Chaudhary, Sarah (2014) Self-help groups as sites of active citizenship: a qualitative study of the democratising role of self-help in the public sphere. PhD thesis, University of Nottingham.

Self-help groups as sites of active citizenship: a qualitative study of the democratising role of self-help in the public sphere

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Thesis submitted to the University of Nottingham
for the degree of Doctor of Philosophy March 2014

Abstract

Self-help groups in the United Kingdom continue to grow in number and address virtually every conceivable health condition, but they remain the subject of very little theoretical analysis. The literature to date has predominantly focused on their therapeutic effects on individual members. And yet they are widely presumed to fulfil a broader civic role and to encourage democratic citizenship. The thesis uses qualitative data derived from individual and group interviews with 33 groups in order to provide an outline of the ethos, aims, activities and structural arrangements of a broad range of self-help groups in Nottinghamshire, UK. It then uses these findings as the foundation on which to construct a model of self-help groups' democratising effects in the public sphere and as a means of differentiating them from other types of 'health citizenship' organisation such as new social movements. In order to do this it broadly follows the work of Jurgen Habermas, making use of his concepts of communicative action; system-lifeworld integration; lifeworld autonomy and collective identity as an appropriate framework against which to account for these groups in civic terms.

It was found that in their pursuit of personal and collective identities the groups were augmenting individual autonomy through increasing mutual recognition and understanding in the lifeworld. Although at first sight the groups appeared to be structured hierarchically, leaders tended to use their influence to foster a type of communicative equality that sustained the democratic negotiation of these identities. In addition, through their two-way communicative links with the system the groups were adding to the complexity and quality of discourse in the public sphere and increasing the possibility of attaining social consensus. Unlike new social movements who are believed to operate at the protest end of civil society, the self-help groups were oriented to its enabling sector.

Keywords – self-help group; Habermas; social movement; collective identity; citizenship

List of published papers

The following journal articles, which derive from the research carried out for this thesis, have been published:

Chaudhary S, Avis M, Munn-Giddings C (2013) Beyond the therapeutic: a Habermasian view of self-*help groups' place in the public sphere*. Social Theory & Health Vol. 11, 1, 59–80

Chaudhary S, Avis M, Munn-Giddings C (2010) The lifespan and life-cycle of self-help groups: a retrospective study of groups in Nottingham, UK. Health and Social Care in the Community (2010) 18(4), 346–354

Acknowledgements

I am indebted to my supervisors, Professors Mark Avis and Carol Munn-Giddings for their invaluable help and advice as well as their constant encouragement. I thank the University of Nottingham, School of Health Sciences, for funding the thesis.

I would like to thank all the staff at Self Help Nottingham, in particular Caroline Bell for her generosity in sharing her wealth of knowledge about self-help groups. My ever-supportive husband, Simon, and my son Matthew, deserve much credit for putting up with my varying levels of distractedness with unfailing good humour, especially during the months of writing up; and I am especially grateful to my mum, who was a constant source of tranquil good sense (as well as unlimited childcare).

Most of all I would like to thank the group members who participated; not only for making the thesis possible but for acting as a true inspiration.

List of tables

Table of Contents

Introduction

It is 30 years since the voluntary sector organisation Self Help Nottingham was established in order to offer advice, training and practical assistance to local self-help groups. Much has changed in the political landscape over that time; however at least two things have remained constant, the importance of healthcare provision coupled with the increasing costs of providing it (Fitzpatrick 2008), and the on-going concern with democratic disengagement and the perceived decline in active citizenship.

It is widely believed that self-help groups have an important part to play in both of these areas; promoting the good health of their members through undertaking the type of associational activity that de Tocqueville deemed the heart of a vibrant democracy. Yet there appears to have been little acknowledgement of this at the political level. To date Self Help Nottingham remains the only organisation in the UK that is dedicated to the support, promotion and development of self-help groups. Similarly from an academic perspective, although a body of literature has begun to develop around self-help groups' mutual support role and the benefits it brings to individual members, relatively little is still known about how these groups work, why they arise or the impact they have in the broader community – surprising indeed for a phenomenon that is said to involve over 1.5 million active participants in the UK (Elsdon et al 2000).

Of all the assertions made about the value of self-help groups, perhaps the least is known and understood about the role they are believed to play in stimulating democratic behaviour in the public sphere. It is therefore towards this gap in knowledge that the current thesis intends to contribute.

In order to guide the work towards this end and to begin to formulate the types of question I wanted to ask it seemed appropriate to adopt an existing framework that had already conceptualised that area of social life in which self-help groups' part was to be examined. And it emerged early on in my reading that Jurgen Habermas' ideas about civic behaviour clearly resonated

with what was known (or perhaps what was presumed) about self-help groups. For Habermas (1987, 1989, 1996) the public sphere or civil society emanates from the private sphere of life, acting as a space independent of both state and market. Its legitimacy relies on individuals coming together spontaneously and engaging freely in conversation about issues of universal human concern. This model seemed not only to capture what was going on in self-help groups, but also to provide the means by which I could move beyond the traditional focus on them as sites of personal support and therapeutic benefit to individual members. Such emotionally grounded activities seemed at that stage to lack relevance to the broader questions about structural autonomy, ideology and political activity with which I was concerned. Working with the groups in person and gradually becoming acquainted with the data however took me on routes than I had not planned for, leading me back into areas I had not originally seen as important, and to a very different understanding - of both theory and groups – than I had foreseen at the outset: The journey of my PhD is aptly captured in TS Eliot's famous lines

We shall not cease from exploration

And the end of all our exploring

Will be to arrive where we started

And know the place for the first time

Overview of research aims.

My preliminary appraisal of the self-help literature indicated that the view of self-help group members as drivers of democratic activity in the public sphere, whilst commonly held, was under-developed theoretically and lacked the support of adequate empirical data. The overall aim of the thesis is therefore to address this deficit and in doing so to gain a more thorough understanding of any civic role that self-help groups might perform as well as of the types of factor, both within and beyond the groups, that encourage or impede this role.

