the space it occupied in their conversations in group meetings.

### **Individual identity**

In terms of individual identity, one of the research questions drawn from the existing literature was to look at whether, as a result of participation in a self-help/mutual aid group, members were beginning to understand or construct their identity as a carer in a different way. What emerged was that although both active and non-active members shared similar views about the label of carer and the members shared similar views about positives and negatives of caring, non-active members seemed to judge themselves harshly/critically against a supposed ideal of a carer, whereas active members did not. This difference could be attributed to the gains outlined in Section One. The opportunity that active members had to explore their strengths and weaknesses in the self-help/mutual aid group, to have their experiences validated and to 'allow' themselves to take time for themselves and not to see difficult times as 'failures'. It appears, therefore, that active membership of the group enabled over time, subtle reconstructions of their role and identity.

With a view to exploring respondents' views about caring, they were first asked what their interpretation of a 'carer' was and then asked whether they identified themselves with that label. Both active and non-active members found it difficult to identify with the term 'carer', and found it difficult to equate this term with their relationship with and to the person they cared for, particularly in relation to their spouses. The term was usually only adopted when they came into contact with professional services and found themselves defined in that way. This lack of identification with the term was also suggested by two activists as a reason why some people don't come to the group.

Members who attended group meetings were first asked about the positives and negatives of caring and then for their reflections on their role. The latter responses were then compared with those of members who did not attend meetings.

I think the reason that I don't, that people don't put themselves in that category is because it's not a decision you make. You don't say I will become a carer or I will care for this person, unless it's a result of perhaps an accident. (Male, Group 1)

Well I am no doubt a carer, but my wife is my wife, I am her husband and you can't walk away from it in that situation, so it is a couple where you care for each other and it is part of that role. (Male, Group 2)

Yes, I mean it wasn't something that came to me until the Social Services started saying that you are doing the caring and you do this, that I am the carer. It didn't cross my mind that I was a carer. I am just fulfilling my marriage vows, until death do us part. (Female, Group 1)

I don't suppose I ever saw myself as a carer, I think my wife cared for me, in a way. I could talk to her if I needed to... she was a different person to me in a way, I'm a bit smack, bang, go in fighting and she just thought more... So, I mean after my heart attack, as I say, she looked after me. You know, I'm sure a lot of people don't think to themselves, I never saw myself as a carer really. (Male, Group 2)

It's just that at some point you think well yes, this person couldn't cope without me any longer, so I suppose I must be. (Female, Group 1)

I mean mum lives with me now... So I am her carer. (Female, Group 2)

It has always been that I don't know what else we could call ourselves ...you are there as a carer I suppose as well. (Female, Group 2)

I suppose [when it became] full time, I suppose, the carer as a full carer role I suppose I didn't class myself as I have done it before for a short time, but I think once I packed up work, then I suppose yes, it's not just day it's night. (Male, Group 2)

The answers from members who did not attend meetings, by contrast, tended to emphasise their personal coping skills (as described in section one) but held this in contrast to some 'idealised' version of a carer.

I am, I suppose, but I don't think of myself as a true blue carer, as such. I mean I gotta be honest, I'm not, sometimes I can be right nasty. But I cope, I seem to cope and as I say sometimes I don't how, but you do. I mean like this morning, you have to be planned, very carefully planned.

***(Res) What's the difference between what you do and a true blue carer then?***

Um well somebody who devotes themselves. I don't, in my mind I don't feel that, that's a thing I wouldn't want to do, it's not a job I would want to do, that's a job I've been thrown into and have to do. Like duty, love, what have you. But that's what I really mean, my heart, if I could get out of it, I would (Male, NA, Group 2)

The following quotation from a non-active member is particularly revealing. While he uses a work club to vent his frustration and to affirm other aspects of his identity it is clear that, in common with other non-activists, he holds an 'idealised' view of a carer. He reveals a fear of the future but an unwillingness to engage with his fears, whereas active members use the group as discussed in Section One to explore these fears and learn from others' tips/strategies for coping.

Yes; really that was when you see it on the form [the term carer] that's why I would not put myself up and say I'm a carer or a good carer, I wouldn't say I was a good carer, I do what I have to but, when you're a good carer your heart is in it all the time. You've gotta really that's a job. I mean I don't know, in another three or four years how I'm gonna, I don't look at that, but it's a bitterness that builds up in you and you think why me and you begin to feel, you begin to feel sorry for yourself, you know and you think, nobody gives a damn, cos they don't but don't get me wrong, they probably are thinking of you, but you don't know that ..and you hit troubled times and you think, what happens when I want to be cared for, you become lonely yes, yes and that's how my [work] group help me where I go to you see, because at least people come and talk to you and you feel part of it again. (Male, NA, Group 2)

### **Positives of caring**

All those interviewed felt that there had been positive gains from caring. These included insights into their own strengths and weaknesses, feeling a deeper love for the person they cared for because of the experiences they were going through, and positive changes in family dynamics.

That is a good question that one. ... I think your life becomes different as a family. I think we have gained in as much as we are dependent on one another. The children no longer expect us to look after them. It is

more mutual, we help them and they help us. We all need each other. I think that is something that has been a big gain. (Male, Group 2)

Well, I get companionship, you know there is someone there to talk to. I suppose I am very fortunate in as far as mum is still very lucid, we can discuss many subjects. She tells me what's going on in the world more often than not. It's a very different matter to caring for someone who has Alzheimer's, for instance. (Female, Group 1)

### **Negatives of caring**

Although it was not addressed specifically in the research, it was clear that differentials existed in terms of the physical demands on carers. However, as shown in the earlier sections, the pressure of caring is as much to do with the emotional impact it has as the physical tasks required. Caring takes place within a pre-existing relationship and the quality of the relationship both before and during the times that someone is being cared for affects the experience. The key areas that respondents picked out were seeing someone you loved degenerating, loss of spontaneity, the time and mental energy involved in planning a trip and loss of personal time and space.

I, I think seeing your partner getting worse before you, before your eyes. That's hard to handle. (Male, Group 2)

I suppose it rules your life, your whole life is down to caring. It dictates everything I can and can't do. I couldn't just get up one morning and say – let's go for a ride unless Janet feels like it, I couldn't just go off. If Janet comes that is a burden, getting into the wheelchair transferring to the car, worry about toilet and all sorts of things. (Male, Group 2)

I shall never forget the passion I felt when I lost my 40 minutes, once a week, to have my own shower and wash my hair....it was so precious, I felt murderous didn't want to have it in the middle of the day [the only possibility because of husband's needs] ...it felt like an imposition and I will never forget what it felt like. (Female, Group 1)

There was a general consensus in the responses from both active and non-active members alike that being a carer encompassed a range of physical and practical tasks and was bound up with expectations of love and duty. There were however two key differences

between active and non-active members as the earlier discussion has shown. Members who came to meetings showed a heightened awareness or ability to be open about the emotional impact of caring and a much readier acceptance that they could not be expected to be a 'perfect carer'. Non-activists tended to have a fairly low opinion of their caring capabilities and (with the exception of the man who worked) no reference group or way to challenge such a perspective.

## **CONCLUSIONS**

Overall, the findings suggest that active membership of a self-help/mutual aid group leads to a number of benefits both for the individuals that attend but also potentially for the broader community. This broader impact of groups is explicit in terms of the collective action taken by Group 1, but also implicit in both groups in terms of the potential consequences of individual gains such as increases in confidence and assertiveness which could be seen to equip members with the skills with which to engage in their dealings with others (professionals or otherwise) in their local communities.

Members from both groups felt more empowered individually to raise queries and make challenges regarding their situation because of the "validation" they had had of their own assessment. They also felt they had the backing of the rest of the group to support them. Non-active members said they raised issues but had no support in doing so.

It is interesting that it was the facilities in the community rather than professional services that Group 1 had attempted to challenge. This reflects the social model of disability outlined in Chapter Two where the disabling factors are seen as lying in societal attitudes and structures and replicated in professional services. It has been suggested in Sections Three and Four that one feature that differentiates active from non-active members was their ability to challenge their own internal ideal of a carer. Sections One and Two indicated that the group's role in validating and developing people's perception of their own experience meant active members had less guilt about leaving the person cared for, and finding a space for themselves. They had also learnt new and alternative ways of



**copied with their situation. Although it did not appear to be at a conscious level, combined they have suggested that these features contribute to a subtle yet powerful deconstruction by active members of what caring is all about.**

**The other outstanding feature is the importance that Group 1 attributed to their geographic identity which consolidates the views expressed in Chapters Three and Four that self-help/mutual aid groups should be seen as forming a part of the broader fabric of community networks and activities. The features that group members have attributed to self-help/mutual aid groups does suggest that they have an intrinsic value that it would be difficult to imagine could be filled by either the statutory or formal voluntary sector services. This does not imply they are a substitute for these services but suggests that in terms of social relations, organisation and form, they offer something unique that is an important and irreplaceable part of voluntary action in civil society. The findings from the fieldwork are discussed in the next chapter with reference to relevant existing literature.**

## **Chapter Seven**

### **Discussion of the fieldwork findings**

#### **INTRODUCTION**

In presenting a review of the literature in Chapter One, it became clear that there was no sustained or developed body of work about self-help/mutual aid in the UK – rather there is an *ad-hoc* literature that is dispersed across disciplines. In addition, with few exceptions (such as: Wilson, 1995; Wann, 1996; Elsdon *et al*, 2000) the focus tended to be more about the ‘condition’ or ‘issue’ that self-help/mutual aid groups were addressing than the phenomenon itself. Comparing the results of the fieldwork study to existing literature in the area therefore means comparing findings predominantly with those from the USA, which is useful, but also has its limitations. As the desk research has shown, it is clear that different expressions of self-help/mutual aid need to be contextualised – to be situated historically, socially, economically and culturally. This chapter therefore draws together the key findings from Chapter Six and discusses them in relation to the existing literature reviewed in Chapter One and the relevant themes that emerged from the desk research (Chapters Two – Four). In addition I draw on new literature that has emerged during the course of this study which has relevance to the fieldwork findings.

The chapter is structured into three main sections. Firstly, I discuss the reasons for joining groups and the gains associated with this. Secondly, I discuss the ‘uniqueness’ of self-help/mutual aid groups in terms of social relationships, processes and forms of knowledge, arguing that the groups provide something that could not be replicated by either the state or formal voluntary sector. Finally, I discuss the impact of active membership in the groups on the active member’s identity and broader relations. The discussion will lead into the penultimate chapter that draws together the findings from both the desk and field research looking at the overall implications of the study regarding the relationship of self-help/mutual aid groups to social policy.

## **THE MOTIVATION TO JOIN SELF-HELP/MUTUAL AID GROUPS AND THE REWARDS**

### **Why join a self-help/mutual aid group?**

The primary reasons stated in this study by active members for joining self-help/mutual aid groups seem in line with the previous findings both in the UK and USA. Diminishing social support and isolation are key factors that prompt people to join groups and become active members as well as the desire to gain more information that may be useful in their situation (such as, Wann 1995, Kurt 1990, Trojan 1989). In particular those interviewed in the study expressed a strong desire to meet with others who were in the same situation because of the assumed empathy that would be expressed.

I was hoping to have someone to talk to occasionally and with whom I wouldn't have to go through the preliminaries... they would know.  
(Female, Group 1)

This motivation to meet others in the same situation also correlates with previous studies.

However, comparing the data with non-active members revealed some interesting and novel differences, which had previously not been widely explored. Firstly, prior positive experiences of being a member of a group seemed an important motivator. This was the case in general but had a particular relevance for the founder member of Group 1 and the subsequent Chair, both of whom had a history of community activism (in the church and local community groups). This would suggest that although self-help/mutual aid groups that evolve from non-professionals are 'organic', they do need a certain type of person to instigate them in the first place. A hypothesis can be drawn that such people are likely to have a strong history of group membership (work, leisure or community) before they instigate a group. Secondly it may be noted that compared with non-activists, active members (not just founders) had a history of contributing either to church or other formal voluntary organisations. This link across different forms of voluntary action seems important and worthy of future exploration.

Thirdly, the conscious wish of active members to engage with the likely future consequences of their situations and to learn from others who were in that position was a major differentiating factor between active and non-active members. Some of the latter specifically expressed the desire to keep coping on a 'day-to-day' basis and felt that they might not learn anything from the group. In a recent UK article Charlton and Barrow's (2002) small-scale study of the coping mechanisms of eight people with Parkinson's Disease (four were members of a self-help group, the other four were not) revealed similar results. In the thematic analysis of in-depth interviews with the people concerned Charlton and Barrow found that the four non-participants' coping centred around maintaining a 'normal life' and denying the condition a central role in their lives. The four who attended the group had by contrast accepted the disease and its consequences and felt they had much to learn from others in the group about how best to manage it. Participants (active members) therefore saw the group as supportive, whilst non-participants (non-activists) perceived even the thought of the group itself as a source of distress.

The original assumptions by both the groups and myself that access and transport issues were the key reasons for non-attendance were therefore not borne out by the findings. Additionally, Group 1's attempt to increase membership during the study by changing the venue and timing did little to increase numbers<sup>1</sup>. However, the results are not much comfort to the groups who struggle perennially to keep a viable core membership. As Chapter One has shown, there has been very little previous exploration of non-membership and although these are the results of a small sample study the findings seem to give significant leads for future research.

One of the accepted views of self-help membership is that people join primarily because they do not have the support they need from existing social networks (Jacobs and Goodman, 1989). Although both active and non-active members referred to their increasing social isolation there was no significant difference between the external social support available to active or inactive members. Rather the suggestion by Thiots (1986) that people who attended groups were looking for qualitatively different

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<sup>1</sup> During the study Group 1 changed venue three times to try and increase their membership but this did not resolve their difficulties. Eventually (sometime after the end of the study) the group evolved into a Health and Information Service co-delivered with a local professional (Care Advisor). The original core group continues to meet under the auspices of the new remit.

support (only available from people with experiential knowledge) seemed to resonate with the findings of this study. Additionally the groups' potential to 'normalise' their experience and confirm that they were not alone in their situation confirms previous research. A finding, however, for these two groups that is at variance with earlier research was the lack of evidence of active members contacting each other (by phone or in person) outside of the meetings. Even though support was offered outside the meeting (evident from section three of the findings p.208) and telephone numbers swapped, data from the semi-structured interviews suggested that the important part was the psychological support gained by knowing that someone was there if needed although this was rarely actioned. By contrast Borkman (1999) has noted how important the contact and activities outside the group are for members. This differentiation may be specific to the two groups studied but may also be attributable to the fact that members of Group 1 often met outside the monthly meetings for community events (as a group) and that Group 2 were geographically dispersed. It may also point to differences in the UK and USA context.

Certainly in terms of social support the group did not seem to attract members because of lack of statutory or voluntary professional services but because the group could offer people something that professionals, friends and family just could not. As Elsdon *et al* (2000) noted, even for individuals who join on the recommendation of a professional, the formal and usually limited stated objectives of a group are seldom what active members themselves come to value.

### **Gains attributed to the group**

Looking at the range of 'gains' identified by active members one consideration was whether these could or should be provided through any other source. In the fieldwork findings group members identified a broad range of gains which were emotional, practical, personal and interpersonal.

**Table 10: Emotional, practical, personal and interpersonal gains attributed to active group membership**

<b>TYPE OF GAIN</b>	<b>GAIN</b>
Emotional	Empathy, coping strategies (short and long-term), validation, peer-support, friendship, 'holism', monitoring, acknowledgement and use of other skills/knowledge
Emotional/Practical	Experiential knowledge
Practical	Information (services, resources, specific professionals)
Personal/Interpersonal (Skills Development)	Confidence, assertiveness, self-reflection, listening, non-judgement

These areas identified by groups would broadly correspond with those of previous studies outlined in Chapter One (see my summary in Table 5, p.22). Elsdon *et al's* (2000) suggested fourfold categorisation of the learning that occurs in self-help/mutual aid groups also outlined in Chapter One may be useful here (content learning, occupational learning, social and personal learning and political learning). In terms of 'content learning' active members identified information relevant to the current condition of the person they cared for but equally attributed importance to information about possible later stages of their partners' illnesses. The tendency of professional groups to concentrate on the current situation to the exclusion of the future was illuminated in the exchanges of the experience about 'assessments' (p.214) which fail to capture the reality of caring for someone with a degenerative condition .

Occupational learning related to active members' exchange of coping strategies, local resources and services. With the latter it is important to emphasise just how detailed this 'map of information' was; it was very specific, cut across professional boundaries and therefore was not something that even in the days of care management could be provided by any one professional. It was compiled and compared directly in relation

to active members' own experience and that of others in the group. This is illustrated well in relation to the example given in section three of the findings regarding the use of hoists (p.203-204).

In line with Elsdon *et al's* (*op cit*) results it is clear from both the interview and transcript findings that interpersonal gains were considered the most significant by members. That is, the gains made through mutual support, sharing the burden and not feeling alone in the situation. This mattered both practically and psychologically. In terms of social and personal learning, active members attributed increase in confidence, assertiveness and self-reflection directly to their membership of the self-help/mutual aid groups. These findings correspond with earlier studies. However, they also identified some new areas, these being learning to listen and learning to be non-judgemental. These attributes/skills appeared to be linked to the type of discourse that occurred in groups and that can be seen as an integral part of the mutual aid process (which is discussed further below). Another important aspect identified was that active members felt able or enabled to contribute their existing skills and knowledge and have these recognised and valued by the group. This sharing of other aspects of themselves is quite distinct from their situation within professional-client relations where the opportunity and/or appropriateness of such an exchange would seem rare.

A distinguishing feature of the groups was that the issues raised and the gains attributed to membership straddled both emotional and practical domains. These domains were not separated as they might be in encounters with professionals, but formed an integrated part of the meetings. This was reflected in the discourse of the group and again the conversation regarding the use of hoists is a good example of this (p.203-204). These types of exchanges appeared to lead to a particular type of intimacy because members had allowed their vulnerabilities to surface. Reflecting the type of relationships they had developed active members framed their relations as 'friendships' (p.190) although they rarely met outside of the meetings. In 1996, Maire referred to the particular type of friendship built in self-help/mutual aid groups as an 'impersonal fellowship' which she defined as 'a friendship that is impersonal and independent of existing close interpersonal relations between group members.'