Rather than attempting to create a theoretical framework from scratch, the thesis utilises the existing work of Jurgen Habermas. His concepts of communicative action and the public sphere (1984, 1987, 1989) are used in framing the research questions as well as informing the analysis of the findings in order that a coherent civic model of self-help groups can be developed. By analysing the groups in these terms the thesis aims also to contribute to broader models of 'health citizenship' by providing the means to make comparisons with other lay health organisations. At the same time the emergent data will be used to reveal the adequacy of Habermas' theoretical concepts as tools with which to explain a real life social phenomenon.

The detailed research questions are given in the methodology section; however the overarching issues that the thesis aims to address are as follows;

- To what extent and in what ways can we understand self-help groups as drivers of democratic behaviour in the public sphere?
- In what ways are self-help groups similar to or distinct from other lay health organisations in terms of their effects on active citizenship?
- How useful are Habermasian frameworks in accounting for the phenomenon of self-help groups as civic actors?

In order to address these broad themes, I will ask questions in the following areas;

- How does a group's structure affect its ability to sustain democratic discourse? How inclusive and egalitarian are the groups?
- What is the relationship between self-help groups and public services? How autonomous are the groups?
- To what extent do groups foster individual autonomy and empowerment?
- How far do groups contribute to community empowerment?
- What values underpin self-help groups and from where do these values come?
- On what political ideologies are groups grounded, and what are the effects of different political standpoints?

- What do groups talk about? According to what types of framework do they conceptualise their health condition?

Structure of the thesis

Chapter 1 will examine the general self-help group literature in order to build a picture of the self-help group phenomenon. This will provide a context for the subsequent theoretical and empirical analysis. I shall begin with a brief account of the difficulties inherent in defining self-help groups and the approach to this issue taken in the current study. I then provide an overview of self-help groups in terms of their social origins, purpose and perceived benefits as well as what is known about who uses them.

Chapter 2 introduces the theoretical framework that will guide the analysis of the self-help groups. Prior to this I will outline the existing approaches that have been followed with a particular emphasis on the minority of studies that conceptualises groups from broad community perspectives. These include ideas about self-help groups as part of the third sector; as normative communities and as parts of social capital networks. I shall also briefly consider the roles attributed to self-help groups within voluntary sector and sociological literature. In addition this chapter will provide an outline of the growing field of literature that I refer to as 'health citizenship'. This entails various strands of theory that attempt to account for the growing political and academic tendency to see health behaviours as a means of sustaining democracy. I will consider how far these models intend and are able to explain the specific role of self-help groups and will suggest that Habermasian ideas about communicative action may provide a means through which to incorporate self-help groups more fully within them.

The remainder of the chapter will provide an explanation of those aspects of Habermas' work that relate to the current analysis. These will include the concepts of system and lifeworld, the contrast between strategic and communicative action and the requirements of rational, unconstrained communication. These ideas will be illustrated by reference to the existing

self-help group literature in order to ask how groups' structure, ethos and purpose may either encourage or impede their democratising effects. The theory will also be used to draw out the ways in which current health and social care policy agendas might affect self-help groups' civic role.

Chapter 3 provides a discussion of the theoretical basis of the methodological approach. It includes an outline of the methodological and sampling strategy, research instruments and approach to data analysis and considers their advantages and drawbacks. The ethical issues are also discussed as well the limitations of the study.

The findings are presented in Chapters 4 to 8. The first four are concerned with the substantive purpose and activities of the groups, namely their role in providing support and sharing information both within and beyond the group. The last chapter describes the ways in which the groups are structured, the reasons why they had adopted their particular structure and the effects of how they were organised. This section places particular emphasis on the differences in the roles and status of leaders and regular members. It discusses who participates in group tasks and in the various types of decision that are made by groups.

Throughout all the findings sections the data will be used as a means of highlighting the ethos, ideologies and values on which the groups are grounded as well as indicating the nature of their relationship to public service providers.

Chapter 9 includes the Discussion and Conclusions. It draws together the data from the findings that are most relevant to the conceptualisation of self-help groups as democratising agents in the public sphere. The discussion section is divided into two parts. The first offers an explanation of the processes through which self-help groups act as creators of personal and collective identity and examines the effects of this identity formation on communications in the lifeworld and discourse in the public sphere. It considers how the use of collective identity as a conceptual tool allows self-help groups to be differentiated from other health citizenship organisations. The second part is concerned with the communicative role that self-help groups play at the boundary between the system and lifeworld. It examines the ways in which the

groups use knowledge from different sources and belonging to different conceptual frameworks in order to pursue their own goals. It considers the extent to which this gives rise to an integrative link between system and lifeworld, and thus adds to the complexity and quality of discourse in the public sphere as well as to the likelihood of attaining social consensus. The chapter ends with conclusions and reflections on the strengths and limits of the thesis.

1 Background to the study of self-help groups

1.1 Introduction to the literature

Searching the self-help literature in a systematic way presents a number of difficulties. Firstly, self-help research is still relatively new and undeveloped and, as Borkman (1999) states, it is not situated within a broader, contextualising body of knowledge that would give a coherent basis from which to develop further study or new approaches to the topic. Research conducted on self-help groups is spread across a number of disciplines such as psychology, organisational theory, nursing and sociology; and, with the exception of the International Journal of Self-Help and Self-Care, whose output of publications has been erratic in recent years, it does not have its own dedicated journals. The lack of specificity of the term 'self-help' is such that general searches reveal 1000's of entries most of which are not relevant. Furthermore the lack of UK literature has meant that researchers have been drawn into reliance on international studies when conceptualising self-help groups. Whilst these studies are undoubtedly valuable and provide much insight into all self-help groups, care has to be taken in applying their conclusions in different national contexts. Self-help is believed to evolve into unique forms in response to the political economy, and particularly the attitudes towards welfare provision, of the country in which it is based (Karlsson, Jeppsson, Grassman, Hansson 2002) and thus the ability to make generalisations across national boundaries will be limited.

The disparate location of the literature meant that it was necessary to take a broadly incremental approach to its review. This entailed following up what appeared to be the most relevant references cited by the main authorities. Furthermore, as some of the research questions in which I was interested pertained to aspects of self-help groups that had received very little attention and a theoretical framework that had not been commonly used in their analysis it was important to maintain a very broad approach in order to glean material

from studies which were not directly concerned with the questions I was asking, but which nonetheless contained information that was relevant to the formulation and development of my research strategy.

1.2 Defining self-help groups

In view of their proliferation over recent years and their "staggering" diversity of form and function (Borkman 1999, Munn-Giddings 2003 p19) it is perhaps unsurprising that defining self-help groups has tended to be the subject of disagreement resulting in a lack of clarity over what is included within this term. Despite the importance of attaining conceptual clarity, limitations of space mean that only a brief overview of the main definitional arguments will be provided in this chapter. The issue will however arise at various points with respect to the task of differentiating self-help groups from other types of health citizenship organisation.

As may be expected with any social phenomenon, but particularly with one that tends to arise spontaneously rather than through official or bureaucratic planning, there are extensive grey areas surrounding the concept of a self-help group. This is compounded by the different terminology used within various national contexts. For example US literature tends to use mutual aid or peer support instead of self-help and in the UK groups will frequently refer to themselves in alternative ways such as "community" or "support groups" (Seebohm, Munn-Giddings, Brewer 2010, ESTEEM 2011 p20).

The difficulties in ascertaining accurate boundaries between self-help groups and associations with which they share numerous characteristics, such as service-user groups, are amplified because self-help groups frequently have numerous, concurrent aims and functions (Wilson 1994, Munn-Giddings & McVicar 2006). Indeed different members of the same group may point to different roles as being the group's primary purpose (Radin 2006). And many groups exist in a state of on-going evolution, gradually morphing into, for example, service-user organisations or social movements (Borkman & Munn-Giddings 2008). Indeed the boundary between self-help groups and social

movements is one around which there is a particular blurring, with some authors using the terms interchangeably (Kelleher 2001, Chamak 2008, Troman 2008) whilst others differentiate them according to a range of criteria (Kelleher 2001, Brown, Zavestoski, McCormick, Mayer, Morello-Frosch, Gasior-Altman 2004). Paradoxically the very flexibility and subjectivity which makes self-help groups so hard to define, may itself be one of their central characteristics.

The precise meaning of the term self-help group is made more difficult to capture because it is itself in a constant state of evolution. This is illustrated by the fact that over recent years Self Help Nottingham's own definition has developed from one in which groups were unequivocally "run by and for the members" (2000) to one in which today "some [self-help groups] are run or facilitated by health and social care professionals" (SHN Toolkit 2011). Similarly social and technological changes such as the proliferation of the internet and the emergence of social media (Seebohm et al 2010) have also added to the complexity of defining these groups. Despite these challenges though it is possible to discern some core characteristics that have generally been agreed upon as key to any definition of a self-help group. These are;

- Membership of the group is voluntary
- Group is self-organising
- Group addresses a shared experience or problem
- Group members provide mutual support
- The control and ownership of the group rests with the members
- The structure is informal and non-hierarchical

(Wilson 1994, Elsdon et al 2000, Steinke 2000, Munn-Giddings 2003, Borkman 2010).

For some authors, certain core elements are deemed essential, for example Levy (1976) states that true self-help groups must have an express primary purpose of providing support. However care must be taken in asserting such prescriptive criteria. Self-help groups frequently arise spontaneously and

develop informally along unplanned paths, therefore according to Levy's rules this would exclude those groups that have evolved into primarily supporting groups, but which nonetheless have never articulated this expressly. Indeed the informality that many authors see as a central feature of these groups means that establishing their primary purpose can be a difficult task. Many groups have a number of concurrent aims (Gray et al 1997, Adamsen & Rasmussen 2001) such as education, dissemination of information and campaigning in addition to their supporting role. And, as Gray *et al's* study exemplifies, different group members may prioritise very different aspects of the group at different times. This subjectivity in how members' perceive the role and value of the group may itself be an important feature of self-help groups, to which, too rigid a definition appears ill-suited.

The approach taken in the current thesis was therefore not to consider any of these core characteristics as crucial in itself but to conceive of them collectively as a bundle of attributes and ask whether groups possessed enough of them and to a great enough degree, to counteract the absence or less extensive possession of others. Having said this the existence of some element of member control, even if it is merely de facto, arising, for example, through the particular, sympathetic character of a professional, who, despite nominal authority allows the group to steer its own course, does stand out as a particularly vital characteristic. The absence of this feature may therefore demand very special circumstances for a group to be classed as self-help.

1.3 Origins, scope and purpose of self-help groups

Self-help groups aim to address virtually every conceivable health condition or social situation (Jacobs & Goodman 1989, Madara 2008). The most common categories include; physical illness, mental health issues, disability, addiction, carers and social issues such as parenting, bereavement or divorce (Wilson 1994, Elsdon et al 2000, Chaudhary, Avis, Munn-Giddings 2010). Within these categories groups may be concerned with very common or extremely rare

illnesses and situations; they may or may not be specifically for those with a medical diagnosis or for sufferers at particular stages of illness or recovery.

Several difficulties are inherent in discussing self-help groups' purpose and benefits. Firstly, it can be hard to elicit the objectives of those groups that have no formally articulated aims. And for those groups with formal, written objectives there is the problem of frequently significant disparity between the official group purpose and the aims as perceived by individual members (Elsdon et al 2000), which themselves may be widely divergent (Gray et al 1997, Radin 2006). In addition, benefits that are cited as arising from participating in the group may appear to come about as a result and hence provide evidence of a group's purpose. In fact however they may be by-products of processes that are ancillary to the primary reasons for the group's existence, for example, the personal skills and empowerment derived from contributing to the organisation of the group.

Having said this, people obviously instigate and join self-help groups for a reason, with the aim and intention of achieving something through it. And the prevalence of self-help groups and their frequent longevity (Chaudhary et al 2010) suggests that they are fulfilling objectives and producing the types of benefit that members expect from them. The personal gains for individual members provide a common focus within existing empirical studies, which have tended to emphasise the therapeutic effects of participation. However the current study is not primarily concerned with this aspect of groups except insofar as it produces repercussions within the broader community or on the evolution of the groups' structure, philosophy and perception of its locus in relation to public services. This section will therefore only provide an overview of the purpose and benefits of self-help groups.