In terms of political learning both groups were reluctant to see their activities as 'political' (see Section 4 in Chapter 6), largely because they associated 'politics' with the party politics inherent in the UK context. Whilst they may have developed organisational and leadership skills, this was not something they identified. However as we have seen, both groups at either an individual or collective level had attempted to make changes in either their personal relationships with professionals or as a group with service provision. In both groups individuals felt that they were supported by the group when they took up personal issues and the monthly meetings offered a 'monitoring' of their situations. In terms of acting as a collective however, the importance of having a professional associated with the group seemed significant. For Group 1 their attempts to change local community provision was an integral and expected part of their wider relations with the local geographic community. In Group 2 however, collective concerns were referred to the original social worker founder. This is discussed further below.

The context in which these gains were made was very significant – these are twofold. Relationships within the group were both reciprocal<sup>2</sup> and holistic. The latter of these points was stressed at several stages in the findings and was eloquently summarised by one of the women in Group 2:

I feel valued as Mary, as me. People are interested in other parts of my life like my painting – they are also interested in [my husband] as a person, what he likes and dislikes. (extract from Female, Group 2)

As was seen from Section Two of the findings, active members placed a great deal of emphasis on being able to share all facets of themselves and the person they cared for in the group meetings. This important theme has only relatively recently been stressed in the existing self-help/mutual aid literature:

In contrast with the specialisation and segmentalism inherent in contemporary society, many self-helpers find self-help/mutual aid

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<sup>2</sup> As noted in Chapter One, many writers on self-help/mutual aid have observed 'serial reciprocity' in self-help groups. This is where new members contribute relatively little as they are socialised into the group where they are offered information when they most need it by longer-term members. Over time new members become the mature members able to pass on support, information and advice themselves. This process was not apparent in the two case-study groups, possibly because interviewees were all core members having been in the group for at least two years. The only exception to this was the 'silent' member in Group 2 – this however appeared to be more a matter of personality than process.



organisations to be an arena where they are received as subjects, not objects, and where all facets of their selves can be revealed; where they are, indeed, whole persons. (Borkman, 1999, p.25).

Active membership and participation in self-help/mutual aid groups therefore seem to offer something unique which would be highly unlikely if not impossible to replicate in professional-client relations. Therefore, contrary to the suggestion that self-help/mutual aid groups fill the gap where state provision should be, the groups appear to provide something that the state or other professional groups cannot directly provide. However, the processes and gains from these groups do not negate the need for professional services as the data shows members of these groups are more likely to know how to negotiate with formal authorities and be supported by their other active members in doing so. This is an important point since it underlines that membership of these groups does not reduce the need for statutory/formal provision; rather it assists members in deciding what they really need and at best supports them in getting it. I say at best since there was only tentative evidence that dissatisfaction expressed in the group evolved into action taken and more research is needed to establish why some concerns were taken up and others were not.

## **REACHING THE PARTS OTHER SERVICES/RELATIONSHIPS JUST CANNOT REACH?**

A powerful critique of self-help/mutual aid groups identified in Chapter One was the contention that they exist solely because state (and/or formal voluntary sector) services were not available and by implication could be replaced by them. Moreover that supporting such groups colludes with a model that stresses private solutions over institutional ones (Kitzinger & Perkins, 1993; Wolf, 1994). Whilst Chapters Two – Four have illustrated that most self-help/mutual aid activities, including contemporary groups in health and social care, have arisen in response to ‘gaps’ or inappropriate services (such as, HIV/AIDS, domestic violence), it has also illustrated this is not their only function. Rather both the fieldwork and desk research findings point to the significance of self-help/mutual aid as having a distinctive and integral part to play not only in relation to services but also more broadly in civil society.

In relation to formal service provision (statutory or voluntary) it is arguable that contemporary self-help/mutual aid groups are both a complement and challenge. In both form and process they can be viewed as antithetical to professional provision and to a social system that promotes relationships based on hierarchy and competition. Their uniqueness can be summarised as relating to their social relations, processes and forms of knowledge. The findings from this study are explored in each of these areas in relation to the existing knowledge base.

### **Uniqueness of the social relations**

At several points in the findings the reciprocal nature of the relations within the group were referred to and confirmed by evidence from active members (such as, pp.162, 173, 178, 191). Whilst it is important not to romanticise these groups, since inevitably there were tensions (for example, see the subtle exchange of 'who is worse off' in Section Three (p. 211) self-help/mutual aid groups that endure like the ones that formed this case-study lead to a particular form of social relations based on peer reciprocity.

For active members it was both desirable and possible to combine the roles of being both a giver and receiver within the group context. By contrast, non-active members could not conceive of themselves as being able to learn (receive) anything from others in the group and cast themselves as both copers and givers. In terms of relationships with professionals, although the group was very sympathetic to the constraints on practitioners (resources and systems) and could both identify and recommend particularly 'good' practitioners, they also recognised the uses and limitations of these relations. These relationships were discussed in terms of dependency and contrasted with the mutuality in the group. These features exemplified by both groups would place them within the 'developed' group category of Borkman's schema outlined in Chapter One, where group members are increasingly secure in the authority they invest in their own knowledge base and therefore increasingly aware of the place and limitations of relationships with professionals.

As we noted from Wilson (1995) in Chapter One, professionals do not seem to be aware of the extent and strength of self-helpers' isolation and distress, or appreciate

the ways in which helping others is useful. Rather it is assumed that people join groups primarily in order to influence services rather than as a source of mutual support and information. Elsdon *et al*'s study also indicated that this was still the case in 2000. Another significant difference noted by both Richardson and Goodman (1983) and Knight and Hayes (1981) was that in 'therapeutic groups' facilitated by professionals outside contact was actively discouraged or not considered important. Knowing support was available outside the meetings, however, was psychologically important for self-helpers in this study (whether utilised or not) and has been a significant component of the reciprocal support in other studies (Borkman, 1999).

Although professional perspectives on the role of self-help/mutual aid groups were not addressed explicitly in this study, the service-led consultation exercise described on p.201 (where self-helpers were asked to frame their 'issues' for a service-led consultation exercise) was indicative of the gulf that still exists between professional and self-help/mutual aid worlds. In Wilson's (1995) study self-helpers said that requests by professionals for input into service consultations was sapping their energy and leaving them little time for their main purpose, which was to meet, discuss with and support one another. Wilson found that self-helpers rarely mentioned formal ways of commenting on services as being of value to them; rather they were concerned with the benefits to them as individuals in taking part in groups or of less formal ways of influence, for example, at the individual practitioner level (*ibid* p.15). Both this study and the wider policy analysis in Chapters Three and Four suggest that groups are still being viewed through the lens of professional frameworks rather than understanding them in their own right.

One way to conceive of the differences in social relations that are possible between relationships based on mutuality and dependency is in terms of the 'roles' that are engendered. The concept of role is a complex one, which has been explored from sociological and psychological perspectives (such as Parsons, 1951; Goffman, 1961; and Laing, 1961). A detailed analysis of role theory is not appropriate; briefly, the term 'role' can be said to represent a set of expectations that the person is required to fulfil by virtue of their position in relation to that of others (Ruddock, 1969).

In the UK role expectations are part of the code of conduct defining professions, for example, within social work and counselling, the importance attributed to keeping their relations with service users/clients within strict 'boundaries' (regarding time and relations). With very few exceptions this makes it very difficult for professionals to engage with the emotional side of clients except in a therapeutic sense. This underlying concern with professionalism feeds the wariness of some professionals that self-help/mutual aid groups might do more harm than good in terms of both information exchange and assumptions that members may not have the skills to cope with any emotions unleashed. Yet in this study and the wider literature (see Borkman, 1999) it is clear that one of the key strengths of self-help/mutual aid groups is their potential to create an environment where peers can safely express their emotions precisely because they transcend conventional role relationships.

The voluntary nature of group membership is pertinent in two ways here. If (as professionals and non-active members fear) attendance at the group could lead to discomfort or distress with individual or group disclosures, whilst a session may be uncomfortable, members would not be under any further obligation to return to the group. They are not 'captive clients'<sup>3</sup> as many people are in relation to professional service provision. Secondly, information giving is not 'one-off' since the group meets regularly, active members have the opportunity to put 'advice' into practice and reflect on its relevance or otherwise. For example, the advice given in relation to coping with anger would/could be revisited via the 'monitoring' process identified by members (see p.177).

Processes in groups *over time* are very important; as Borkman *et al* (2000) have noted, research on self-help/mutual aid groups tends to embody assumptions that the identification of a shared common problem is enough to evolve the mutual trust and fellowship apparent in self-help/mutual aid groups. Following Borkman (*op cit*) the findings of this study suggest the processes in groups are equally important. The next section discusses two of the key aspects identified through the study.

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<sup>3</sup> This term was used by Fisher, 1983 in relation to service user evaluation of services, where he cautioned against the simple understanding of social service evaluations by clients who were obligatory users of services, such as in child protection cases.

## **Uniqueness of the processes**

In keeping with existing literature (Cain, 1991; Humphreys, 1992; Rappaport, 1993), the form of communication in the two self-help/mutual aid groups was almost exclusively enacted through the relaying of personal stories as illustrated in section three of the findings. However as Borkman *et al* (2000) noted, perhaps equally important with the storytelling is the style and format of the conversation in groups (p.9). Certainly in this study the processes in the two groups seemed an integral part of building the trust that enabled members to share their vulnerabilities with one another. In this section of the chapter I draw out two key features of this process that seemed both novel and significant – the form of dialogue and humour used in the case-study groups.

### **Dialogue**

In Chapter Six the discussion of the findings revealed that there was something quite striking about the type of conversation that was occurring in the groups. It was supportive and non-challenging in a conventional sense, and yet through a variety of means members were able to introduce new or alternative ways of looking at the same situation. Primarily this was done by ‘adding to’ the main narration so that other members’ own stories complemented or offered a different perspective. Additionally, group members sought clarification of issues and interjected questions that elicited the cared for’s perspective. In particular it was noted that the women in both groups opened up the potential for members to discuss their own feelings and those of the person they cared for. Finally, these different perspectives appeared to act as a source of validation or reflection for the main narrator.

In the original literature review that framed this study I was unable to detect anything in the existing UK or US literature that had previously illuminated these processes. However in 2000 Borkman, *et al* presented a paper at the ISTR Conference that described the results of a study they had conducted with four open AA (Alcoholics Anonymous) meetings in a suburb of Maryland, USA <sup>4</sup>. The parallels in the findings

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<sup>4</sup> They undertook the study because there had been no previous attempt to examine the process of group communication in 12-step groups to determine the core practices that promote successful group processes. Of note is that this is a study of 12-step groups which in contrast to the grassroots groups I studied exhibit many formal ground rules. The similarities and differences in the studies are outlined in Appendix 5(ii).

are quite striking and provide a useful way in which to conceptualise the importance of the 'uniqueness' I detected in the discourse of these groups.

Drawing on the work of David Bohm<sup>5</sup> (1990) Borkman *et al* (*op cit*) noted that the type of conversation exhibited in self-help/mutual aid groups is antithetical to that exhibited in most organisations and formal institutions. They use Bohm's term 'dialogue'<sup>6</sup> to classify it as a very particular kind of conversation demarking it from conventional modes of group conversation and exchange which is termed discussion and debate. The core characteristics of dialogue are the suspension of judgement, the promotion of active learning, the surfacing and identification of tacit, core assumptions and the promotion of active inquiry and reflection. Groups that exhibit these features are seen to be engaged in a successful collective learning process. This is compared to the 'usual' modes of conversation in agencies, with professionals and in institutions (schools, work organisations, businesses) where discussion takes place in 'a task focused exchange in order to win by making points to the exclusion of others' (*ibid* p.4).

In the case-study it is of note that active members had themselves identified two of the key attributes that form the basis of Bohm's notion of dialogue. In section one of the findings they referred to the suspension of judgement – or, as they termed it, learning to be 'non-judgemental'. This seemed inextricably linked to their identification of the development of listening skills in the group setting:

Yes ...not jumping in, which I used to... now I back off a little, I listen more and try to understand. (Female, Group 1)

It was as part of this process that self-helpers were appreciating both the similarities in their situations with others in the group and their differences in terms of other members' experience or interpretation of experience.

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<sup>5</sup> David Bohm is a theoretical physicist and his work on 'dialogue' arose from his frustration with the argumentative and competitive-based processes of scientific inquiry, which he saw as leading to fragmented debate in the sciences. His concern was to identify a theoretical and practical way of discussion and practice within and between disciplines that would harness the potential synergy and insights that he felt were being lost because of the dominant mode of the scientific community. He dedicated the latter part of his career to inquiring into the core premises and processes of successful group collaboration. His theories have since been adapted by amongst others Senge (1990) and Yankelovich (1999) to teach groups in organisations how to facilitate co-operative learning and problem solving.

<sup>6</sup> From the Greek word *dialogos* which means 'through the meaning of the word' (Bohm 1987).

The gentle nature of the questioning that occurred did indeed surface and identify the core assumptions and values of active members, although members would not have named them as such. See, for example, the conversation on p.200 regarding the carer who has just moved her husband into care and the opportunity that existed to revisit this type of situation in later meetings via the 'monitoring' active members described (in section one of the findings). This part of the process can be seen as analogous with the inquiry and reflection component of Bohm's work. Of importance here is that the groups could be viewed as at least in the second stage of Borkman's schema and viewed therefore as 'developed', where the group was composed predominantly of long term members who had been meeting together for around five years. Therefore exchanges were not 'one-off', rather they formed part of an ongoing cycle of inquiry and reflection at both the individual and collective level. Of key importance was that the starting point for these groups was sharing an explicit common concern, this formed the foundation stone of all the processes involved.

Borkman *et al*'s study (*op cit*) concluded that 12-step self-help/mutual aid groups have a form and style of speaking that is indicative of Bohm's dialogue<sup>7</sup>. In their study this is partly attributed to the formalised rules in 12-step groups, although it is hypothesised as potentially applying to other self-help/mutual aid groups. As was shown in this study these attributes seem to evolve 'naturally' within self-help/mutual aid groups. A tentative suggestion is that because the social relations are different in the groups to other settings, these inevitably engender a different form of conversation. Members have nothing to gain by conflict or competition which would defeat their common purpose. Kurtz (1979) noted that underlying AA philosophy is an open acknowledgement that all human beings have limitations and are therefore in co-operative interdependence with others – the real strength therefore lies in interdependence which is exemplified in self-help/mutual groups. Whilst it is debatable as to whether the absence of direct challenge is always useful in moving thinking forward it may be also be that overtly contesting personal accounts is more difficult than contesting an abstract or ideological view that someone might hold.

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<sup>7</sup> Although 'dialogue' is more likely in mature self-help/mutual aid groups (which they term as having a core membership of over 2 years) and into which therefore both the groups studied would fit.

Overt competition was a redundant concept within the self-help/mutual aid groups since everyone had a vested interest and expectation that they were there to gain from each other: primarily to benefit themselves but also to assist others. Certainly there were no arguments or major disagreements that occurred in the taped sessions or others I attended. It is only in the struggle for supremacy of knowledge that these tensions are likely to occur. This has been noted, for example, in the US by Mark Chesler *et al* who observed the tensions that arise between national, regional and local self-help/mutual aid groups for parents of children with cancer once they try to influence services (Chesler and Chesney, 1995).

### **Humour**

One of the other important aspects identified in both the in-depth interviews and in the tapes of the group sessions was the use of humour as a way of relieving tension about the difficult situations and emotions the carers confronted. Making light of difficult situations is not new and Freud in 1906 discussed 'gallows humour' (sometimes known as black humour) where the jokes about 'condemned men' or 'hopeless victims' (sic) were often generated by the victims themselves. An important aspect, however, of humour within the self-help/mutual aid groups is the shared understanding of the seriousness of the situations they faced: it appeared that the type of humour used could only be expressed legitimately in the group itself.

The humour generated in the group usually stemmed from one person's story that others began to identify with, sharing humorous insights about a shared theme. In this study the use of humour was neither self-conscious nor rehearsed, it arose either as a 'story' or as 'quips' spontaneously as active members relayed their stories. It was rare in the groups for the primary story to be relayed in a humorous way; rather the humour would tend to arise as other members identified with the story and added their own tale, giving a humorous twist to the narration (see for example the hoist stories in Chapter Six). This then served to legitimise 'seeing the funny side of things' at other points in the meeting.

Being able to laugh in the group setting also served the purpose of both enabling and allowing people in difficult circumstances to find a space to reclaim 'happiness' as was noted in the analysis of the depth interviews. For example, where one of the



women refers to the enormous significance of seeing people laugh in a self-help/mutual aid group for bereaved people '...to see people laughing, having survived, it stayed with me...I thought yes, if they can survive, so could I' (Female, Group 1).

In relaying their stories, many of the carers in the self-help groups allowed their vulnerabilities to be apparent and the use of laughter seemed to enable them to relax about their struggles, triumphs and mistakes. The linking of stories and added humour appeared to both affirm the shared nature of their situations and legitimise their strengths and weaknesses as carers. This happened both at the group level and the individual level.

Although to date there is no apparent literature on the role of humour in relation to self-help/mutual aid groups the wider literature on humour is illuminating here. Coser (1960), for example, argued that humour is to be detected primarily in the common concerns of groups and humour can also be a means of socialisation in the group including the affirmation of common values of teaching and learning, of asking for and giving support. Moran and Massam (1997) conclude therefore, that humour can be both a means and consequence of socialisation. Understanding humour as part of group behaviour has more recently been applied to studies of its role in organisations generally and within peer groups in the caring professions more specifically (for example, Broussine *et al*, 1999; Moran, 1990; Kuhlman, 1988). In these studies group norms appear to have a strong influence on the acceptance of humour in any context and there may be implicit rules about the humour. For example, in McCarroll *et al*'s (1993) study, emergency workers restricted their humour to when they were out of the range of the public and as was seen in this study self-helpers were conscious of the inappropriateness of their humour outside the group setting.