In trying to ascertain self-help groups' aims it is often necessary to make inferences based on the reported outcome of groups as these are far more frequently discussed and are more extensively grounded in empirical data than questions regarding groups' purpose. Little UK evidence exists about founder members' motivation and aspirations upon instigating self-help groups (Munn-Giddings & McVicar 2006). This has contributed to the tendency to rely on

presumptions grounded in more structural social theories in order to explain the reason for the growth of self-help groups. A common contention is that such groups arise in order to provide a sense of community in response to the erosion and disintegration of traditional social systems (Damen, Van Hove, Mortelmans 2000, Adamsen & Rasmussen 2001, Hatzidimitritriadou 2002, Katz 2003-4) such as religion or the extended family; However there is evidence that self-help group founders and organisers are frequently active participants in other types of voluntary and social association (Munn-Giddings & McVicar 2006), suggesting the existence of persistent and strong, rather than eroding, social ties. This of course is illustrative of the difficulties involved in trying to unpick the aims and objectives of a complex social phenomenon and the fact that the purpose for something such as a self-help group rarely exists on only one level (Maton, Leventhal, Madara, Julien 1989, Melucci 1989). Group founders may indeed themselves have extensive social networks, but this does not necessarily tell us anything about networks at the level of the broader community or the group founders' beliefs about them.

Academic studies also frequently suggest that dissatisfaction with and mistrust of expert, professional services motivates many self-help groups (Kush-Goldberg 1979, Katz 2003-4, Baldacchino & Hussein Rassool 2006). However again this is not necessarily borne out by evidence that suggests frequent and growing alliances between self-help groups and public providers (Adamsen & Rasmussen 2001, Ben-Ari 2002). This kind of ambiguity is fairly typical of much of the literature that attempts to account at a broad social level for the existence of self-help groups. Groups are said to arise as a response to pervasive feelings of powerlessness and lack of control (Jason 1985, Katz 2003-4), yet are seen as a function of discourses of empowerment (Wann 1992, Dickerson 1998); they are sometimes seen as addressing a general loss of choice (Katz 2003-4) but at the same time as part of the consumer choice movement (Dickerson 1998, Hatzidimitritriadou 2002); they are supposedly a medium for promoting the idea of self – responsibility (Borkman 1999, Baldacchino & Hussein Rassool 2006) but are sometimes regarded as a key driver of medicalization and 'victim' status (Conrad 1974, Elsdon et al 2000, Barker 2002); they are believed to arise as an outlet for the type of public

disclosure typical of a 'talk show' media culture (Jacobs & Goodman 1989) but also to act as a foil to this type of inauthentic "post-emotionalism" (Borman 1999 p58, Kelleher 2001); and they are said to grow from the demise of religion (Katz 2003-4, Baldacchino & Hussein Rassool 2006) and yet evidence suggests that religious activity is a strong predictor of participation in voluntary associations (Davis-Smith & Hedley 1992).

This does not mean of course that broad structural or ideological factors play no part in the creation of self-help groups, but rather that care must be taken to ensure that presumptions about the reasons for the establishment of self-help groups are not simply perpetuated uncritically. These divergent views of why self-help groups arise also serve as a reminder of their diversity and the fact that researchers approaching different types of group from a range of academic fields and from various national contexts may come to very different conclusions about the reasons for their proliferation.

At a more tangible, individual level the objectives of self-help groups have been collated loosely into two categories; instrumental and expressive. In self-help literature this is usually conceptualised in terms of inner-focused and outer-focused groups (Rootes & Aanes 1992, Borkman 1999, Adamsen & Rasmussen 2001); the intention of the former being to cause an individual to change their own behaviour or attitude, whilst the latter intends to affect the broader society by challenging prevailing norms and values.

Self-help groups' most frequently cited purpose would fall into the inner-focused category. It entails group members' provision of mutual support, the appropriateness and unique value of which derives from their all having lived through similar experiences or situations (Wilson 1994, Nash & Paxton 2002, Munn-Giddings & McVicar 2006). Members express the need to simply be with people in the same circumstances in order to feel normal and to feel properly understood. This ability to empathise provides a sense of togetherness to counteract the feelings of isolation experienced after life-changing situations or difficult diagnoses. Instead of emotional, personal support some groups prefer to manifest this shared solidarity as less intimate social activity that still however, frequently results in real friendships or even occasionally marriage

(Ablon 1981, Radin 2006). In common to both types of group is the concurrent desire to use the understanding, normalising and safe environment of the group as a means of challenging the stigma with which their condition so often means they have had to live (Ablon 1981, Dickerson 1998, Williams 2004). This latter observation illuminates a number of issues about a self-help group's purpose. Firstly it can highlight the blurred reality that makes instrumental – expressive dichotomies seem too simplistic. Combatting stigma can clearly require changes in the way that individual members construct their identity and perceptions of themselves (Williams 2004). At the same time it poses a direct challenge to society's values. It also indicates the possible range of perceptions as to a group's purpose amongst different types of member – group leaders and long term participants probably being more likely than new members or those in acute crisis to see this type of long term strategy as a group aim.

In addition to support, sharing information is a key process that arises through members' common circumstances. The information sharing or "experiential social learning" (Borkman 1999 p42) that takes place within groups is grounded in large part on the members' own experience. Information is commonly about clinical matters which can focus narrowly on, for example, symptoms or treatments (Kush-Goldberg 1979, Coreil & Behal 1999, Radin 2006) or more broadly on learning to live positively with a condition. When coupled with the support that takes place, this information sharing is a key factor in one of the primary purposes of many self-help groups, that is, the development of coping strategies (Rootes & Aanes 1992, Gray et al 1997). Helping members to cope with their condition or situation also means that self-help groups have a role in ensuring they are able to get more from the 'system' and from their encounters with professionals, consequently groups are seen as a forum for education about navigating and more effectively accessing the labyrinth of health, social and welfare services (Munn-Giddings & McVicar 2006, Madara 2008). Again this could be seen in both instrumental and expressive terms; helping members to address professionals more confidently, but also changing the attitudes of professionals regarding the extent to which they respect the autonomy and competence of service users.