Much of the organisational literature concentrates on the benefits of humour as a 'tool' of communication as well as providing emotional bonding particularly in stressful work situations. See for example, Kuhlman's (1998) study of humour amongst staff in a maximum security forensic unit where he also notes that certain medical environments provide little or no sense of accomplishment for staff and therefore staff must rely on each other for this. This could be related to self-help

group members' use of humour as one way in which they validated each other's experience and ways of coping.

It can be hypothesised that seeing their circumstances through a 'humorous' lens does afford group members one opportunity to reflect on and revise their interpretation of their circumstances. Across many theories of humour it is accepted that as well as providing some form of tension release, its use can facilitate a reinterpretation of a given situation or event (Koestler, 1964; Martin and Lefcourt, 1983). Reinterpretation is often seen to occur as the result of incongruity between the seriousness of the situation and the funny events that occur in the reality of dealing with it. Broussine *et al* (1999) in their study on the use of humour by social workers suggested humour arises as an incongruity or disjunction 'from serious or official organisational professional discourse'. This example has its parallel in the example given by a carer of how 'official documentation' given by agencies should contain a picture of a dishevelled carer who has been up during the night and is now exhausted (see p.190). The story whilst displaying a humorous juxtaposing of the 'official' image of caring and her reality, is clearly making a serious point. The potential therefore for laughter to be a mechanism by which active members began to subtly reconceptualise their situation is significant.

More generally<sup>8</sup>, the positive effects of humour and in particular laughter have led to multiple claims for its effects on physical and mental health (Moran and Massam, 1997). There is no consensus in the literature as to whether 'black humour' is indicative of heightened or reduced sensitivity to circumstances. Not all theorists see humour as healthy; for example, Haig (1986) describes it as a form of denial, a potential suppressor or a way of avoiding dealing with anxiety. However the majority of writers concentrate on its beneficial aspects. Moran and Massam's review of studies<sup>9</sup> suggests that people with a high sense of humour do not experience less stress

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<sup>8</sup> The study of humour is now ironically a serious business spanning many disciplines – linguistics, theatre, sociology, psychology and anthropology.

<sup>9</sup> In this review it was suggested that humour may also serve more specific functions such as challenging, self-defeating or harmful thoughts or in more extreme circumstances to either protect the self by distancing the individual from the stressor (Dixon, 1980) or as a mechanism for coping so that negative feelings can be developed into positive acceptance (Maier, 1989).

but are able to generate humour to cope with the stress (Martin and Lefcourt, 1983; Nevo *et al*, 1993). Moran and Massam (1997) define three types of humour: a sense of humour (characteristic of an individual), appreciation of humour and generation of humour. They posit that the research generally suggests that generating humour is more psychologically protective than simply appreciating humour (*ibid* p.8). In this study all three are evident in the self-help group but the shared generation of humour seems the most powerful.

In many senses, then, humour can be viewed as potentially an integral part of the mutual aid process. It was also indicative of the type of intimacy that it would be difficult if not impossible to replicate within the role relationships of professional and user/client.

### **Uniqueness of the form of knowledge**

As has been noted, the unique form of social relationships and processes in self-help/mutual aid groups is key to understanding the particular type of support available from these groups. The type of knowledge generated is a core component of this support since as the discussion of the gains from groups illustrated this combines both emotional and practical knowledge. Comparing the results with the discussion in Chapter One reinforces both Borkman (1996, 1999) and Wilson's (1995) notion that the experiential knowledge built in self help/mutual aid groups is a different type of knowledge from that held by either lay or professional people.

Firstly, it is a form of knowledge built from the direct personal experience of members of the group. This knowledge, as is evident in both the depth interviews and transcripts contains specific but broad ranging advice from the names of dentists that will do home visits (p.174) to places to visit that have good wheelchair access (p.217). The generation of this knowledge and the 'maps of information' that are built from within the group are possible only because of the relationships that are developed in the groups which have enabled active members to transcend the roles they have to adopt with professionals.

Secondly, the advice given and knowledge that is built takes account of emotional dimensions as well as practical, diagnostic ones. The extract of dialogue about ways in which to cope with anger or frustration on pp.210-213 is a good illustration of this. This passage both acknowledges and validates the experience for the main narrator and then involves a variety of members in the group in suggesting coping strategies based on their direct experience of dealing with the same situation. The extract about the hoists similarly blends both practical and emotional advice. As was noted above the length of time core members had been attending the group was important; long term membership both reflects and engenders the trust that is necessary for active members to make themselves so vulnerable. Possibly unlike in any other setting, it is the vulnerability of all the participants that allows them to be more explicitly emotional. The 'emotionscapes' created by self-helpers are seen by Borkman (1999) as directly attributable to the potential for self-helpers to find new meanings in their situation (see below).

There is a different dimension to experiential knowledge in regard to professional knowledge, which McIntosh (1983) has pointed out, is because it deals with everyday life, the private and lateral spheres of relationships and life maintenance. The transcripts have been particularly illuminating in this respect where within one conversation the practicalities, technicalities and emotions of the situation have all been integral to the topic of discussion (see pp.203-204). Self-help/mutual aid groups do provide active members with an alternative knowledge base.

As was evident in this study, this enables self-helpers to both learn and appreciate the uses and limitations of professional knowledge. This was apparent in the findings from section two, where it was clear that self-helpers were not anti-professional as such, recognising both the financial and role limitations that professionals worked under. As active members exchanged advice and views they became more aware and active users of services rather than passive ones, as was illustrated by the individual actions that had resulted from discussions of their situation with other members of the group (p.205). This would fit well with demands from users and the importance of empowerment processes (Ramón, 2002).

An important implication of these findings, developed in the next chapter, concerns the inadequacy/limitations of current policy initiatives in recognising the unique knowledge base held by self-help/mutual aid groups. Knowledge built over time in a group setting is quite different to the experiential knowledge held by one service user. Clearer recognition is needed of both the form of knowledge, how it is imparted through storytelling and the type of knowledge held by groups.

One of the claims made in Chapter One is that self-help/mutual aid groups hold within them the 'seeds of change', the potential for collective reconceptualisation by active members of the commonly understood notions of their condition or situation. This claim is re-assessed against the findings of this study.

## **IMPACT ON IMAGE AND IDENTITY**

### **Identity as carers**

In earlier chapters, it was noted that some self-help/mutual aid groups moved towards a radical reconceptualisation of their situation, for example, in the fields of domestic violence and disability. In this study, subtle deconstructions took place rather than a complete reconceptualisation through the processes of being an active member of the case study groups (which may be seen as typical of grassroots self-help/mutual aid groups that are not part of a radical movement). A very significant finding was that although active members' views on caring varied little from the established literature and from non-active members, a subtle shift appeared to have occurred with regards to their expectations of themselves in their role as carers. This can be seen as related to the processes in the groups outlined above which seemed to have facilitated a subtle yet powerful reinterpretation of their situations.

For example, the responses about the definition of a carer and their own identification with the term did not vary between active and non-active members. Neither active nor non active members thought of themselves as carers, rather that they were doing their duty as spouses or parents within the context of an ongoing and significant relationship. These responses accorded with the results of major studies on caring (such as, Finch, 1989; Graham, 1983; Land, 1991; Twigg, Atkin & Perring, 1990). It

appeared however that active membership of the group led participants, over time, to adjust their expectations of themselves in the light of empathetic and experiential exchanges with each other. Their 'measure' of being a (good enough) carer was against others in the same situation in the group rather than some abstract, ideal carer which appeared to be the case for non-active members summed up by one of the non-active male carer's reference to 'true blue carers' (p.231). This may also relate to active members' potential to affirm what they did well, since others from the group listened to their advice and views.

As the analysis of both the depth-interviews and transcripts revealed, it was the process of sharing and exchanging stories about similar situations faced that made it possible for active members to share what they did well (their coping strategies) and to expose the difficulties that they faced. Again it seemed that the group offered a unique opportunity for this since even supportive family members were thought either not to fully understand or to need to be shielded from reality. Self- helpers also stated that they found it difficult to expose these vulnerabilities to caring professionals, which seemed primarily to stem from the fear that it would involve further intervention into their relationship. In the group, however, the exchanges were made within an atmosphere of mutual trust and vulnerability.

What was clear in the findings was that members of the self help/mutual aid groups were engaging seriously with the emotions and feelings that were part of their day to day experience as carers. As has been noted, it is this emotional knowledge that forms a significant part of self-helpers' experiential knowledge which enables them to manage the impact on their lives. It is this specialist, cumulative and collective knowledge that Borkman sees as leading to the development of new meaning systems. As she notes, professionals have little interest in people developing new meaning systems because they tend not to be interested in the everyday feelings and coping that users and carers undergo (although they may be responsive to suggested new models – see for example Farquharson, 1995).

This adjustment of individual/collective expectation may also be related to the length of time that core members had attended the group. In Borkman's terms the case-study groups were 'developed', with long term members (over two years). It was noted in

Chapter One that generally the self-help/mutual aid research base is still at an early stage in understanding why it is that some self-help/mutual aid groups transcend the 'official' definition of their condition. Recently, Borkman (1999) has developed a schema which derives variables from her extensive research that provide pointers as to the likelihood of a self-help/mutual aid group moving towards what she termed as 'transformational perspectives'. She noted that there is likely to be a distinction between those groups whose primary purpose is to assist their members with coping against those where there is a high degree of stigma or 'social differentness' attached to the condition, transitional or illness which is therefore more likely to require identity or lifestyle changes. However, she also noted that all self-help/mutual aid is formed in part in reaction to the stigma projected by others friends, professionals, neighbours. In this case study being a carer is not a stigmatised condition as such but it does cause isolation. Additionally, some of the carers were caring for those with stigmatised conditions and it is difficult to separate the two.

Within the UK new work is currently under way (by the Sainsbury Centre) researching the history of the user movement. This new research may be illuminating, but to date the focus has been on catalytic events rather than any in-depth look at the processes involved in the growth of this movement. Certainly, from both existing literature and the findings of this study, it can be seen that the processes involved in any self-help/mutual aid group bear the potential to enable this re-conceptualisation process. In this sense, the very existence of self-help/mutual aid groups can be seen to be a symbolic challenge to existing orthodoxies. However, although all self-help/mutual aid groups hold within them the seeds of change, not all groups do present a challenge to the existing authority. Emerick's (1989, 1991) studies for example in the mental health field have shown that self-help/mutual aid groups for past users of either psychotherapeutic treatment or mental health services hold a range of views and attitudes towards both mental health and service providers.

It was hard to assess quite how far the Carers Movement and state legislation regarding carers' rights in the UK had heightened the awareness/expectation of members of the group. Both groups were affiliated to Carers UK (formerly Carers National Association CNA), although the relationship was a passive one, whereby at each meeting the national news in the CUK newsletter was disseminated. The very

fact that there is now a definition of a carer in the UK and the issues are discussed in the popular media means that there is an explicit acceptance that carers need some support and assistance. Despite this and although active members were happy to identify at some level with the term it was not apparently seen as a politically contested arena. This may be a reflection of the age of people in a group and it would be interesting to note how self-help groups for young carers might differ on this issue.

However, looking at the impact of the group on individual and collective identity in terms of caring was not the only significant factor. An important difference that emerged in the findings between the two groups related to the importance that one group placed on their geographical identity.

### **Double identity – caring and community**

One of the major differences between the two groups in the case studies was the importance attributed to the attachment and integration with local community activities that the group (Group 1) which had evolved in a locality, demonstrated. This appeared significant to their motivation, ability and success as a collective to taking up issues of general importance to the group. These differences are summarised in the table below.



**Table 11: Similarities and differences in community and service based groups**

<b>Group 1 (Community based)</b>	<b>Group 2 (Service based)</b>
Founded by local carers	Founded by Professional
Open to all carers in the geographic locality	Open to all carers within the service boundary area
Shared identity as carers	Shared identity as carers
Shared geographic identity	
Connect group activities with community events	Focus activities on 'carers' issues
Action individual issues with the support of the group	Action individual issues with the support of the group
Action collective issues at a local level	Defer collective (and sometimes personal) action to the professional
Groups that straddle both interest and community politics are likely to be more active at the local level Founders of groups (where not professionals) are likely to be/have a history of community activism?	Groups that have a professional input are likely to defer 'action' to the professional who is both accorded and accepts that role

These findings, whilst needing further substantiation in a larger-scale project, are indicative of the differences that might occur between groups initiated by professionals and self-initiated groups that evolve 'organically' in a locality. Despite the sensitivity and facilitative manner of the founding professional in Group 2, the group had been developed in relation to a service understanding of carers' needs and concentrated on the perceived or diagnosed condition of group members. Therefore whilst both groups shared an identity as 'carers' it is very clear that Group 1's concerns extended beyond the group to a shared common concern for the ways in which local facilities might impact on themselves or the people they cared for. This had led them to develop a more general concern with the plight of carers and they took responsibility for attempting to change things at a local level. One way of doing this alongside the formal lobbying described was the profile they maintained in all local events (see for example, the discussion about involving the local mayor in their stall at a local event p.220). This was not part of a conscious political strategy and was more related to members' own needs to feel a part of the local community but it can be seen as a powerful adjunct and way of making abstract issues real to those in the vicinity. Local councillors engaged with the issues raised by the local carers

group and also knew some of the members personally and this gave an added dimension to the potential impact of their concerns.

As we saw in section four this had broader implications, since Group 2 did not take collective action on issues outside of the group but rather deferred common concerns (and sometimes individual ones) to the professional. The earlier discussion regarding roles is important here as it seemed that although the professional no longer ran the group her continued association meant she was still cast as the person who would try and make changes to service provision.

One way to conceptualise this difference between groups is to view self-help/mutual aid groups as potentially belonging to at least two types of communities – a geographic community and an interest community.

Wilmott (1986) stated that the notion of a community is derived from having things in common (ibid p.83). Tönnies' work in 1955 characterised 'community' (*gemeinschaft*) by shared mutual links, shared values and dependence. This was contrasted with 'associations' (*gesellschaft*) which had formal rules and conventions. As Payne (1999) noted 'community implies interpersonal solidarity based upon features of the social environment; association is less natural and has to be constructed'<sup>10</sup> (ibid p.75).

Common distinctions of 'community' include those based on location, interests, or attachment (Payne, 1999). In the former the fundamental base is the geographical locality but as Payne (*op cit*) points out this extends beyond proximity to the frequency with which people interact over a variety of aspects of life. Payne refers to this as 'social lifestyles' where these 'communities' share experience and values of which they are aware.

Communities of interests tend to be defined as arising when people have common connections and interests whether these are related to leisure, work or other social contacts. Another term for these types of communities are 'communities of

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<sup>10</sup> These descriptions offer a useful way to consider the differences between formal voluntary sector organisations and self-help/mutual aid groups. The description also fits with the typifications of professionals' as against self-help/mutual aid groups in the work of Borkman (1999) and Wilson (1995).

attachment' where people identify with particular social interests. These definitions would encompass self-help/mutual aid groups generally and the service-user movement in particular where there are networks of people who share the same position. Communities of interest or attachment could refer to those in a similar structural position, diagnostic position or lifestyle situation.

Payne (*op cit*) maintains therefore that 'community' is both a symbol and a construction, a vehicle giving people a comprehensible way in which to understand and define aspects of their complex lives. It is a shared perception and understanding of how things are. It follows that community is about self-identity. Community exists where people perceive or experience themselves as being in association with each other in special ways. People in a community, whether of place or interest, share attachments in two ways: they imply inter-personal connections in a network and they imply shared social interests. With regards to the findings of this study it is clear that Group 1 had a dual identity based both on locality and shared interests, whereas Group 2 shared only the latter.

## **CONCLUSIONS**

The findings from the case-study have raised a number of important issues and themes that have relevance to an understanding of contemporary self-help/mutual aid groups' role in relation to their members, professional/formal services and civil society. In turn these features contribute towards developing a multi-dimensional voluntary action approach to both understanding and locating self-help/mutual aid groups in relation to social policy. This placement offers a different model of their relationship to social policy than that currently existing in the UK.

The case-study findings regarding people's motivation to join groups and the types of gains attributed to active membership largely concur with existing research (both in the UK and USA) however, two novel findings arose that seem particularly relevant to developing a voluntary action approach in the UK. Firstly, the links that have emerged regarding active members' previous/current activity in other forms of voluntary action, for example, church, voluntary work and community activism. This feature differentiated active from non-active members and can be seen as pertinent in

light of the newly-emerging broadening of the definition of philanthropy outlined in Chapter One. Secondly, a new categorisation for groups has been developed from the findings, differentiating between those groups which form a community of interest based solely on their condition/issue and those groups who share, in addition, a geographic/local identity. This latter dual identity appears significant in terms of the likelihood of groups to engage in action outside of the group and reinforces the importance of viewing self-help/mutual aid groups as part of the broader web of community activity as suggested by Perri 6. Current UK policy makes a partial consideration of the contribution of self-help/mutual aid groups to the former identity (through the service user and carer participation agenda) but currently ignores their relevance to the latter.

In the UK context, a voluntary action approach to studying self-help/mutual aid groups leads to the suggestion that it will be important to develop a more complex understanding of the many identities that self-help/mutual aid groups might hold. This may be a more useful way to consider groups than the classic inward-looking outward-looking groups typified in the USA literature in Chapter One and that is already left wanting in relation to Group 1 whose activities straddle both definitions. This may also provide an important feature to consider during the further exploration needed on why some self-help/mutual aid groups become politicised and others do not. It also has important policy implications at both the conceptual and practical level since it goes some way to resolving the overly simple equation that is being made between self-help groups and the service user movement in which self-help/mutual aid groups are perceived only in relation to professional services.

The findings also indicate the uniqueness of contemporary self-help/mutual aid groups in relation to other forms of social support: professional services, family and friends. These features, as has been demonstrated, relate to the social relations, knowledge base, organisation and processes integral to self-help/mutual aid groups, in particular, the weaving of emotional and practical information and support. The findings have a broad concurrence with existing literature but offer new insights into the holistic nature of groups and the type of dialogue that facilitates many of the gains that members attribute to groups. Cumulatively these processes and gains have been shown to have a subtle yet powerful impact on the identity of active members as

opposed to non-active members. These features begin to illuminate the connections between these contemporary grassroots groups and the other forms of self-help/mutual aid activity described in Chapters One to Four. As more of the seeds of these processes are illuminated, there is a clearer insight into the types of features of these groups that may have resulted in more radical deconstructions of “official versions” (lay or professional) of groups’ condition/situation.

Overall then, it appears that self-help/mutual aid groups offer something that cannot be replicated in professional/user relations. However, the data from non-active members clearly demonstrated a common-sense point that these groups are not for everyone. In addition to the existing explanations outlined in Chapter One, the study indicated that joining groups requires a belief in the benefits of group activity and, in the case-study example, a willingness to engage with the longer term consequences of their situation. Despite its many benefits, therefore, self-help/mutual aid activity is not a substitute for professional services, rather it serves a different purpose for members and the findings suggest may lead to more confident and appropriate use of existing services as well as challenges to them.

Overall the findings suggest contemporary self-help/mutual aid groups can be conceived of as part of the rich fabric of civil society as observed by de Tocqueville and Havel in Chapter One. The next chapter draws together the findings from both the case-study and the desk research to discuss and re-assess their implications for an understanding of the relationship between self-help/mutual aid groups and social policy.

## **Chapter Eight**

### **Policy Implications and final conclusions**

#### **INTRODUCTION**

**This chapter weaves together key findings from both the fieldwork and desk research to revisit the original research questions and to consider the implications for the overall aim of the study. That is, an enhanced understanding of the relationship between contemporary self-help/mutual aid groups in health and social care and social policy. The Chapter begins with a summary discussion of the core contribution the overall study has to offer to this understanding. It is suggested that as a result of the findings a fundamental re-framing of the relationship is required at both a conceptual and practical level by both UK policy makers and academics. This re-framing needs to contextualise and understand contemporary self-help/mutual aid groups as part of voluntary action in UK society. The implications of adopting this approach are then discussed in relation to key current concepts and policies from which self-help/mutual aid groups are currently excluded. The chapter concludes with specific policy and research recommendations drawn from the study.**

**As was stated in Chapter One, the study implicitly adopted and subsequently developed a voluntary action approach to understanding contemporary self-help/mutual aid groups. Doing so enabled:**

- The location of contemporary self-help/mutual aid groups in relation to the broader history and tradition of different forms of self-help/mutual aid activity in the UK**
- Re-affirmation and evidencing of the long tradition and central importance of self-help/mutual aid activities as a core form of voluntary community action in civic society**
- Identification of self-help/mutual aid's uniqueness in terms of social relations, process and knowledge**
- The distinction of self-help/mutual aid from philanthropic traditions and activities**
- A clarification of contemporary self-help/mutual aid groups' relationship to and distinction from the contemporary service user movement**

- Identification of the potential dual identity of contemporary self-help/mutual aid, both in terms of communities of interest and geographic communities
- Identification of self-help/mutual aid's consequent distinct relationship towards and with the state.

Separately and together these components of the approach have implications for current social policy concerns, particularly the New Labour agenda. Collectively these areas are about the key theme that has run implicitly throughout the thesis – the politics of 'place'. This overarching theme is concerned with how to understand self-help/mutual aid activities as a core component of voluntary action in UK third sector society and to:

- a) therefore locate contemporary self-help/mutual aid groups within this broader understanding, and
- b) shed some understanding on the ambivalent relationship that these groups have held over the years with and towards the state.

A summary discussion of the overall findings is therefore first discussed under these two main headings before turning to the implications for policy and practice.

## **SELF-HELP/MUTUAL AID AND VOLUNTARY ACTION**

Situating contemporary self-help/mutual aid groups within a broader historical tradition of expressions of self-help/mutual aid has enabled me both to reconfirm the particular importance of this type of civic activity to the third sector and to affirm its importance as a distinctive form of voluntary action.

Tracing a history of self-help/mutual aid activities generally has served the purpose of clarifying the distinctive origin and nature of self-help/mutual aid in relation to the philanthropic movements of welfare provision in terms of its original class basis, social relations, type of knowledge and membership (see Table 6, p.69). It has also illustrated the differences in purpose and nature between contemporary forms of self-help/mutual aid and the formal voluntary sector. This distinction is implicitly recognised by governmental policy making which has responded with ambivalence and in an *ad hoc* way to the former and increasingly moved towards a partnership

model with the latter<sup>1</sup>. Similarities and differences between the service user movement and grassroots self-help/mutual aid groups in health and social care have also been clarified. Whilst both are from the same wellspring, both the literature and fieldwork findings suggest that grassroots groups are more concerned with the welfare of their membership (in terms of the exchange of coping strategies and information and support) than they are of specifically attempting to change service provision. Nevertheless as the fieldwork findings have illuminated the personal gains that members get and the processes which they go through hold the potential for active members to 'deconstruct' state or professionally defined identities and to support one another in challenging services and/or local community provision.

Chapters Two to Four have shown that the thread that connects different forms of self-help/mutual aid, is that they are composed of groups of individuals who share the same economic, health or social condition. For example, in Chapter Two we have seen that both the friendly societies and the co-operative movement were developed from the industrial working classes who in the absence of a welfare state had to band together to construct forms of economic and social support. We have also seen how this generated models of welfare that informed and were incorporated into the Beveridge welfare state, for example, the notion of collective national insurance contributions. This acknowledgement of self-help/mutual aid's contribution to social policy has not been continued nor developed in an understanding of the place for contemporary single-issue self-help/mutual aid groups as evidenced in Chapter Three by the partial and ad-hoc policy making regarding self-help/mutual aid since the 1970s.

The different historical examples of self-help/mutual aid have also shown the particular significance of the social relations and knowledge generated in self-help/mutual aid groups and how these differ from those in the state and philanthropic sector because the groups are based on peer reciprocity and mutuality. This suggests that self-help/mutual aid has a core that transcends historical periods, but groups take particular forms and expressions according to the historical, political, social and economic context. Forms of self-help/mutual aid can be economic, structural or

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<sup>1</sup> The benefits and tensions inherent in this partnership are reflected in the recent Plowden Report (2001), the HM Treasury report, *The Role of the Voluntary and Community Sector in Public Service Delivery* 2002.



conceptual. Whilst economic forms of self-help/mutual aid existed because of the absence of state support, currently single-issue groups take a form which the fieldwork findings suggest offers something that the state or formal voluntary sectors cannot.

We have seen that throughout history, self help/mutual aid has always been important for women; this was the case earlier in the women's guilds and separate co-operative organisations, and more recently is shown by demographic studies from the USA and in the UK (see Chapter One). This suggests that self help/mutual aid has a particular relevance for women whose agency in these groups can be seen as an important antidote to their under-representation in formal structures (Munn-Giddings, 1998). However, the case study findings suggest that a more critical perspective needs to be applied to the wider literature, which has tended to assume that women are dominant in the membership of groups. We have also seen from the case study that for both genders the processes involved have enabled some subtle reconceptualisations of their roles (as carers).

Another important finding from both the desk and fieldwork parts of the study is that self-help/mutual aid activity is an important expression of both communities of interest and geographic communities. This is explored later under policy implications, but it is significant to note from the historical review that the different forms of self help/mutual aid have always been an important part of the community web in the UK. This further roots self-help/mutual aid into the third sector and assists in widening the potential contribution contemporary self-help/mutual aid groups have to make to the broader policy arena.

Overall then, the study suggests that self-help/mutual aid has been, and is, a very distinct form of voluntary action and an important part of the third sector and of the web of civic activity that lies outside state structures and regulation. This 'evidence' contributes to the challenge (such as Horton-Smith, 1997, 2000) to studies such as that led by the John Hopkins University that has excluded this form of grassroots activity from influential new theorising on the relations between the third sector and the state. The historical review, case-study and wider literature all suggest that all forms of self-help/mutual aid hold an actual or symbolic challenge to the status quo

and ways of knowing or doing. This is probably in part responsible for the ambivalent response of the state now discussed below.

## **SELF-HELP/MUTUAL AID AND THE STATE**

The historical review in Chapters One to Four has shown that, over the years, the state response to self-help/mutual aid activities has been peppered with ambivalence and highly dependent on the ideology of the governmental administration. Self-help/mutual aid has a broad appeal to both the Left and Right in politics but a very different appeal which is broadly encapsulated in the two distinct philosophical traditions that are associated with the phenomenon. Smiles, with his emphasis on individual self-help appeals to the Right as we have seen from the flavour of the policy initiatives in the 1980s. Kropotkin's emphasis on the value of locally-based collective action has broadly appealed to the Left and has been resurrected to some extent through the Social Exclusion Unit (SEU) by New Labour.

Another important theme that is highlighted throughout the study is that self-help/mutual aid is a largely *invisible* phenomenon (Wilson, 1995), which happens outside formal structures in people's *private* time. Its visibility is *ad hoc* and partial, for example, in the case-study through being involved in agency consultations or raising disability issues in a local area. In the wider literature, self-help/mutual aid becomes visible when it becomes part of a named and recognised wider movement such as the co-operative movement or the user movement. It is only at this point in latter years that any policy interest has been shown.

Also underlying governmental responses is the importance or otherwise that they have attributed to voluntary action having an intrinsic value; here we have seen nuances of opinion within different administrations. For example, early forms of self-help/mutual aid were economic and clearly developed in the absence of state welfare support: Beveridge was keen not only to draw on models developed by these groups and incorporate them into the developing welfare state but also to recognise their continued importance as a source of democratic activity (1948). This opinion was not shared across the Labour Party as many members saw any form of voluntary action as indicative of the need for state intervention.

More recently, we have seen New Labour's communitarian philosophy embracing and supporting the role of 'community self-help/mutual aid' although this definition has not included the health and social care groups. Underlying this philosophy however is the belief that voluntary action is a contributor towards 'community cohesion' and evidence suggests that this may, at times, be mistaken. Whilst the case-study does not show grassroots groups that are a hot bed of radical activities it is clear that the processes groups go through do hold the potential for dissension. The wider literature suggests that self-help/mutual aid processes have been the wellspring for many social movements that have posed significant challenges to governments and services. This may in part account for the apparent reluctance by successive governments to fully engage with such a wide-spread phenomenon. Self-help/mutual aid can variously be harmless, colluding, supportive or threatening to the state.

Contemporary forms of self help/mutual aid as shown by the fieldwork findings fulfil largely emotional needs as well as social support needs in ways that are uniquely based on peer reciprocity and sharing of the same circumstances. As the fieldwork findings also suggest, this is a qualitatively different relationship to that between professional and service user/client. It is possible to conclude with some certainty that the gains derived from active membership of these groups cannot be directly replicated or replaced by state/professional services. However, the state could find policy initiatives that both enable the creation and support of contemporary self-help/mutual aid groups and recognise their contribution to the policy agenda.

Both the historical review and case-study findings have suggested that in doing so there does need to be clarity about the purpose, strengths and limitations of self-help/mutual aid groups. Whilst they clearly do provide many benefits to active members they are not attractive to everyone, and ad-hoc both in nature (that is likely to spontaneously evolve and equally likely to disappear), and coverage (geographic or health/social care areas)<sup>2</sup>. The unique form and organisation of groups may mean that intermediary bodies such as Self Help Nottingham (see Chapter Three) are

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<sup>2</sup> The historical review also suggests that areas where there has been a strong history of collective action such as industrial Midlands is where the existing support is for self-help/mutual aid groups (such as Self Help Nottingham).

required to understand and mediate the very different agendas of grassroots groups and national and local policy makers.

## **IMPLICATIONS FOR POLICY AND PRACTICE**

Locating evidence and bringing it to bear on an understanding of contemporary self-help/mutual aid groups as an important component within the web of voluntary action and community relations leads to a much clearer conceptualisation of the ways in which they could be fruitfully linked into the current Social Policy agenda. The practices, processes and outcomes illuminated through the literature review, desk research and case-studies have illustrated the important contribution that self-help/mutual aid groups could make to a range of contemporary policy debates and practices in the health, social care and community fields from which they are currently excluded. This contribution needs to be considered initially at the conceptual level before the links with current policy become clear. In this section of the chapter, I therefore take three of the most dominant conceptual areas of New Labour policy (social capital, participation and citizenship) and discuss them briefly in relation to the findings of this study before concluding with specific policy, practice and research recommendations.

### **Social Capital**

An area that relates closely to the way in which I have conceptualised self-help/mutual aid (above) is that of the increasing currency in social policy theorising and practice of social capital. Social capital was a term coined by the political scientist Robert Putnam<sup>3</sup> who is now an advisor to Blair's government. Social capital refers to the elements of a community, which are characterised by a rich associational life, demonstrated through a variety of strong social networks. These networks involve institutions, associated facilities and relationships in the voluntary, state and personal spheres. Together Putnam views them as forming the 'civic community'.

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<sup>3</sup> Putnam, a political scientist used the theoretical concept of social capital as an explanation of his findings from a 20-year study of regional government in Italy (1993). Social capital is viewed as features of social organisation, such as the trust, norms and networks that contribute to develop the health, wealth and industry of a community. These networks are seen as encouraging and enabling an active and participative civil society. Reciprocity is an important component of social capital – either direct or serial; where in the latter people will undertake activities that are of no immediate personal reward but will directly benefit others, in the belief that they in turn will also gain (Campbell, Wood and Kelly, 1999).

Civic identity is derived from people's sense of belonging to these communities, together with their sense of solidarity and equality with other community members. The norms governing the functioning of the relationships will be those of co-operation, reciprocity and trust (Campbell *et al*, 1999). The concept is currently being used by New Labour to inform both community development and health promotion policies.

As can readily be seen from the findings of this study, these characteristics are reflected in the dominant features of self-help/mutual aid groups. I have shown how these groups form part of the web of 'associational life' in a community. This holds true for both the historical review and the contemporary case study. The norms of reciprocal help and support are the essence of self-help/mutual aid groups and encapsulated in the social relationships of the group. It is the reciprocal nature of the relations in groups that builds the level of trust commented on by members in Chapter Five and observed in the group processes. This is important since trust is seen as an essential feature of social capital, generated through the norms of reciprocity and civic engagement.

As has been argued in Chapter Seven, self-help/mutual aid groups are part of several communities. They are their own community of interest and can form an important part of the web of a geographic community; they are also potentially connected to the broader community of interest (trade, diagnosis, social situation or condition). This has an historical precedent illustrated in Chapter Two where early forms of self-help/mutual aid, the Friendly Societies and the co-operative movement, were also part of both interest (trade) and geographic communities. Morris (2000) explicitly recognised that these groups were an early form of social capital in her challenge to their exclusion from the historical component of the Johns Hopkins-led study.

Active participation in contemporary groups, as Chapters Six and Seven have discussed, clearly leads to a strong sense of shared identity within the group as well as the potential to deconstruct professional or lay ascribed identities<sup>4</sup>. Analysis of the processes in groups combined with the benefits that members themselves attribute

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<sup>4</sup> The absence of a clear hierarchy and the reciprocal nature of the exchanges in groups suggests a form of 'equality' within the group.

directly to their participation in the group has been shown to equip active members with the skills, confidence and support to participate more actively in their dealings with professionals and their local community. Elsdon *et al* (2000) would frame it as translating personal and social learning into political learning. Messer and Borkman (1996) make a similar point about 12 Step self-help/mutual aid groups in that the skills members gain – such as trust, commitment and reciprocity – are social capital skills in and of themselves. In terms of activity in the broader community (interest or geographic) the desk research suggests that historically self-help/mutual aid groups have been the ‘well-spring’ for a number of social movements (feminist, disability, civil rights). In relation to contemporary grassroots groups the fieldwork findings suggest that whilst the processes in groups hold the potential for collective consciousness raising and social action the dominant concern of these grassroots groups is with assisting their own membership. Broader participation at the local geographic community level appears to be more likely when a group holds both interest and geographic identities.

In these senses then, self-help/mutual aid can be seen as an important part of the ‘associational life’ of both local and national communities. Active membership is in and of itself civic participation but equally the processes and practices hold the potential to enable active members to engage in wider civic activities. The inter-relation between activity in self-help/mutual aid groups and other associational networks is an area for further research (see below) but it is interesting to note that the fieldwork findings suggest that active members are also likely to have (or have had) active membership in other voluntary action networks such as volunteer work or religious groups.

Linking self-help/mutual aid into the debate on social capital is important as this concept is now increasingly being used to underpin community, public health and health promotion policies (see below). Whilst certainly not without its critics, such as Budlender and Dube (1998) who argue the emphasis on social capital may divert attention from health inequalities, the social capital approach has an important contribution to make through pinpointing the types of community networks and community relationships that enhance health. This also links the approach to other key health and social care literatures: as Campbell *et al* (1999) point out, whilst

historically there has been an emphasis on the health-enhancing benefits of receiving social support, recently a new and interesting literature is emerging that is beginning to develop on the health enhancing benefits of giving social support (p.23). Other relevant fields are the community health literature (Rissel, 1994) which is concerned with similar concepts such as social support and social networks, where the health of individuals is being related to the extent to which they are located within strong and supportive social relationships. There is also the radical health promotion literature drawn from Freire's work (1973) which advocates health promotion networks based on the shared identity of participants in order to understand and take action against the social conditions that undermine their health.

The contribution of self-help/mutual aid groups in health and social care needs to be made visible and brought firmly in to contribute to these debates.

### **Participation agenda**

The broad notion of public participation in local health and community arenas has been developed by New Labour and has given rise to policy initiatives that encourage and support forms of service user participation in relation to professional service development. As we have seen, the New Right was very serious about participation. Consumerism was the framework within which they defined the role and expectation of user involvement and choice. As part of their market driven political ideology, service user participation was increasingly built into welfare legislation, policy, practice and guidance during their administration. As Beresford (2001) notes, New Labour have now reframed this in terms of their philosophy of citizenship, social inclusion, partnership and best value. Apparently user and civic participation can now be expected from any future government.