In order to fulfil these objectives self-help groups do not limit themselves to reliance solely on their own experiences as a source of knowledge. Many groups aim to "shatter the professional information monopoly" (Radin 2006 p591) and to create their own epistemological system (Williams 2004) that incorporates all sources of information that might be useful to their members' better coping – and that at the same time will ensure they are taken more seriously within the system and by professionals. Self-help groups frequently therefore invite expert speakers to meetings to provide the technical knowledge that would not otherwise be accessible to members (Wilson 1994, Nash & Paxton 2002). Acquiring and making use of this type of scientific knowledge is clearly a very significant part of how many self-help groups now see their purpose as entailing not just support, but also as an alternative source of expertise within the biomedical world (Williams 1989). This knowledge is frequently used to ensure that members can access the best and most cutting-edge treatments (Dickerson 1998). It is this mastery of technological developments that enables those groups that address new or unacknowledged health conditions to campaign, often successfully, to have them recognised by medical regulatory bodies (Barker 2002, 2008).

The increased knowledge and confidence that arise through participation in self-help groups are said to result in improved relationships between professionals and group members (Adamsen & Rasmussen 2001). This constructive rather than confrontational approach is indicative of the aim, which now appears to be held by many self-help groups, of working alongside, in complement to or even in partnership with public health and social care services (Stewart 1990, Emerick 1991, Ben-Ari 2002). Groups' goals frequently incorporate numerous ways of working with professionals; most commonly this entails having an input into professional training programmes (Maton et al 1989, Coreil & Behal 1999, Adamsen & Rasmussen 2001, Madara 2008) or attending consultation exercises. In addition they might work together to promote awareness of a condition amongst the general public or potential sufferers (Wilson 1994, Radin 2006). Indeed some self-help groups and medical professionals have even formed campaigning alliances in the face of increased bureaucratisation of and managerialism in health resource

allocation (Epstein 1995, O'Donovan 2007). This dovetailing of aims between medical institutions and self-help groups is also manifested through some groups undertaking, sometimes extensive, fundraising activities to support increased scientific research (Williams 1989, Kelleher 2001, Katz 2003- 4). Furthermore, self-help groups who see their purpose in terms of treatment and service provision appear to have begun, albeit not necessarily consciously, to perceive themselves as a component of, rather than mere complement to, the mainstream system. This is indicated by their desire to receive direct referrals from public health and social care agencies (Stewart 1990, Wilson 1994, Dunne & Fitzpatrick 1999) thus potentially positioning them under the aegis of state governance structures.

Self-help groups do not, however, always aim to operate from a position of cooperation within the system. Their input into debates surrounding service provision or policy spans a range from participation in state sponsored consultation and alliances with medical professionals through independent advocacy to outright opposition to the biomedical establishment (Emerick 1991, Buchanan & Walmsley 2006). For a minority of, mostly mental health, groups, the overriding purpose of the self-help 'movement' (Emerick 1991) is to create a space for radical opposition to dominant ideas, labels and practices (Chamak 2008). These groups see themselves as overtly 'anti-psychiatry' (Emerick 1991, Dickerson 1998, Crossley 2006) and hold this ideology as being so central to what they do that they may see non-oppositional self-help groups as entirely different entities to whom they also stand in opposition (Emerick 1991). In many ways they appear to be closer to social movement organisations than to typical self-help groups and in this they provide an interesting example of the blurred boundary between these types of association. Certainly they hold core aims such as empowerment, identity reconstruction and challenging negative labels that are usually associated with the former (Chamak 2008).

Less radical groups who engage in campaigning and advocacy generally tend to see this as secondary to their main purpose of providing support and information to members (Gray et al 1997, Borkman 1999, Elsdon et al 2000). Indeed this role sometimes evolves completely informally through the

activities of individual members rather than as part of the group's design (Radin 2006). The majority of less radical groups that engage in campaigning appear to do so with quite narrow aims, usually involving improved services for their membership constituency (Katz 2003- 4 Radin 2006). And some commentators feel that despite reference to self-help as a 'movement' (Emerick 1991, Steinke 2000) there is little evidence for most groups' wanting to be part of such an idea (Adamsen & Rasmussen 2001). However it may be that even these moderate groups can play a role in informing or increasing awareness of broader political debates, such as those surrounding the controversial areas of genetic screening or assisted dying, or aim to affect the negative, pejorative language implicit in much media coverage of populations perceived as stigmatised.

Any purposive association of individuals will, to some extent, be grounded in a system of normative values, however in many cases these will be presumed rather than overtly promoted as ideology. This appears to be the case with many self-help groups. Groups generally state their aims in the seemingly value-neutral terms of offering support, information or ways of coping. However the means through which this is done could be said to be grounded on a range of principles such as personal responsibility, confidentiality, solidarity and non-judgemental attitudes (Borkman 1999, Adamsen & Rassmussen 2001, Munn-Giddings & McVicar 2006), even if these are not expressly articulated group aims. Some groups however do openly espouse a value based ideology as intrinsic to their purpose. The most obvious example of this is with the '12 step' programmes such as Alcoholics Anonymous and Gamblers Anonymous that are more typical to the US rather than British conception of self-help. These groups promote a system of personal admission, responsibility and behavioural change grounded in rules derived from permitted texts – in effect advocating a type of spiritual approach to self-help. Groups may also overtly advocate more political ideologies as part of their purpose, for example those anti-psychiatric groups discussed above or groups espousing feminist ideals (Kush-Goldberg 1979, Borkman 1999) or challenging dominant labels and attitudes (Ablon 1981, Chamak 2008).

1.4 Outcomes and benefits

The majority of the literature that discusses the benefits of self-help groups entails small, qualitative studies that gauge members' own subjective feelings (Katz 1981). The lack of more generalizable quantitative data has led some to warn against imputing positive effects of self-help groups without further, more robust evidence (Bottomley 1997). However, as the main outcomes of self-help groups pertain to personal feelings, self-perception and identity the former methodology does seem to provide an appropriate measure of these groups' impact. Furthermore, despite their being small in scale, the numerous studies tend to be in broad agreement with, and can thus act as a means of validating, each other. The research almost unanimously report personal gains to members that derive directly from the purpose and objectives of groups discussed above, for example, decreased feelings of isolation, better ability to cope and a more positive attitude (Scanlon-Schilpp & Levesque 1981, Gray et al 1997, Williams 2004, Munn-Giddings & McVicar 2006). In addition groups' social activities result in friendship, marriage and other personal relationships (Ablon 1981, Docherty 2003, Radin 2006) that are clearly of the utmost significance to members.