The findings of the study suggest that to date the only way in which self help/mutual aid groups have been considered in these agendas is as part of the initiatives to involve service users where, amongst others, their views may be canvassed about service development. However, as the findings have also shown it is important to distinguish self-help/mutual aid groups from the service user movement. As Wilson (1995) noted, increasing calls on the time of self-help/mutual aid groups to give their views can disrupt the primary purpose they have defined for themselves. This

primary purpose, of providing support to their own membership, was clearly demonstrated in the case-study findings. Having to divert their attentions into consultation exercises would dilute the potency of their processes.

There is however tension here, since as we have seen, self-help/mutual aid groups do have a very specific form of collective knowledge developed over time which could be useful both for service development and broader community development. This currently is not recognised in any national policy. Although recent policy development (since the desk research was completed) has further acknowledged the importance of experiential knowledge such as through the National Service Frameworks and in the Expert-Patient initiative (2001)<sup>5</sup> and made some moves towards appreciating the relevance of collective views, there has been no concurrent strategy for involving self-help/mutual aid groups.

If policy makers are to seriously engage with the type of knowledge that self-help/mutual aid groups may be able to offer (particularly in relation to their collective knowledge built over time as against that held by an individual user) the findings have also suggested that it is important for them to engage seriously and sensitively with the different style of organisation that self help mutual aid has as opposed to formal services. I have already suggested in Chapter Six that groups do not frame their struggles as 'policy issues' rather the issues are implicit in the stories that people exchange within the group. Consequently, more creative approaches are required by policy makers to capture this knowledge (such as by attending meetings) than by the unrealistic expectation that groups contribute to alien structures and agendas.

It has been suggested that groups are potentially part of two communities; it follows that local self help/mutual aid groups have a role to play in the development of

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<sup>5</sup> *The Expert Patient*(2001), sets out what it terms 'a new approach to chronic disease management for the 21 st century. This notion was first put forward in the white paper *Saving Lives: our Healthier Nation* (1999) and then reaffirmed in the NHS Plan. It has two starting points:

- the predominant disease pattern in this country is of chronic rather than acute disease.
- today's patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-management programmes, often led by people who have the same condition can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy. (p 5) (Harrison, 2001).



community services, not just professional ones, and can contribute to a much broader arena and set of agendas, such as those concerned with social capital. It is interesting to note that a similar argument is being developed by the user movement itself to acknowledge the much broader range of activities that they have been involved in both challenging and creating (Beresford, 2001). This move goes some way towards addressing Campbell's (2000) criticism (see Chapter 3, p.97) that single-issue groups have rarely made the connections between their concerns.

However, these suggestions may not be easily assimilated. Although they fit with the rhetoric of 'involvement' and 'participation', strong vested interests still exist in professional and local government settings resistant to alternative viewpoints that arise from collective activity outside formal structures. Essentially, this is a struggle about the politics of knowledge. As has been observed in Chapter Six, we are at a relatively early stage in understanding what processes or factors lead some groups to become politicised and present a challenge to existing understandings and bodies of knowledge about a particular condition or situation. The very process of sharing experiences in a group without professional intervention offers the potential for challenge to existing orthodoxies.

Ultimately this must also have implications for the research agenda itself. To argue that a unique knowledge base is held by self-helpers must logically and ethically mean that self-helpers should be enabled to define research agendas for themselves. Just as professional interpretation of service users' experience and knowledge is seen as problematic, so also is the professional researcher's interpretation of self-helpers' views and experience. It is self-helpers who are best placed to generate critical questions and knowledge about their concerns and priorities. This suggests an adjustment to the social relations of research where self-helpers need to be involved in all stages of the research process, starting with defining the research agenda. This argument complements the giant strides made by the user involvement movements who are now involved at all stages of research organisation and conduct (Beresford, 2001).

## **Citizenship**

Finally, as Dean (1999) has stated, central to any discussion of the changing role of the state in relation to welfare provision is the concept of citizenship, both as a status attributed to different members of society and as a social practice involving governance and participation. Citizenship can be seen as an overarching theme into which both participation and social capital fall. We saw in Chapter Three that differing notions of active citizenship have been central to both Conservative and New Labour platforms: Major's 'active citizen' and Blair's 'responsible citizen' respectively. The language of citizenship as rights and responsibilities continues to lie at the heart of New Labour's reform and the concept is seen as underlying much of Blair's policy making.

Citizenship is a fundamentally contested concept and whilst this is not the place to debate the various philosophical positions taken on citizenship<sup>6</sup>, about which there is an ample literature (for example, see Turner, 1993; Lister, 1997), it is useful to summarise the defining positions. Dean (1999) states that the different positions broadly concern views about the relations between the individual and the state and the collectivity and the state. He makes a distinction between liberal or contractarian ideas (which are by implication exclusively focussed on freely participating individuals) and republican or solidaristic ideas (which are by implication focused on the membership of a collectivity). These tensions have their parallels in the dual philosophies underpinning self-help/mutual aid and in the opposed emphases by Smiles on the individual and Kropotkin on the collective.

As we saw in Chapter Three during the years of Conservative rule there was a clear neo-liberal perspective that saw the 'individual' as paramount. The New Right came increasingly to equate citizenship with civil rights rather than social rights. New Labour however draws on contradictory notions of citizenship and uses both

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<sup>6</sup> In its original meaning citizenship denoted 'free' residence in a city, therefore implying freedom. Its essence was not defined in relation to the city, nation, culture, or people but to the political practices of free men and the state they created (Habermas, 1994). Two distinct traditions emerged. One of these envisaged a form of social contract in which sovereign power is negotiated between the individual citizen and the state: this is the solution posed by classical liberal theory. The other sought to subordinate sovereignty to solidarity and the need for citizens to achieve social integration and mutual cohesion: this is the solution of civic republicanism. The contractarian conception of citizenship which sought to protect the liberty of the individual subject is inimical to the solidaristic conception of citizenship which seeks to promote fraternity or belonging (neither conception necessarily upholds equality).

solidaristic discourse and contractarian ideals (Dean, 1999)<sup>7</sup>. This tension is replicated in the form of the communitarian philosophy that is underpinning much of New Labour's community policy (Christian democracy), as outlined in Chapter Four. This seeks to connect individual choice with collective responsibility by translating the principles of reciprocity appropriate to membership of a small association to the realisation of the common good within a national community. In New Labour's vision, citizens have both rights and responsibilities.

One way of understanding the findings within this framework is to emphasise that active self-helpers are engaging in activities in which they take the responsibility to explore their situation and support one another, coupled with their increased awareness and confidence to argue for their rights. This is not about the 'state' conferring rights onto individuals and collectives, but relates to the fieldwork findings that members become aware of their 'rights' and, as seen in the broader literature, may campaign for new types of rights such as women's and civil rights.

The findings of the study suggest that in terms of its practice, processes and outcomes, self-help/mutual aid has a contribution to make in terms of a broader understanding of citizenship in at least two ways:

- (i) The unique processes that participants of these groups go through and the social relations they develop equip participants as citizens who develop their potential to effect change on their own and others lives. This is similar to the ways in which it has been argued above that self-help/mutual aid builds the qualities of active members that could be considered to be a form of social capital.
- (ii) Mutual aid activity can be seen in and of itself as an expression of both civil and political citizenship – with the potential to challenge and contest what is defined as 'political'.

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<sup>7</sup> Because of the rights and responsibilities emphasis on NL welfare contracts emphasis on paid work as securing citizenship self-help/mutual aid haven't featured on this agenda. Dean argues that New Labour treads an uneasy path between economic liberalism and social conservatism basing much on the ideas that flowed from the late John Smith's Commission on Social Justice (CSJ) that called for an 'investors strategy' which would combine the ethics of community with the dynamics of a market economy (p.95 CSJ, 1994). This tension parallels Beresford and Croft's comments (1993) regarding user involvement that 'the politics of the supermarket do not fit well with the politics of liberation'.

Firstly, the gains of active membership of groups and the processes they involve outlined in the discussion of social capital can be viewed as better equipping active members to act as citizens. In Blair's terms, self-helpers are both taking responsibility for their own situation and themselves and becoming more able to negotiate their 'rights' through an increase in their knowledge about services and their confidence and ability to engage with both professionals (evidenced in both groups) and the wider community (Group 1). Humphreys and Rappaport (1994) have aligned the processes involved in self-help/mutual aid as akin to those in other social networks such as citizen action groups. Lister (1996), in her discussion of the relevance of community groups to citizenship, also discusses the importance of processes within groups and emphasises the social nature of these processes: 'It is not just individuals that change but relations between people' (p8).

Participation in self-help/mutual aid groups is shown by both the wider literature and case study to lead to individual, collective and (sometimes) wider social change; as such it can be viewed as an expression of both civil and political citizenship. It is civil, because it encapsulates the right to freedom of thought and expression and is testament to the personal and collective changes that may result from informal activity; it thus also provides a challenge to conventional understandings of 'political'. This form of political citizenship can be both challenging to and/or complementary to activity in formal democratic structures.

As the case-study demonstrates, people generally do not join self-help groups with the intention of taking part in a broader or alternative movement, but primarily from a desire to meet with people experiencing the same things as themselves. However, participation in the group and the building of experiential knowledge hold the potential to reconceptualise the conditions and concerns that members share. This removes the emphasis of being consciously 'politically' motivated and aware whether the group is formed and members join, since many clearly are not, but the *processes* involved may lead to this. There are considerable subtleties and complexities involved in the processes of personal and social change. The more subtle conceptual changes identified in the fieldwork question the necessity of having *explicit* political goals; rather these are *implicit in the processes of self-help*.

The 'political' importance of civic activity, of which self-help/mutual aid it is argued forms a part, is increasingly being recognised by social and political theorists as important for effective government (Borkman, 1996; Lister, 1996; Putnam, 1993). Yet as long as grassroots self-help/mutual aid is an invisible and private activity it does not appear to impact on the government's social policy agenda. However, even before it is 'visible', the fieldwork findings suggest that active membership in these groups does impact (if subtly) on active members' personal, professional and public/community relations. The 'invisible' activity is therefore still an important part of civic activity and an unacknowledged expression of citizenship. Although more research is needed on the impact of self-help/mutual aid on complex interactions between individual, group, and community narratives and relations, this is clearly a fruitful area. Bubeck (1995), writing on carers and citizenship, states that private practices and relationships can serve as resources for political reflection. She further posits that private concerns or contents may be translated into public ones, hence 'political agendas may change based on concerns derived from experience' (p25). These may, but need not be, specific or sectional concerns. This type of translation will often follow the feminist model of re-politicising what are now perceived to be wrongly or even oppressively de-politicised rather than truly private issues; or it may simply bring to public awareness issues that would be relatively easily accepted as political issues but are not widely known about or are actively suppressed.

How the 'political' is constructed and who has the power to decide what is political and what is not translates into the importance of civic activity outside of formal structures – particularly in developing the knowledge base to contest established orthodoxies. Formal and informal activity is not mutually exclusive. The challenge is to develop a more dynamic notion of citizenship that combines the perspective of empowerment *within and outside* public institutions and organisations. There is a necessity, drawing on feminist arguments, to address issues which are usually thought of as non-political and private because their de-politicisation and privatisation is part of the way in which oppression has been historically established and reproduced (Wilson, 1977; Pascall, 1997).

## **CURRENT POLICY**

I chose the conceptual areas above because they are key areas of current social policy theorising and underpin a range of policy initiatives by New Labour. However they clearly transcend party politics and in different conceptual ways have always occupied the minds of government. As de Tocqueville and Havel noted, (discussed in Chapter One) the relationship between the government, state and institutions and 'their' citizens has always been important. In particular, notions of both civic and service user participation have been firmly on the political agenda from the 1970s onwards (Chapter Three).

Currently there is a raft of UK policy that could and should include a consideration of the role and place of self-help/mutual aid groups. New Labour now has a range of initiatives, which are the general outcome of social approaches to public health and health promotion. For example, the government's public health strategy 'Our Healthier Nation' recognises that the solutions to major public health problems such as heart disease, cancers, mental health and accidents are complex. They will require interventions that cut across sectors, and take account of the broader social, cultural, economic, political and physical environments which shape people's experiences of health and well being. It was within this strategy that the Health Education Authority (HEA – now the Health Development Agency) developed its first Research Strategy 1996-99 which initiated a programme to investigate the concept of social capital, but excluded self-help/mutual aid groups from their definitions of community associations and failed to consider them.

There are also other policy initiatives that give emphasis to community participation as well as inter-agency working, collaboration and partnership such as 'The New NHS' (DoH, 1998) and Modern Local Government (DoE, T&R 1998). A number of initiatives have arisen from these, such as the NHS Plan (2000), the development of Primary Care Teams, Health Improvement Programmes, Health Action Zones, Healthy Living Centres, Health Co-ops, Health Impact Assessments. Yet it is only in the NHS Plan that we see explicit reference to the benefits of self-help/mutual aid groups. There is apparently no strategy for involving groups at the National level.

Similarly, in New Labour's social exclusion agenda, whilst financial and practical forms of self-help/mutual aid are being included in their community agenda under the title 'community self-help/mutual aid', self-help/mutual aid groups in health and social care do not feature. This is in contradiction to their general emphasis in health policy, which, as Campbell *et al* (1999) point out, has seen the shift in the locus of health promotion from the individual to the community and the acknowledgement that the community can take very many different forms.

In terms of community development the new strategy frameworks explicitly recognise that community participation, local democracy, social networks and prioritisation of need are key tools in producing change (such as New Deal for Communities, Social Exclusion Unit, 1998). As Chapter Three showed, both policy writers (Burns and Taylor, 1998) and policy makers (SEU Community self-help/mutual aid, 2000) recognise contemporary forms of economic and neighbour self-help/mutual aid – it is now time to add health and social care groups to the equation.

## **RECOMMENDATIONS FOR POLICY, PRACTICE AND RESEARCH**

Several suggestions arise from discussion of the findings which could now usefully be debated with policy makers and with groups themselves. It is clear that groups want and need the space to be 'left alone' to do what they set themselves up to do in the first place. However this does not preclude creating both the opportunities for them to contribute to and benefit from policy that recognises their unique contribution. Whilst this may well be occurring in an *ad hoc* way at some local levels (we currently have no way of knowing this) there is no clear or consistent national policy making to support a systematic approach. Partial or at worst muddled thinking about self-help/mutual aid groups has led to their exclusion from areas that they should rightfully contribute to. A self-perpetuating circle has evolved that is a consequence of the lack of attention by policy makers and academics in the UK to this area (Munn-Giddings, 1998). This means that little funding is available to fund research in this area, lack of research has meant under-theorising and a lack of relevant informed UK

policy making. The following therefore are recommendations<sup>8</sup> for policy, practice and research that flow from this study:

### **Recommendations for policy and practice**

1. Conceptually to frame self-help/mutual aid within a voluntary action paradigm and therefore to include a consideration of the contribution and role of self-help/mutual aid groups in relation to policies that are being developed to promote
  - (i) social capital,
  - (ii) community involvement/health promotion,
  - (iii) participation both in public and health and social care settings,
  - (iv) citizenship.
2. To value the specificity of collective knowledge in long-term (developed/mature) self-help/mutual aid groups and to explore more appropriate ways of gaining insight into such views (such as, by attendance at group meetings rather than service-led consultation exercises.)
3. At the national level, to consider reconstituting a national centre(s) for self-help/mutual aid which:
  - (i) co-ordinates, networks and supports self-helpers, researchers and practitioners,
  - (ii) interfaces with the National Council for Voluntary Organisations (NCVO), and
  - (iii) contributes to governmental policy on support for the voluntary sector and a national strategy for supporting diverse forms of self-help/mutual aid in the localities.
4. To explore the potential development of intermediary bodies at the local level such as Self Help Nottingham to support and network local groups and to represent their local interests at the national level.

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<sup>8</sup> These recommendations are most relevant for central government and consideration by NCVO.



5. To acknowledge the potential contribution of self-help/mutual aid groups to the health and well-being of communities, and to the preventive/public health work of Primary Care Trusts and Health Development Agencies.
6. For the role and value of self-help/mutual aid groups to be reflected in educational and training programmes for professionals and local policy makers.
7. Participatory monitoring and evaluation of all developments.

### **Recommendations for research**

To consolidate, co-ordinate and develop a UK research and theoretical base related to the role of self-help/mutual aid in civic society by:

1. The funding and strengthening of a research network (such as the existing SHAMARN) to map, co-ordinate and disseminate research related to self-help/mutual aid. This network could form part of the recommended National Centre (above)
2. In-depth historical research that uses appropriate methodologies (such as documentary analysis) to trace the impact of self-help/mutual aid activity on state and voluntary sector policy.
3. Studies that explore the relationship between self-help/mutual aid and other forms of voluntary action in UK society.
4. Studies that incorporate the various dimensions identified in this study to compare and contrast similarities and differences in group activities and gains. For example:
  - (i) Groups that have both geographic and interest communities as against interest communities only.
  - (ii) Groups for stigmatised and non-stigmatised conditions.

(iii) Groups in geographic regions that have support for self-help/mutual aid as against those in unsupported areas.

(iv) New groups as against developed and mature groups.

(v) The role and attributes of specific groups based on areas such as gender or ethnicity.

5. The relationship between local self-help/mutual aid groups and national bodies that represent their interests.

6. Mapping exercises in different regional areas of the UK.

7. Longitudinal research to explore the effects of self-help/mutual aid groups on individuals and communities.

8. Culturally comparative studies.

9. Consideration of self-help/mutual aid groups in relation to emerging but relevant theories such as, those concerned with new social movements and emotional democracy<sup>9</sup>.

10. Consultation with groups to develop participatory projects related to the direct concerns of groups.

## **FINAL CONCLUSIONS**

This thesis has shown that the lack of UK social policy interest in the largest-growing form of voluntary action – self-help/mutual aid groups in health and social care – cannot be understood out of context. Rather, it is due to four main reasons.