Some of the most important and commonly reported outcomes of self-help groups may initially be unintended by-products of the group's supporting and educational roles, although in some cases, particularly in more mature groups, there will no doubt, have been contemplation of these benefits as forming part of the group's purpose. Increased personal empowerment (Kush-Goldberg 1979, Dickerson 1998, Cheung, Mok, Cheung 2005), one of the most important benefits in itself, is also seen to be at the heart of related gains such as better self-esteem and confidence, improved self-image and more positive, reformed, de-stigmatised identities (Ablon 1981, Cameron & Birnie-Lefcovitch 2000, Adamsen 2002, Williams 2004). These effects feed into a greater sense of independence and members' control over their own lives (Steinke 2000, Hatzidimitritriadou 2002) which in turn are factors in improved coping, with regards to both day to day living, as well as with members'

specific physical or mental condition (Hidlingh, Fridlund, Segesten 1995, Cameron & Birnie-Lefcovitch 2000). In addition participants report fewer incidences of stress, anxiety and depression (Trojan 1989). Similarly, this empowerment, effected through group support and information, derived from both peers and experts, is reported as resulting in the ability to obtain more value from interactions with professionals both in terms of members' personal conditions and through perceptions of having greater influence on policy and service provision.

As well as the qualitative studies of members' perceptions, Kryouz and Humphreys (1997) have reviewed larger quantitative and longitudinal research in which self-help group membership was tested against control groups. Their report on the effects of groups in nine areas (mental health, weight loss, addiction, bereavement, diabetes, care-giving, old age, cancer and chronic illness) found very similar benefits to those already discussed. Nearly all the research they reviewed reported improvements on self-esteem and independence as well as less incidence of depression and anxiety.

Kryouz and Humphrey's review also found that the research with mental health, addiction, weight loss and chronic illness groups suggested the potential cost effectiveness of using self-help groups as part of a treatment programme. In some cases this was due to self-help groups being as effective as professional services and in others because participation resulted in decreased use of publicly funded health and social care facilities. According to the findings they summarised, group members needed fewer hospital admissions, shorter hospital stays and even took part in less criminal activity and risk taking behaviour after their involvement with the group. These findings are supported by numerous qualitative studies that also report members' more efficient use of services (Trojan 1989, Borkman 1999) and decreased need for acute intervention; for example, Cameron and Birnie-Lefcovitch's (2000) study in which families' participation in self-help groups resulted in fewer children being taken into care.

The outcomes summarised by Kryouz and Humphreys clearly suggest repercussions beyond the group in terms of efficiency and resource allocation.

In addition their review supports the many qualitative studies that point to further extraneous advantages. Most immediately friends and family are said to benefit from better relationships with group members (Adamsen & Rasmussen 2001). Beyond this, the community at large is believed to be a beneficiary of the "network formation," (ibid p909), "social linkage" (Lieberman & Snowden 1999 p47) and social capital (Folgheraiter & Pasini 2009) that arise from self-help group activity (Rappaport 1994, Cameron & Birnie-Lefcovitc 2000). And these beliefs have probably contributed to the prevailing view of self-help groups as providing spaces for democratic participation in civil society (Damen et al 2000, Elsdon et al 2000, Hatzidimitritriadou 2002). As will be discussed in subsequent sections, making this kind of broad inference from the available data requires caution; however, those outcomes said to derive from self-help group participation such as the development of organisational skills (Elsdon et al 2002, Madara 2008), knowledge of the administrative system (Gray et al 1997), the adoption of an expanded worldview (Folgheraiter & Pasini 2009) and a positive impact on labelling and identity achieved through the development of a collective voice (Williams 2004, Kam Pun Wong & Fong Chow 2005) are all factors that are generally agreed to as being essential to a healthy civil society.

1.5 The use and extent of self-help groups

Literature from international sources including the USA, Scandinavia and the UK are in broad agreement that there has been a large increase in the number of self-help groups and their membership in recent decades (Elsdon et al 2000, Hatzidimitriadou 2002, Munn-Giddings & McVicar 2006). However, ascertaining self-help group usage is notoriously difficult particularly in the UK where the only city which has an official 'clearing house' or agency dedicated to supporting and collating information about these groups is Nottingham. Indeed even in America, where clearing houses are far more widespread, Lieberman and Snowden (1999) have stated that a lack of good quality empirical data about self-help groups means that even broadly estimating the numbers involved is difficult. The very nature of many self-help

groups means that research is beset by methodological difficulties (Goldstrom, Campbell, Rogers, Lambert, Blackow, Henderson, Manderscheid 2006). Firstly there will always be groups that "[do] not want to be found" (ibid p99) and thus remain beyond the reach of academic interest or official statistics. Secondly groups' reliance on key members or group leaders can mean that when the leadership changes researchers can lose contact with the group (ibid). In addition a lack of definitional uniformity (Jacobs & Goodman 1989) means that different studies may not be comparing like with like, and that some groups that some authors would define as self-help groups may be omitted by others, and similarly some groups widely regarded as not coming within the definition of self-help may choose to call themselves such (Elsdon et al 2000) leading to groups being erroneously included in counts.

Having said this, recent years have seen a growth in the body of literature about self-help group membership (Lieberman & Snowden 1999, Goldstrom et al 2006). This includes Elsdon *et al's* 2000 study that estimated that there were over 23 000 groups in the UK with a membership of more than 1500 000. Furthermore he projected a subsequent growth rate of 9% per annum. However, these figures must be treated with caution as his study was based solely in Nottingham and his findings then extrapolated to provide national estimates. And it is likely that Nottingham, as the only locality with a dedicated clearing house that helps self-help groups become established and supports them throughout their existence, would be unrepresentative of the UK.

There is some ambiguity about the characteristics of self-help group members both in the UK and internationally. A number of authors such as Barnett, Barnett, Pearce and Howes (2006) in New Zealand and Katz (1981) in the USA suggest that self-help groups tend to be used by the middle classes. Lieberman and Snowden (1999) and Jacobs and Goodman (1989) suggest that income levels do not seem to be as important as education levels in predicting self-help group membership – with usage higher amongst the more highly educated. Borkman (1999) however, disputes this stating that self-help groups are used by all socio-economic groups. Elsdon *et al's* study which is based on

the biggest sample of any UK research supports the former view, finding that self-help groups are rarely used by social groups D and E.