Firstly, a lack of clarity regarding the distinct contribution that self-help/mutual aid groups have to offer not only to their members but also to society. This has been compounded and perpetuated by a lack of academic interest in this area and a

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<sup>9</sup> Such as Mellucci (1984, 1989), regarding new social movements and Giddens (2000) regarding emotional democracy.

resulting over-reliance on US studies which need substantiation or refutation in the UK context. An outcome is a tendency to see these groups as an adjunct to the UK user and carer movements and to consider them only in relation to professional health and social care services.

Secondly, the lack of interest can be attributed to UK social policy's dominant concern with state provision. Whilst there has been a steady increase in both interest and policy regarding formal voluntary sector relations with the state, we have seen that despite self-help/mutual aid groups being once considered the 'heart' of the voluntary sector in the UK, in recent years the definitions adopted by both governments and national policy organisations (NCVO) now exclude self-help/mutual aid groups from consideration.

Thirdly, the 'invisible' nature of self-help/mutual aid activities, which take place outside formal structures and within individuals' own time, has compounded the marginalisation of these groups. UK social policy has been almost exclusively concerned with only visible public activities, despite the history of self-help/mutual aid activities influence on policy models and approaches. Fourthly, it can be attributed to a recurrent ambivalence by the state towards the political tension inherent in activities that embody both individual and collective tendencies.

Whilst other 'individualistic' paradigms/approaches to researching the benefits and role of self-help/mutual aid groups have offered an understanding of the gains to active members, in terms of understanding their broader role in society, it has left them fractured and displaced. A clearer understanding of self-help/mutual aid groups therefore has been developed throughout the thesis by an approach which sits within a voluntary action paradigm that explored the history and current role of groups within a UK-specific context.

This approach has illuminated:

- contemporary groups' place in a long tradition of self-help/mutual aid voluntary action in UK society, clarifying the specific shared nature of these types of activity;

- the specific relationship that self-help/mutual aid activities have held in relation to the state over time;
- the ambivalence with which the state has treated self-help/mutual aid activities;
- the relationship between the gains active members of groups attribute to group membership, the process through which they evolve and the impact this has on their ability to effect both individual and collective change;
- the uniqueness of the organisation, social relations, knowledge and processes in groups and therefore their particular role against that of other forms of social support;
- the place of self-help/mutual aid groups within the broader web of community voluntary action;
- potential links between active membership in groups and previous/current involvement in other voluntary action activities; and
- the strengths and weaknesses of self-help/mutual aid groups.

As such, the thesis has developed a framework which offers a different way in which to conceptualise self-help/mutual aid in relation to social policy and consequently makes hitherto unmade links between self-help/mutual aid and the contemporary social policy agenda. A framework is offered which augments the currently partial and underdeveloped UK theorising, policy and practice, and also transcends the current narrow and professionally-led vision of self-help/mutual aid groups viewing them only as an adjunct to both professions and the service user and carer movements. In doing so, self-help/mutual aid is accorded a central place in voluntary action and third sector theorising where it has been a phantom for too long.

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## **APPENDICES**

- Appendix 1: Examples of contemporary self-help/mutual aid groups**
- Appendix 2: Research instruments**
- Appendix 3: Consent form**
- Appendix 4: Carers' testaments**
- Appendix 5 (i): Content and issues raised during the taped group sessions**
- Appendix 5 (ii): Comparative table of discourse in 12-step and non 12-step  
Self-help/mutual aid groups**
- Appendix 6: Personal reflections on the thesis**



## **Appendix 1**

**Examples of contemporary self-help/mutual aid groups in health and social care – drawn from the Self Help Nottingham 2000 Directory.**

A selection of 52 from 181 listed in 2000 (Nottingham and District)

### **Abuse**

Incest and Sexual Abuse Survivors

Roshni Asian Women's Aid

SAM – Sexually Abused Men

### **African and Afro-Caribbean Communities**

OSCAR – Organisation for Sickle Cell Anaemia Research (Nottingham)

### **Alcohol**

Al-Anon Family Groups

Alcoholics Anonymous

### **Alzheimer's disease**

Alzheimer's Society (Nottingham)

### **Anxiety**

E.A. Emotions Anonymous

Self Help Group for Depression and Anxiety (Hucknall)

### **Arthritis**

ACHE – Children Suffering from Arthritis

### **Asian Communities**

Asian Mothers' Special Needs Support Group

Mukti (for divorced Asian women)

### **Asthma**

Breathers Self Help Group (BSHG)

### **Bereavement**

Compassionate Friends

Cruse (Beeston)

Young Widowed Group

### **Birth**

Arnold Twins Club

### **Bisexuality**

Base 51 Lesbian, Gay, Bisexual Group (LGB)

### **Breast Cancer**

Nottingham Breast Cancer Support Group

### **Breathing Difficulties**

Asbestos Diseases UK

### **Cancer**

Let's Face It Together

Testicular Cancer Group

### **Carers**

Care Free Group

North West Carers' Group

### **Children with disabilities**

Asian Mothers' Special Needs Support Group

Parents of Children with Diabetes (QMC)

Parents of Children with M.E.

Space (Sensory Loss)

### **Chronic fatigue syndrome**

Flame (Lesbians with M.E. Group)

### **Depression**

Nottingham Manic Depression Fellowship

Self Help Group for Depression and Anxiety (Hucknall)

### **Diabetes**

Diabetes Self Help Group

### **Disabilities**

Hucknall Disabled and Able-Bodied Group

Nottinghamshire Disabled People's Movement (NDPM)

**Divorce**

Association of Separated and Divorced Catholics

Mukti (for divorced Asian women)

**Domestic violence**

Roshni Asian Women's Aid

**Drugs**

Narcotics Anonymous

**Facial injury/disfigurement**

Let's Face it Together

**Fertility**

Ace Babes

**Hearing impairment**

Dizzy Self Help Group (for people with balance problems and vertigo)

**Hearing voices**

The Listeners Hearing Voices Self Help Group

**Hysterectomy**

Hysterectomy Self Help Group

**Incest**

Incest and Sexual Abuse Survivors

**Narcolepsy**

Narcolepsy Self Help Group

**Parenthood**

ACe Babes

National Childbirth Trust (Nottingham Branch)

Parents of Diabetic Children Group

Triplet Club

**Self harm**

Cutting Back

**Speech disorders**

CLAPA – Cleft Lip and Palate Association

Nottingham Self Help Group for Stammerers

## **Appendix 2**

### **Research Instruments**

1. Interview guide for first meeting with groups
2. Individual in-depth interview guide for active members
3. Postal questionnaire to non-active members
4. Individual in-depth interview guide for non-active members

## **Ph.D. Research - Self-Help/Mutual Aid**

### ***First meeting with groups:***

Questions to be addressed to whole group or appointed member as appropriate.

Explain purpose of research - get group to think of additional questions for focus groups and additional interviews.

Ask to consider whether would keep a diary (2 main groups only)

### **Questions**

#### **1. Profile**

When was the group founded?

Who founded it?

How many members? - Age, gender, Race

How many core members?

How do they advertise/get referrals?

How often do they meet ? for how long?

Where (why?)

Do they set an agenda? How?

How many people left the group? Why might that be?

#### **2. Organisation**

Formal? Informal? why?

Are there any set roles?

What are these?

How are people chosen?

Is there a relationship to a national/international group? What is this?

How if at all, does that affect the way in which the group is run?

#### **3. Support**

Is the group funded? By whom?

Are there any other ways in which the group is supported?

In what ways

By whom?

What, if any, impact does this have on the group?

#### **4. External relationships**

What, if any, relationship does the group have with local formal bodies. e.g. stat/vol

Relationship with other groups locally

## **Individual in depth interviews**

gender

age

race

### ***Being in the group***

1. How long have you been a member of the self-help group?
2. Why did you join this group?  
(How did this come about? At what point in the caring career?)
3. What did you hope to gain?  
(Why this group and not another? Previous involvement with self-help)
4. How often are you able to attend meetings?  
(Would you like to go more often? What is it that prevents you?)
5. Would you say that the group has fulfilled your expectations?  
If so, in what ways?  
If not, why not? in what ways?
6. Do you contact other members outside the meetings?  
How do you do this?  
How often do you do this?  
How important is this contact to you?  
What do you talk about/do that you couldn't in the larger group?
7. What do you feel that you have gained *most* from being part of the group?  
(tease out what carer thinks has been *learnt* from the group and how they feel that learning has come about)
8. Are there things that you find difficult about the group?  
What are these? Have you attempted to change them?

### ***Views on caring***

1. Tell me a little about how you see your caring role  
(How do you describe this to the variety of people you must be in contact with - GP/Consultant/SW/other carers etc.)  
What would you say you find most difficult?  
what would you say you get out of it? Probe meaning of this)
2. Do you think your views about your role have changed over time?  
If yes, what do you think have been the key influences on this?

### ***Impact of being in the group***

I'd like to explore with you a range of ways in which being part of a self-help group may have affected your life

1. When has the group itself been particularly helpful/important to you?  
(similarities/differences for other members of the group)
2. Does being a member of the group help to lighten the 'caring load'?  
(probe & base on carers own view of their own role)  
If yes, in what ways? If no, why not?)
3. Would you say that it has affected the way that you feel about your caring role?  
In what ways? How has this happened?
4. Would you say that it has had an impact on your the way you think about yourself?  
In what ways?  
(prompt: self-confidence, self-esteem, self-knowledge, knowledge of 'caring' - political agenda)
5. Have you tried to affect services that are available to you? What happened?  
Would you have done this if you hadn't been part of the group?
6. Do you feel it has any wider impact on your relationships with others  
(personal/community/political)? In what ways?
7. Are there any other things that have changed in your life that you would attribute to being  
part of the group? What are these?
8. Can you tell me in your own words what you feel has changed most in your life as a result of  
being part of the group? (explore other important life events)
9. Are there any other issues you would like to raise/talk about?

**Thank you for your time and support in completing this interview with me.**

**With a sample from core members:**

You may want time to think/reflect on the above, it would be very helpful for me if you would agree to keep a diary over xx weeks, writing reflectively on the impact that being in the group is having on your life. This will involve 'jotting down' cuttings, thoughts, events that you feel are significant in relation to your caring role and how you feel about it (could leave open or be prescriptive about areas/themes?). You could make entries at any time that suit you but may find it a useful prompt to make an entry just before and just after your self-help group meeting.

## To all Carers on CODS Carers Newsletter List

This letter is being sent to you, on behalf of Carol Munn-Giddings, a Researcher from Anglia Polytechnic University, by ~~Pat~~ to request some information that will be useful:

1. To develop the CODS Carers Self-Help Group
2. To help with Carol's study into the role and impact of Self Help Groups (please see attached outline)

Carol would be most grateful if you would fill out the questionnaire below and return to her in the attached Stamped Addressed Envelope. All information received will be treated in the strictest of confidence and will be seen only by Carol. Any information that Carol passes back to Pat will be presented in summary form; no individual will be identified in any way or at any time and not in the final report.

Please return to Carol by Friday 20 November 1998. If you have any queries you can contact her on (01206) 852301 ext. 4513 or leave a message on ext. 4502 (Tuesday - Friday). Carol's address is:

Carol Munn-Giddings  
Director of Research  
Anglia Polytechnic University  
School of Community Health and Social Studies  
2 Boxted Road  
Colchester  
CO4 5HG

Self Help Group Questionnaire



COD

Please complete the following questionnaire by ticking either YES or NO boxes or writing a little more where requested.

Section One : Basic Information

Please could you tell me a little more about yourself

1. Are you  Male  Female

2. Please tell me a: Your age   
Please tell me b: Your ethnic origin

3. Please tell me your current or previous profession/job  
.....  
.....  
.....

4. Are you currently working?  Yes  No

if Yes - is this  full time or  part-time

5. Have your caring responsibilities had an impact on your paid work.  Yes  No

If yes, please state in which way eg. have had to give up work, have had to go part time etc.  
.....  
.....  
.....  
.....  
.....

**Section Two: Caring**

Please could you tell me a little bit about yourself as a carer (a difficult term I know but please bear with me and fill the questions in in terms of how long you have thought about yourself as being a carer). **Again, please tick the relevant box.**

1. How long have you been a carer?

less than a year
1 to 5 years
5 - 10 years
10 years +

2. Who do you care for?

wife	husband
son	daughter
mother	father
other please state	

3. Do you live with the person you care for?

Yes

No

4. Does anyone help you with caring or your caring tasks?

a. Professional Help eg. District Nurse, Social Worker
b. Other Help eg. Daughter, Son, neighbour etc.

Type of Help eg. Assistance with bathing, night cover etc.
Type of Help eg. Assistance with bathing, night cover etc.

Section Three: The CODS Carers Self Help Group

Please will you tell me about your experience with the CODS Carers Self Help Group.

1. When did you first hear about the Group? [ ]

2. How did you come to hear about the group? eg. GP, Leaflet, Friend etc. [ ]

3. How long have you been on their mailing list? [ ]

4. Can you tell me which of the following best describes you

- I attend nearly every meeting [ ]
- I attend only occasionally [ ]
- I attend as often as I can [ ]
- I went to a few meetings but never returned [ ]
- I have never attended a meeting [ ]

5. If you do not attend the group at all, or if you attend only occasionally please could you say why this is (tick any of the following that apply)

i	The time of the meeting is inconvenient	Yes	No
ii	The venue of the meeting is inconvenient	Yes	No
iii	The subject matter is not useful to me	Yes	No
iv	I found the group difficult to get along with	Yes	No
v	I do not like groups	Yes	No
vi	I would need transport to attend the meetings	Yes	No
vii	I can not leave the person I care for	Yes	No

viii Other (please state) [ ]

If you have answered Yes to any of the above, can you suggest any changes that the group might make that would encourage/enable you to attend?

.....  
.....  
.....  
.....  
.....  
.....  
.....

6. a. If you have attended any of the meetings;

a. how many have you attended? .....

b. what did you hope you would get from the group?  
.....  
.....  
.....

c. did the group meet you expectations? .....  
if no, can you explain why not .....  
.....  
.....  
.....

7. Do you attend any other support groups for carers?  Yes  No

If yes, please state which one(s)  
.....  
.....  
.....  
.....



### Self Help Group Study

Thank you for your help in completing the questionnaire. As a further stage in the study I am hoping to compare the views of those people who attend self help groups and those who do not and would therefore be most grateful if you would be prepared to undertake an interview with me (in your own home or convenient location) which will last at the most an hour. This is to assist specifically in the research detailed in the attachment. It would be such a help with the study if you are prepared to do this.

If you are willing please fill in the attached form and I will contact you as soon as possible.

Yes, I would be happy to be interviewed in relation to the carers self help group study.

Yes

No

Name:

.....

Address:

.....  
.....  
.....  
.....  
.....

Contact

Number:

.....

Best time to

telephone:

.....

**Thank you once again for all of your help.**

Thematic Individual in-depth interviews: Second group (NON-ACTIVE MEMBERS)

Gender

Age

Race

### *Relationship to the group*

1. You said in your response to my postal questionnaire that you have been on the .....self help group mailing list for .....  
(how did this come about? At what point in the caring career?)
2. Have you found being on the mailing list useful?  
(What ways/why not?)
3. You said in your response that you have been to the group ..... times, can you tell me a little about this?  
(Explore expectations/impressions/reasons for low/non-attendance).
4. If did attend - was it useful to meet others in a similar situation? (what got out of it).  
If doesn't attend - do they think it would be useful to meet others in a similar situation/do they in other ways?

### *Caring*

1. Can you tell me a little about how you see your caring role?  
(Positives/negatives - most difficult/get out of it).
2. Do you see yourself as a carer?  
(What does the term mean to you?)
3. Have you others in your family/close friends who have been carers?  
(How important? Do you have the sense others in the same boat?)
4. Do you have anyone you can turn to when things get bad?  
(Info/emotional support/opp's to get out).  
(Anyone who knows about situation ongoing way).
5. What do you do when things get on top of you?  
Have you ever phoned the .... line? Could you imagine when you might?
6. Is there ever/Are there times when you feel more than a carer? When is this?  
What do you do?

### *Relationship to Professional/Politics*

1. How have your dealings with professionals been?  
(felt other than a 'carer'?)
2. Do you feel that there are services for carers?
3. Have you ever been so upset/angry that you have pressed for things to be changed?  
(What/How/outcome)  
(Individual or as a group)
4. Is there anything you feel should be changed for people in your position?



*Development of ...self-help group*

1. Is there anything that the group could offer you that you would value if you can't attend meetings?
2. Is there anything that would encourage you to attend more regularly?

**THANK YOU VERY MUCH FOR YOUR TIME.**

## Appendix 3

### Consent form

#### Study on the Role and Impact of self-help/mutual aid groups

Carol Munn-Giddings, Director of Research,

School of Community Health & Social Studies, Anglia Polytechnic University

January 1998

The study is being conducted in accordance with the ethical guidelines produced by ARVAC (Association of Researchers in Voluntary and Community Work), which are attached. All data collected through interview and group discussions (focus groups) will be treated in the strictest confidence. No participant in the study or the person they care for will be identifiable in any presentations or publications resulting from the study.

#### Consent Form

I have been fully briefed about the intended study and have a copy of the research proposal. I understand that any information divulged as part of the study will be treated in the strictest confidence and any resulting presentation/publication will ensure the anonymity of myself and the self-help group, unless I decide otherwise. I understand that I can withdraw my consent at any point during the research project. I am giving my consent to take part in

1. Both stages of the research      YES/NO (Please circle appropriate answer)
2. Stage one of the research only      YES/NO (Please circle appropriate answer)

Signed: .....

Date: .....

NB :Protocol amended for non-active members

## **Ph.D. Study on the Role and Impact of self-help groups**

Carol Munn-Giddings, Director of Research,

School of Community Health & Social Studies, Anglia Polytechnic University

Brief for self-help groups

### **What is the study about?**

The study is about exploring, with members of self-help groups, the meaning, impact and effect that being part of a self-help group has had on their lives. Research in other countries, notably North America, has consistently demonstrated the benefits of being part of a self-help group related to health and social care. These studies suggest that membership may help people to feel better about themselves and more confident; sometimes groups have acted collectively to effect change at a local or national level.