There is also uncertainty about the nature of members' existing social networks. If self-help group membership is disproportionately from higher social and educational classes this would suggest stronger social networks and this is backed by Hidlingh et al (1995) who found that self-help groups tend to be used by more sociable, extrovert individuals who similarly tend to have stronger and more extensive social networks. Similarly Munn-Giddings & McVicar (2006) found that many self-help group members have participated previously in other voluntary activities, which suggests pre-existing social ties. However, Adamsen and Rasmussen (2001) believe that self-help group members tend to be those who are ostracised from other social networks – and, as previously discussed, a number of authors see the growth of self-help groups as being caused by a breakdown of social networks (Cameron & Lefcovitch 2002, Hatzidimitriadou 2002, Katz 2003-4). It should be noted that these authors generally do not support their claims with empirical data – however, Lieberman and Snowden's (1999) study that found the divorced to be highest users of self-help groups could be used to support their view.

Unsurprisingly there has been little demographic breakdown of UK self-help group membership and so the knowledge we have about the make-up of groups is patchy. Elsdon et al found an overall ratio of approximately 1:2 men to women, although in small groups this decreased to 1:3. Munn-Giddings & McVicar on the other hand, found that 40% of the members of the carers groups they studied were male. The analysis of Self Help Nottingham's closed group database found that there were more than six times the number of women's groups than men's groups in operation and that the latter were significantly more likely to fold in their first few years (Chaudhary et al 2010).

In terms of the age groups of members, Elsdon et al found that whilst the most frequently occurring groups had a mixed age range, the reality within these groups was that most of the members were over 55. The second most frequently occurring age range was groups with a membership wholly over 55. This information was not available in the closed group analysis; however, it is

significant that within that sample the second most frequently occurring type of group was for parents, accounting for 18 per cent of groups, which suggests the likelihood of a significant proportion of younger participants, at least in certain types of group.

There is a common perception of self-help groups as predominantly white (Coreil & Behal 1999, Gosine 1999, Lieberman & Snowden 1999) and as underused by ethnic minority communities. However, again, the evidence for this is inconclusive and this may, in some part, be related to questions surrounding the definition of self-help groups. It has been suggested that, whilst self-help activities may be the most popular form of voluntary activity amongst black people (Obaze 1999) and can have very beneficial outcomes within such populations (Gosine 1999), the title 'self-help' is not popular in many ethnic minority cultures where it is seen as undermining their more collective, community based ethos (Ben-Ari 1998, Avis et al 2008). Ethnic minority groups may therefore be in operation in a guise that plays down the 'self' and reflects this communal focus. Furthermore Avis et al found that these groups may prefer to define and name themselves according to the activities, such as cooking or sewing, that are undertaken within the group. These differences may thus result in ethnic minority groups being omitted from the data on self-help group usage. Within Self Help Nottingham's database of closed groups 66 groups out of 936 were exclusively for ethnic minorities. And in fact black groups were found to be more likely than any other category to survive into maturity beyond their first few years and become fully established (Chaudhary et al 2010).

Separate questions are thrown up with regards to the ethnic variety within non-exclusive self-help groups. But again there is little firm information about these groups' demographic mix. Munn-Giddings and McVicar's paper (2006), one of the few recent UK studies to address this issue, cites the uniformly white membership of the groups that were studied, but acknowledges that this may simply be a reflection of the make-up of the local population.

2 The theoretical contextualisation of self-help groups

Introduction

The current chapter is divided into three main parts the overall aim of which is to provide an introduction to the theoretical conceptualisation of self-help groups and to indicate how the thesis intends to build on this.

It begins with an overview of the analytical approaches that have been employed within the current self-help group literature. The bulk of work in this field has adopted an individual, therapeutic model; however, a minority of authors has always engaged with groups in more community orientated terms, exploring them as a form of voluntary association, as constituents of social capital networks and, most importantly, with respect to the concerns of the current thesis, as a type of normative community whose culture is a product of the group's narrative resources. It is the possibility of such community focused roles that has resulted in a range of authors beyond the field of self-help postulating these groups as key providers of civic spaces in which democratic participation and debate is enabled.

The chapter then provides a brief introduction to the growing body of 'health citizenship' theory, the purpose of which is to conceptualise health policies, communications and behaviours in terms of their effects on democratic activity and institutions. An overview of the political origins of this field is presented in addition to its central academic concerns, perhaps the most important of which is the development of the theoretical tools as well as an adequate body of empirical evidence that will allow for clearer differentiation between the different organisations that operate within it. The discussion then moves on to an examination of the place that self-help groups have been seen to occupy within this literature, with particular emphasis on the ambiguity around their relationship to social movements. It identifies a number of analytical concepts, many of which originate in the work of Jurgen Habermas, which can help to address this lack of clarity.

The final section provides a detailed account of Habermas' key ideas and justifies their relevance to the analysis of self-help groups as well as to the advancement of health citizenship theory. The main focus is on rational "communicative action," that is, the form of inclusive, egalitarian dialogue about issues of public concern upon which, according to Habermas, democracy depends; personal autonomy in the private sphere or "lifeworld;" and the communicative relationship between the lifeworld and the institutional sphere of relationships that Habermas terms the "system."

2.1 Overview of theoretical approaches

Since the 1970's when self-help groups began to develop into the current single issue, health focused form in which we most commonly see them today, their theoretical conceptualisation has been somewhat limited and attempts to broaden the range of explanatory frameworks has been sporadic (Katz 1981 Adamsen & Rasmussen 2001). In their early years there were only occasional attempts to contextualise self-help groups within sociological or organizational models (ibid). And whilst some early explanatory concepts, such as Reissman's "helper-therapy principle" are still widely used today (Borkman 1999 p91) there has been relatively little progress; theoretical understanding of self-help groups still being seen as under-developed, given the scale and continued growth of the phenomenon (Borkman 1999, Elsdon et al 2000).