Despite this, there has been very little research in this country, particularly from the point of view of members of self-help groups themselves. My study is therefore designed to work with a small number of local self-help groups for carers. I wish to explore from the participants' perspective how membership of the group has (or hasn't) impacted on their thoughts and feelings about themselves and the caring role they undertake and any effect this may have had on their personal and professional relationships.

I am particularly interested to see whether the effects of membership are affected by the participants' age, gender (male/female) or other personal circumstances.

### **CONFIDENTIALITY**

All of the information gained through either personal interviews or group discussions conducted with self-helpers will be treated in the strictest confidence. The study will be conducted to be sensitive self-helpers views and needs and no individual or the person they care-for will be identifiable in any resulting presentations or publications.

### **How will the study be conducted?**

I aim to work co-operatively and collaboratively with self-help groups who choose to join the study. The study will take place over a year and be in two main stages.

#### ***Stage One:***

(a) One-to-one interviews with members of the self-help groups in their own homes or a location of their choosing. The interview will last about an hour and a half and the purpose will be to discuss membership of the group and the persons thoughts and feelings about it.

(b) A group discussion at one of the groups planned meetings. We will look at the purposes and achievements of the group. Issues raised during the one-to-one interviews will be raised here; although be assured that nothing personal will be divulged.

### ***Stage Two:***

I would either like to attend or discuss with groups 3-4 meetings over the course of the year to explore the ways in which group members are helping one another and the types of issues being raised. A few people will be asked to keep a diary jotting down their thoughts, feelings, relevant clips from papers etc. that relate to their caring role and/or their group membership.

\*\* A complimentary stage will involve contacting a sample of carers' who are aware of the groups existence but who do not attend the self-help groups meetings. A postal survey will seek their reasons for non-attendance. Follow-up semi-structured interviews will seek to compare non-attendees views on their caring role with members of the self-help group.

Each stage will be finalised in consultation with participating carers' groups.

### **How will the study be used?**

The study is primarily for a higher degree, it is NOT a commissioned piece of research by a local agency. However, it comes from my long-standing interest in the issues and as an experienced researcher who has worked in local services for over 10 years before joining Anglia Polytechnic University I wish to produce work which is useful to the groups who have participated as well as raising the profile of self-help nationally. We can discuss how best to use the information particularly at the end of the study.

## **Appendix 4**

### **Carer's testaments**

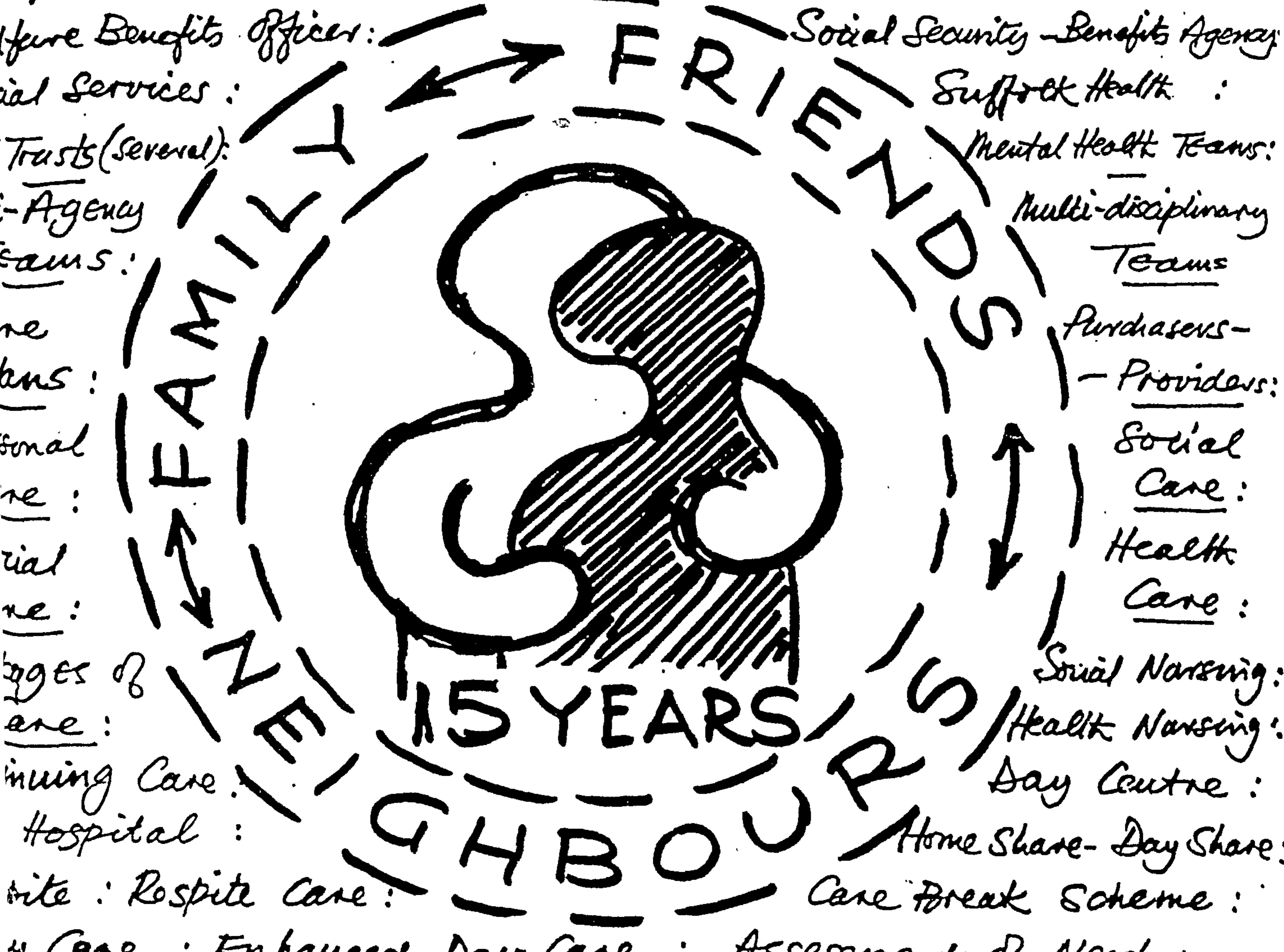
Extracts from letters/writing received from carers during the course of the study.

1. Picture illustrating the impact on a carer and his wife after the early onset of his wife's Alzheimer's. The picture illustrates the range of terms and services they became involved in during the period of caring\*.
2. Short non-fiction story of a carer's reflections on caring\*.
3. Extract from a presentation given by a carer to professionals based on their personal experience of caring.

\* Both 1&2 are now in the public domain. The author's name has therefore been left on the work with the author's permission.

# WHO CARES?

Community Psychiatric Nurse : District/Community Nurse : Research Nurse :  
 Psychogeriatrician : Neurologist : Clinical Psychologist : G.P. :  
 Nursing Auxillary : Psychiatrist : Continence Adviser : Practice-  
 Nurse : Community liaison Nurse : (Community) Physiotherapist (2) :  
 Medical Assessors - (Benefits Agency) : Solicitor : Social Worker :  
 Home Care Manager : Community Care Manager : Home Carers :  
 Occupational Therapist : Hospital Social Worker : Care Attendant :



Financial Assessment : Carers Assessment : Eligibility Criteria (NHS)  
 Eligibility Criteria (Social Services) : Wheelchair Service : Nursing Homes :  
 Residential Homes : Private Homes : Social Services Homes : Housing -  
 Association Homes : NHS Funded Beds : Dual Registered Homes :  
 Disabled Facilities Grant : Attendance Allowance : Invalid Care Allowance :  
 Disability Allowance : Severe Disability Allowance : Enduring Power of Attorney :  
 Local Authority Funding : Motability Scheme : Orange Badge Scheme : Legislation - including  
 and Community Care Act + Carers (Recognition & Services) Act : Alzheimer's Disease Soc.  
 Roads : Suffolk Carers : ACCE : Carers National Assoc.<sup>n</sup> : Red Cross : D.A.B. :  
 University Health Council : + (trabablu) manu nival

## REFLECTIONS ON CARING

It started with my glasses. We were standing in the hallway, Pauline facing me with her back to the glass panelled street door. I forget why we were there, but everything else is firmly implanted in my memory. She stared at my face in a curious but strangely concentrated way. Then a smile spread across her own lovely features, and she pointed.

I couldn't make out what she was on about. Had I got a dirty mark on my face? I turned to look at myself in the hall mirror. No, the same somewhat dishevelled and perpetually worried expression stared back at me - no dirty mark or anything unusual.

By this time Pauline was convulsed with laughter. It was good to hear her laugh. So much of life since Alzheimer had visited some years ago and had decided to set up shop to ply his wares from her brain, did not easily promote such hilarity.

"Look". Her speech was already reduced mainly to single words and sometimes even these needed a room full of interpreters to understand. But the "Look" and the pointed finger actually touching my glasses now made it quite clear that it had something to do with my spectacles. I took them off, inspected them myself and then found Pauline looking deeply into my eyes. Years ago intimate eye to eye contact like this would have brought all sorts of notions into my mind that were best not pursued in narrow hallways. But these things had long since disappeared from our repertoire of togetherness - Alzheimer didn't encourage such things.

We both examined the glasses still held lightly in my hand. Pauline touched them again but then lost interest. As I raised them to my face, I saw the door panel reflected in their curved surface, but, still none the wiser, I put them on again. With a lifetime of poor eyesight I felt very uncomfortable and vulnerable when not wearing them. The world becomes a blur, full of strange shapes that have little meaning unless I am in very familiar surroundings. It occurred to me that this was probably how Pauline's Alzheimer brain perceived her surroundings too. But for Pauline, there were no magic spectacles to help her make sense of the strange new world she had entered.

Then Pauline pointed at my glasses again and laughed once more. "Peoples" she said. "Little peoples". Two words! Suddenly, I understood. She could see her own silhouette framed by the doorway and miniaturised on the reflective surface of my glasses. I laughed with her and tried to explain what she was seeing.

I always tried to explain the things that Alzheimer prevented her from sorting out for herself. We held many a one sided conversation. I had learned to construct short, simple, one topic sentences which Pauline seemed to understand - some of the time anyway. But I could never be quite sure.

Pauline, like most people in the early stages of dementia, was a great actor and was able to put on a performance of which any graduate from RADA would be proud. By acting the part of "Pauline - a woman who had control of all her faculties", she had, so far, been able to hide from the casual observer, most of the confusions that enveloped and tormented her. It was her defence, her means of getting on with life in spite of it all, her way of coping with the horrors that Alzheimer forced upon her. She couldn't reject Alzheimer's impositions, only deal with them as best as she could. The acting was obvious to me when the performance was directed at others, but it was more difficult to spot when we were alone. There was, in my mind, no need for her to pretend to me that she was more able than she actually was. I suspected, however, she had difficulties that even I, close as we were, didn't realise, let alone even begin to understand. The acting was for her own benefit - not mine.

Over the following days the reflections in my glasses stayed a source of amused fascination for her. We had many a giggle over them. We usually both tried to make light of the muddles in which Pauline increasingly found herself. Laughter is a great equaliser. If I could participate in the muddle or difficulty Alzheimer had placed her so that we had joint ownership of it, then the pain of embarrassment and the hurt of failure became a shared experience and was all the lighter for it. Laughter healed the wound and the memory of it soon forgotten - in Pauline's mind at least. Painful memories seemed to last longer with her.

The reflections in my glasses continued to amuse for only those initial few days. Slowly amusement changed to concern, the concern to worry, and then to fear. Sometimes this fear evolved into sheer, unadulterated, terror. If I came near her she became frightened, not of me, but of those reflections. Her hand shot out and she tore the glasses from my face and hurled them across the room. This happened not once but every time I went near to her. I am lost without my glasses but I quickly learned to remove them every time she got within grabbing distance. At least we were then both in the same blurred and confusing surroundings.

I thought of non-reflective lenses. Were there such things? The optician told me over the telephone that there were coatings that would reduce reflections. Come and see our samples. Not as easy as that. We lived in a village, a 24 mile round trip away from the optician and making arrangements for Pauline's care whilst I went, took a few days to organise. I did eventually see the sample lenses but by this time Pauline's fear of reflections had transferred to other things. And life become more difficult - for both of us.



Mirrors caused panic, their surfaces and inner depths containing inexplicable terrors for her. I took them all down and stored them in the spare bedroom. I covered the mirror on the bathroom cabinet with paper. I stuck it down with masking tape which I planned to lift when I shaved. But as Pauline followed me everywhere, I was rarely in the bathroom alone, so I learned to shave 'blind' - less bother.

But all kinds of objects hold reflections.

Framed photographs and paintings behind glass had to be removed and stored. The spare room quickly became an Aladdin's cave of glitter and glass, of things that sparkled and shone, each object competing for its share of reflected glory. A fun fair's hall of mirrors had nothing on this room. Fortunately, Pauline never attempted to go in there. She would have entered her own personalised torture chamber had she done so.

The big picture windows generated huge reflected images and produced horror on a similar scale. So I put up net curtains to disguise. The glass doors on the display cabinets in the lounge had to be covered with paper. In the kitchen, the black glass doors on the eye-level ovens were similarly camouflaged.

Pauline saw reflections everywhere. The TV screen, the shiny plastic of the toaster and kettle held equal terrors for her. The light reflecting from the polished wood dining table caused apprehension. I caught her peering suspiciously at the far less shiny Formica surface of the kitchen table. It couldn't be trusted to stay that way. It was almost as though she found some masochistic pleasure in seeking out new reflective surfaces so that she could firstly get into a state about them, and then test my ingenuity in disguising the reflection in some way. Mercifully, for me, as reflections multiplied around the home, her interest in my glasses subsided. At least I could see what I was doing as I experimented by coating objects with Windolene, allowing the resulting chalky surface to dull any chance of it becoming another object of terror.

Strangely, there was one source of reflection that didn't trouble her, in fact it became a friend. This was the large square mirror screwed to the wall between two wardrobes and above a chest of drawers in the run of fitted furniture in her bedroom.

Pauline stood for hours in front of it talking to the person she saw reflected there. It was this person who became her friend. The friend was constant, always there, looked at Pauline, talked with her when Pauline talked, but had the decency to keep her mouth shut when Pauline wanted silence. She could share a good joke too. She laughed when Pauline laughed but when Pauline was sad and cried, she shed a tear as well. She didn't threaten, she didn't get too near. When Pauline wanted to sit quietly on the end of her bed, her friend kept silent vigil with her too. If Pauline became animated, her friend reflected the mood but when this turned to rage at what was happening to her, her friend instinctively understood and they ranted in unison at this, the most cruel of life's inflictions. When Pauline wanted to get closer to whisper feminine confidences, her friend responded and also leant forward for the intimate exchange. They touched.

They held out their hands to each other, fingertip against fingertip. I was forever wiping the evidence of these physical intimacies from the mirror's surface.

They remained friends for two or three years, long after Pauline's fear of reflections had disappeared from her life. Regretfully, other horrors came to fill the spaces previously occupied by those of reflections, but these must remain untold, for the moment.

I should explain one apparent contradiction. Pauline could barely put two words together that made sense and yet she had these enormously long conversations with her friend. How was this? Fortunately her friend could understand gobbledygook, and could speak it fluently too. This was the language of those conversations. Spoken with a full range of inflection, emotion and physical gesture. They stopped if I entered the room, so I often eavesdropped on the pair of them. The tone of voice and body language was quite explicit, but the words were in some foreign language known only to Pauline and her friend. Occasionally, just occasionally, the odd word in English was used just as a source of emphasis, to make a point, or, perhaps, to fool an eavesdropper?

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August 1996  
1741 words.

*reflect1.wps*

*Philip Ingram*

*"I believe quite strongly that the best sort of support is one-to-one contact, preferably with someone who has been there before; someone who can speak authoritively from personal experience; someone who understands; someone who can talk through the options open to you at each stage of the disease; someone who has experienced the costs of caring; someone who knows your financial problems extend way beyond the here and now; someone who knows what you are going through; someone who knows what you are likely still to have to face; someone who has experience of the sort of support services you need and more importantly the ones you are likely to be offered by the professionals; someone who knows of the many voluntary organisation in and outside your area who may have something to offer you at some time in the way of support, advice or services; someone who makes contact with you frequently enough to be reasonably familiar with your changing situation and to establish a rapport with you but not so frequently as to be intrusive or a nuisance; someone to praise your endeavours and be encouraging; someone to be sympathetic and understanding of your mistakes and frustrations; someone who knows instinctively when you want to talk ten to the dozen and has the time to listen; someone who knows when the time isn't right and can back away gracefully, someone who knows there is life after caring and can indicate the ways ahead for you, the carer; someone who knows that caring is hard, very hard and relentless and draining to the point where you never thought you could be so exhausted of everything within you, and still carry on;*

*Contd. . . . .*

*someone who knows that it is no failure to allow others to take over the caring role from time to time or even permanently; someone who knows that making that decision is harder and more brave than anything you have tackled thus far; someone who knows how rewarding caring can actually be; someone who knows that it is a privilege to be able to provide the total care you give to the person you love and is something not afforded to many and should be valued as such; someone who knows that however well you are supported by the professionals, by family and by friends and no matter how inundated you are with visitors, you will often still feel totally alone and desolate; someone who knows how cheered you are by the little 'improvements' in your cared-for's condition that happen from time to time and how worried you become when the opposite happens; someone who can comfort you in the mourning process you go through each time a little bit of your cared-for is lost and gone for good but, importantly, can encourage you to enjoy and savour what remains of them to the maximum possible extent; someone who will help you fill out yet another form when the effort for that becomes too much; someone who knows the importance of bringing their world into yours when you are not able to go out into their's; someone who is close enough to you to have gained your confidence but remains distant enough from you for you to be able to let go occasionally and to wail a million tears over them, or to scream blue murder at, if you need to, whereas professionals, friends and relatives may be embarrassed or offended by such extremes of emotion; someone who is prepared to operate on your timescale; someone who does things when he says he will, someone who keeps you informed and who you are not constantly having to chase up; someone who can be your advocate (or find one) at times of need when you are not up to it yourself; someone who respects your privacy; someone who treats you as a person and not as a case or, dare I say it, not just as a carer. "*

## Appendix 5 (i)

### Content and issues raised during the taped group meetings

The following tables give an indication of the sequence and content of the group meeting. Most of these discussions were focused on individuals' situations but occasionally these were debated at a more macro-level (indicated in *Italics*). The main theme or topic of the 'stories' is indicated in the shaded boxes and the 'issues' that arose in relation to each theme/topic are indicated underneath. The themes/topics are listed in the order in which they occurred – therefore some topics are shown as repeated because they arose more than once during the course of the meeting.

**Table 1: Analysis of the content and sequence of Group 1 meetings**

<b>Group 1</b>	<b>Group 1</b>
Meeting 1	Meeting 2
ATTENDERS ART WORK	SHARING INFORMATION
Wanting to donate work to local hospital ward named after their Town	Alzheimer Society Events
Acknowledgement of carers' other talents (art)	Local Authority new charging policy
NEWS OF FOUNDER MEMBER	PARTICIPATION IN COMMUNITY ACTIVITIES
Continuing links of group to founder after his move to residential care	Forthcoming contribution to local church event and Town festival
WELCOME NEW MEMBER	Allocating responsibilities
PARTICIPATION IN COMMUNITY ACTIVITIES	ASSESSMENT FORMS
Arranging volunteers in the self-help group for various community functions (church event, June festival)	Complexity of the forms
Community 'politics' who they are expecting to assist and assist them (includes the Mayor)	<i>Difficulty for all carers in filling in bureaucratic forms e.g. attendance allowance</i>
ATTENDANCE AT GROUP MEETINGS	<i>Difference in situation for rich and poor people</i>
Concern over numbers	Confusion over benefit allowance
Concern over location	Suggested invite to local Care Advisor
Concern over timing	EXCHANGE OF INFORMATION RE: 'TRUSTED' PROFESSIONALS

	<b>'TRUSTED' PROFESSIONALS</b>
Decision to move day and location of meeting	Where and from whom to get welfare rights advice
<b>ISOLATION OF CARERS</b>	Where and from whom to get technical equipment (e.g. bath, door chimes)
The difficulty in 'others' appreciating their situation	<b>PLANNING SOCIAL EVENT FOR BOTH CARERS AND THE PEOPLE THEY CARE FOR</b>
Lack of time to attend the group	How to encourage people outside of the group to attend
<b>MOVEMENT OF CARED-FOR INTO RESIDENTIAL CARE</b>	Best time and location and type of event
Feelings of 'Loss'	The difficulty of carers getting out
<b>ASSESSMENT</b>	<b>ACCESSIBLE PLACES LOCALLY</b>
Confusion over process	Wheelchair accessible places
Lack of awareness re: carers assessment	Sharing of known places
Complexity of financial assessment	General lack of accessible places and facilities
The number of professionals involved – confusion over 'roles'	Need to invite Care Advisor to address some of the local issues
Length of time involved	<b>PLANNING SOCIAL EVENT</b>
Non-response from professionals to telephone calls	Linking to other community events
<b>MOVEMENT OF CARED-FOR INTO RESIDENTIAL CARE</b>	Encouraging carers and people cared for to go to other community events
Confusion over what type of degeneration would result in a move to nursing care	
Feelings of cared and cared-for	
<b>PRACTICAL ASSISTANCE</b>	
Useful 'aids' available – e.g. fridges, door chimes, emergency bleeps	
<b>ATTENDANCE AT ALZHEIMER'S SOCIETY SELF-HELP GROUP</b>	
<i>Meeting with a Dr doing research on 'loss' (legitimisation of earlier conversation)</i>	
Use and limitations of professionals	
Level of empathy (or otherwise from professionals)	
<b>LOSING CONTROL</b>	
Losing temper with the person being cared for	
Swapping of 'coping strategies': leaving the room, shouting in a 'safe' place, finding 'practical aids' to reduce the inherent tension of the situation	
<b>RESPIRE CARE</b>	
Difficulty in finding 'good' respite care	

Resistance by person cared for	
Guilt in using respite care	
Recommended places	
<b>EMOTIONAL EXHAUSTION OF CARING</b>	
Physical and psychological effects on carers	
Insomnia	
Anger	
Isolation	

**Table 2: Analysis of the content and sequence of Group 2 meetings**

<b>Group 2</b>	<b>Group 2</b>
Meeting 1	Meeting 2
<b>ASSESSMENTS</b>	<b>DIAGNOSIS AND TREATMENT</b>
Difficulty of basing 'need' on an assessment of today's needs, when condition is degenerative AND there are long waiting lists for equipment.	Members experience of being given an insensitive cancer diagnosis
Inequality of service	<i>Hierarchy between different professional groups and its impact on the 'patient'</i>
Gap between those who can afford to pay and those who cannot	Attitudes and health?
<i>Governmental health priorities – that prioritise Viagra above MS treatments</i>	Impact of caring on health
Confusion re: funding for research that is expensive but produces drugs that are not affordable by NHS.	<i>Impact of environmental factors on health (additives)</i>
<b>ENCOUNTERS WITH PROFESSIONALS</b>	<i>Governmental policy and health (individual and societal responsibilities)</i>
Confusion re: role differentiation	<b>CARERS STRATEGY</b>
New 'Gold' Assessments (multi-agency)	Experience of Carers consultations (dominated by Professionals)
Waiting times for service and equipment	Perceived inordinate number of meetings as opposed to action
<b>HOISTS</b>	Confusion and clarification re: new grants and strategy (SW outlined)
Difficulty of using hoists	Key points that arose from the consultation
Lack of information from Professionals	<b>LOCAL FACILITIES</b>
Own coping strategies	Lack of facilities for disabled people e.g. toilets, parks, shops, restaurants

Loss of dignity for the person using a hoist	<i>How best to convey dissatisfaction to relevant authorities</i>
<b>ASSESSMENTS</b>	<b>INTERNET</b>
Lack of acknowledgement by some professionals of experiential knowledge	Use as information source – outline of a site
Waiting time for equipment – effect on carer – physical and emotional	Confusion/fear over use
Suggestions re: useful equipment	Access and cost
Experiences of the ‘gold’ meeting	Carers Diary (produced by NCA <sup>1</sup> ) as a resource
Waiting time for follow-up	<b>RESPITE</b>
Appreciation of the constraints on some professionals ( e.g. social workers)	Use of NCA to apply pressure on the Local Authority
<b>RESPITE CARE</b>	SSI recent Inspection
Limited choice available	Personal experience – lack of feedback
Undesirable nature of some accommodation	<b>CANCER</b> (of member)
Guilt about using respite	Experience of chemotherapy
Resistance by cared-for	Suggestions re: Diet
Lack of information	Effect of the diagnosis – physically and emotionally
Bureaucracy involved in getting respite care	
Lack of resources in SSD	
Worry about the effect on cared-for if carer ill	
<b>INFORMATION EXCHANGE BETWEEN AGENCIES</b>	
The undesirable necessity of having to give personal details (carer and cared-for) multiple times	
<i>Lack of information exchange between agencies</i>	
<b>STRESS OF CARING</b>	
Isolation	
Relentlessness	
Need for respite	
<i>The negative impact of risk management policies in agencies on the cared-for</i>	
Exchange of ‘tips’ on coping when stressed. From experience and the stress management course	

<sup>1</sup> NCA is the National Carers Association established in 19xx in UK to represent carers' needs.



## Appendix 5 (ii)

### Comparative table of discourse in 12-step and non 12-step self-help/mutual aid groups

Borkman *et al* (2000) and Munn-Giddings (2002)

N.B. (italics indicate differences in methods and findings)

UK study (Munn-Giddings 2002)	USA study (Borkman, Zoher, Ney and Bender, (2000)
4 group meetings (2 in each group)	4 group meetings (in the same group?)
Methods: <i>Analysis of taped group sessions plus reflective notes</i>	Methods: <i>Observation guide (based on Bohm and Senge's 1990 notion of dialogue)</i>
<i>Non-12 step groups. No agreed groundrules</i>	<i>12 step AA group. Established rules.</i>
	<i>* No cross-talk allowed</i>
	<i>* No gossiping allowed</i>
	<i>* No criticizing of other members</i>
Chairs attempt to include everyone	<i>* Leader role to include everyone</i> <i>* Leader chooses the topic or reading</i>
Distinctive form of conversation: Grounded in experiential knowledge of the issue	Distinctive form of conversation: Grounded in experiential knowledge of the issue
The basis of the knowledge and authority is experiential not professional	The basis of the knowledge and authority is experiential not professional
Based on storytelling	Based on storytelling
<i>First narrator self-selecting</i>	<i>Leader introduces the first topic</i>
People speak in sequence	People speak in sequence
Others speak of their experience of the topic	Others speak of their experience of the topic
No disagreement or arguing	No disagreement or arguing
Non-judgemental exploration of various views and facets of an issue	Non-judgemental exploration of various views and facets of an issue
General coherent flow of conversation however topics varied in depth, development and elaboration	General coherent flow of conversation However topics varied in depth, development and elaboration

## **Appendix 6**

### **Personal reflections on the thesis**

Finally, I turn to my own reflections on the study. Here I review what I consider to be the main areas of strengths and weaknesses of the thesis before summarising the dominant things I have learnt whilst doing my Ph.D.

### **Strengths and weaknesses**

The limitations that I detect in my own thesis have already been stated in the relevant chapters (see particularly Chapters One and Five). In summary, these relate to limitations of the available literature and the methodology.

I began the study in the context of a dearth of theory and research in the UK. Whilst this provided a strong rationale for the study it has been one of the major difficulties that ran throughout the process of the research. Firstly, since there was not a strong literature to ground the study in or use as a basis for comparison with my own findings, I had to rely heavily on using what I considered to be pertinent material from the USA literature. I was, however, also very aware that this was developed from and within a very different welfare system with quite different state-independent sector relations. This limitation provided the grounds for the historical review of self-help/mutual aid – state relations but since this is not an area of study in the UK I had to draw on literature primarily written for another purpose, mostly that of the relatively new documenting of the formal voluntary sector. I am aware, therefore, that there may be gaps/holes in the review that can only be filled by specific historical research (see research recommendations earlier).

The case study approach by its very nature, whilst giving depth cannot be expected necessarily to be generalisable; rather its purpose has been to provide insights. As mentioned in Chapter Five it would be useful to replicate the study with stigmatised groups, groups that are politically active and importantly, groups that represent the interests of people from ethnic minorities. And finally, the length of time I took to undertake the work limited the potential for participation, in particular the planned

final focus group to check out the overall conclusions I had reached with the group members. By the time I had reached the latter stage neither group existed in their original form nor did one group have the same core membership. This is a cumulative product of my own personal circumstances plus those of working with a case-study group (carers) whose circumstances are likely to change over time.

In terms of my own view of the key strengths of the study, to date there has been little in-depth work in the UK on self-help/mutual aid groups. This thesis, therefore, with its two components, of a specifically UK-based historical review and an in-depth case study exploring the views of group members themselves, I believe, gives a context and a depth understanding of groups not previously available. It also contributes clarity and breadth to an understanding of the relationship between self-help/mutual aid groups and social policy, the primary aim of the study.

The two components of the research (the historical analysis and the fieldwork), although complex, felt to me an important complement to one another. Without placing contemporary groups in their historical context it would be difficult to evidence the continual ambivalence of governments towards self-help/mutual aid and provide a rationale for it. It has also been possible to confirm the similarities and distinction of self-help/mutual aid in relation to the formal voluntary sector, the UK user movement and USA-dominated studies. The historical study combined with the case study has also allowed me to look at the actual and potential broader impact of self-help/mutual and group activity. The evidencing of the dual identity of groups was important since it meant that a range of policy-related initiatives both theoretical and practical became illuminated. Whilst it has previously been suggested that self-help/mutual aid could be related to the broader community, it has not been well evidenced and I believe that the study goes some way to plugging that gap.

The use of a variety of theories to both contextualise the study and explain the findings has been vital, I believe, for such an eclectic phenomenon and necessary in order to broaden the discussion beyond the confines of both a predominantly psycho-social literature and a US-dominated one. Many of the most relevant texts either were only published during the latter stages of the Ph.D. or became relevant at different stages of the Ph.D.'s evolution. Whilst this presented a challenge, to use them rather

than ignore them seemed the only way to do justice to the emerging shape and complexity of the thesis.

Overall the study provides a strong foundation for developing UK specific theorising about the benefits and limitations of self-help/mutual aid groups and their place and contribution to social policy in both community and professional areas.

### **Personal learning**

Traditionally, undertaking a Ph.D. has been viewed as a type of apprenticeship for academia, in particular the construction and execution of the research component has been viewed as a way of “learning the tools of the trade”. My journey, however, was somewhat different to this, since I was not new to research or academia. As I mentioned in the introduction, I have spent the last 15 years doing, teaching, facilitating and managing social research projects. As a starting point that was a good way to delude myself that the PhD was merely an extension of what I already did and knew. I have learnt many things in the seven long years that I have been running this PhD alongside both a full-time job and a full-time life.

Firstly, I would never have kept the momentum for doing the work unless I had grounded it in a subject area that continued and continues to capture my interest both philosophically and politically. Secondly, although constructing a study and undertaking it was not new to me, the depth of reading and connections involved over such a long period of time really was. There were many avenues and cul-de-sacs along the way and I had to both discipline myself and accept my supervisors’ advice regarding what I did and didn’t keep in the thesis. I recognised what I suspect I already knew and can detect in others – that I am a very divergent thinker and keeping the focus and letting go of/saving the many interesting connections that I wanted to make was the only way to keep the “story” coherent over such a long piece of work. I really struggled at times particularly in the first draft of the thesis with getting the narrative lucid.

Interestingly, the single book that I found most useful in helping me with this process was not one about academic writing or doing a thesis, but a book by Natalie

Goldberg, a Buddhist called 'Writing down the bones: freeing the writer within' (1998) which gives advice to creative writers on getting started, keeping the momentum and holding the audience, if you want, in prose and poetry. Many of the anecdotes rang familiar bells: for example, during a point (a critical point) where I negotiated some block study leave I found it almost impossible to apply myself to actually writing. I found myself musing endlessly about philosophical connections between self-help/mutual aid, life and the universe, and the following extract from Goldbergs book helped to both sober me and re-focus me:

There was a period last fall when every time I began to write, I went  
Into a perfect state of blank minded euphoria...I sat in this state, sometimes  
For the whole time I had planned to write. I thought to myself, 'Lo and  
Behold, I am becoming enlightened'! This is much more important than  
Writing, and besides this is where all writing leads.' After this had gone  
On quite a while, I asked Katagiri Roshi [her Buddhist mentor] about it. He  
said, "Oh, it's just laziness. Get to work." (p.157)

I suspect that underlying my inertia at times with the thesis was a lack of both self-faith and my continued ambivalent relationship to academia/scholarship. In the former I was in the uncomfortable position of being head of research within my own academic school, because of my long background in research and yet often in environments and forums where I was the only one without a PhD. In addition I was and am still the only member of my extended family to go to University and as such I was also struggling with a lack of self-confidence and familial example of undertaking work in this depth. This was compounded regularly by my supervisors' constructive despair at my continued grammatical errors, most of which I had been simply oblivious to somehow for many years. So this was a specific learning experience for me both in terms of simple grammatical rules and ensuring consistency with headings and sub-headings over such a long piece of work.

With regard to the latter point, I have a peculiar relationship to academic writing, which I do not find easy and yet gain a particular satisfaction from. I also dislike some of the conventions of academic writing which I feel stifle both expression and

creativity. I have a strong feeling that entering academia concurrently broadened my mind and confined it in the ideas and frameworks to which I was introduced. I believe only experiential knowledge breaks that mould and allowed me (one) to compare the usefulness or otherwise of others work and find a new way of looking at things. Hence my commitment to experiential knowledge! Finding a way, therefore, to balance creativity with expected form was a challenge and I have felt the stages that I need to go to produce that kind of work coming on in waves rather like contractions which I both wish to resist and finally submit to. I know that I write at my best when I am totally immersed in the subject but that has not been easy with the other commitments in my life. I also learnt that my own rhythm (or current one) of writing means that I'm better merely jotting notes in the morning and beginning to write properly in the afternoon. I have also learnt that my increasing age is a limitation since I can no longer stay up until the early hours of the morning, as I used to, unless I wish to take the following two days off!

My ambivalence to academia is also based around the 'so-what?' factor, a concern with the relevance of much social research to the groups of people it is supposed to relate to. During the years that I have been doing the work I have moved and aligned myself more closely to models of participatory enquiry, particularly participatory action research. Ideally, if I were to construct the study again, I would make it more participatory, working from the concerns of self-helpers themselves, as I have suggested under future research. Two unresolved tensions remain, the first being that for the groups involved in the study and, as I suspect, of many self-help groups, they are more concerned with the nature of their group than they are with self-help per se. This parallels both the existing policy response and the professional agenda. To undertake/facilitate, therefore, only research that reflects self-helpers concerns may therefore reinforce the very divisions that I am trying to connect. An eternal conundrum for promoters of any form of democracy, research, politics or otherwise -- how to hold strong views and be democratic. For me, to deny my own views and values in the research would be tantamount to colluding with positivist philosophy that holds the researcher as a 'neutral vessel through which data merely flows. I am not and do not wish to aspire to be! I have therefore come to the conclusion that both types of research, i.e. that suggested by self-helpers and that is an alliance between academics and self-helpers can be useful. In this sense I have both developed and

learnt a pluralistic approach to research. And finally, I have learnt that I can produce such a piece of work, something, which felt impossible at various stages of the process. At last my PhD is not something I am always doing but never finishing.

**THE END.**