Analysis of self-help groups has tended to approach them from a therapeutic or human services perspective (Jacobs & Goodman 1989, Rappaport 1994, Hatzidimitritriadou 2002). According to this view self-help groups are understood as part of an individual's treatment and as an alternative to professional health and social care services (Rappaport 1994, Adamsen & Rasmusen 2001). A number of implications arise from studying groups in this way. Firstly it encourages a single level understanding of how groups work, the main outcomes being understood in terms of clinical or psychological benefits to individual members (Hatzidimitritriadou 2002), with little ability to

account for broader effects at a societal or community level (Rappaport 1994, Steinke 2000), such as their impact in civil society or on democratic institutions (Borkman 1999). Secondly, the methodologies typically employed in this approach tend to result in groups being judged according to criteria, such as efficiency and clinical outcomes, usually associated with, and far more appropriate to, professional services (Rappaport 1994, Kryouz &Humphreys 1997, Kelleher 2001). The use of such methodologies and frameworks, grounded on dominant, professional paradigms, has often meant that self-help groups have simply been seen as "second rate" service providers (Rappaport 1994 p121) with the unique benefits that accrue to members and the broader community being devalued or ignored. Furthermore framing self-help groups as a type of treatment programme or service provider runs the risk of perpetuating their professionalization as funding agencies and practitioners come to expect them to operate in line with professional "ways of thinking" and working (ibid 118)

Although individual and treatment perspectives are clearly not without value in contributing to the understanding of certain aspects of groups, the range of questions they are able to address is limited and hence they can only ever, at best, provide a partial picture. A number of researchers have thus attempted to expand the scope of self-help group theorisation by adopting concepts that can account for groups as components of broader social networks that make up the 3rd or voluntary sector, thereby locating them in relation, not only to public health providers, but also to a wide range of associations, including clubs, charities and political parties (Borkman 1999, Karlsson et al 2002). Self-help groups have thus been shown to function in dynamic relationships with the particular circumstances, practices and ideologies that operate in the communities from which they arise (Maton et al 1989, Karlsson et al 2002). By postulating groups as social networks embedded in local communities and cultures these authors have been drawn towards asking questions about the evolution of groups' structures, leadership models and inclusivity, the ways that these organisational features affect the evolution of the groups' values, ethos and ideology and how these in turn feed back into groups' local cultural context. Such a view of self-help groups has led to their being explained in

terms of their contribution to social capital (Folgheraiter & Pasini 2009), and their analysis in the light of commonly used indicators of social capital, such as personal empowerment, toleration of diversity and community participation has resulted in a generally very positive view of their role as drivers of network formation and as "social linkage systems" (Lieberman & Snowden 1999 p47, Cameron & Birnie-Lefcovitch 2000, Baldaccino & Hussein-Rassool 2006).

It should be noted however, that not all authors share this positive view of self-help groups. For example, Zygmunt Bauman (1999) sees these groups as contributing towards a retreat from community life, as part of a culture in which people focus increasingly on their own narrow concerns (Marcello & Perrucci 2000) and where problems and fears are removed from the public sphere and addressed solely in private spaces.

The analytical focus of network, voluntary action and social capital theories, for example on groups as sites of norm creation and network formation (Coleman 1988), is indicative of a concern that is common to all the broader, community based approaches to the study of self-help groups. This is their preoccupation with processes rather than tangible, measurable outcomes, and it is this which most emphatically distinguishes them from treatment perspectives. Of particular interest to the current thesis are those studies that focus on processes of communication taking place within groups - these discursive practices are seen as the means through which groups develop their identity as normative, value based communities (Borkman 1999). Such theorists argue that groups, through a process of reflexive dialogue, are able to transform members' personal stories into a collective, social narrative in which meanings are created and needs and solutions to members' problems are articulated or reframed (Rappaport 1994, Borkman 1999). Borkman (1999 p16) refers to this process of collective reflection as a form of "communal learning" that is generally seen as grounded on the type of "collective experiential knowledge" that is qualitatively different to both professionally derived information and an individual's "idiosyncratic interpretation" of their own subjective experience.

These narrative theories are especially illuminating as they allow for movement between different analytical levels - the personal stories and collective narrative both changing and being changed by each other. Such exploration of the communicative interplay between individual and group invites us to account for self-help groups in terms of individual and collective identity formation, both of which are believed to be perpetuated through the development of social narratives (Habermas 1989, McAdams, Josselson, Lieblich 2006). From such a perspective groups come to be seen as active producers of their own, unique normative cultures and in turn this encourages the use of methodologies that aim to uncover members' "views of themselves" rather than "our views of them" (Rappaport 1994 p120) which inevitably occurs, due to the epistemological dominance of mainstream, bio-medical paradigms, with those adopted by human services or treatment frameworks.

Of course concepts such as empowerment, identity and network formation are not exclusive to one theoretical area. Consequently achieving nuanced understanding as well as analytical clarity is complex. Ideas within ostensibly quite distinct frameworks will frequently blur, overlap and causally affect each other. For example the development of group norms and values is conceived as a fundamental characteristic of both social capital formation and new social movement establishment (Coleman 1988). The norms that emerge are seen as making up the social capital that is created within a nascent social movement, the existence of which will itself feed back into a community's stock of social capital, which would in turn contribute to the likelihood of its giving rise to social movements.

Anthony Giddens amalgamates many of these ideas in his discussion of self-help groups in the context of "radicalised modernity" (Borkman 1999 p61). This notion of modernity entails the creation of spaces in which identity can be reconstructed and new types of community built through a reflexive engagement with dialectically related frameworks such as; personal trust and impersonality; and abstract systems and day to day knowledge. The negotiation of this type of dichotomy, through their necessary engagement with bureaucratic, scientifically grounded services coupled with the authentic, personal relationships within groups, appears to play a significant role in how

self-help group members experience and address the life-changing situations they have undergone. Giddens (1994, 1998) refers to the principles and activities of community based self-help as an important driver of his "third way" philosophy. Small, grassroots associations are seen to be a key element of a society's civic richness through their contribution to community level support networks and social capital stocks. These support networks act as forces for democratisation by opening up spaces for public debate that provide the opportunity for citizens to challenge accepted, dominant forms of knowledge and to collectively reflect on questions of identity such as 'how we should live' in a complex modern context. Furthermore with the egalitarian internal structure that they are presumed to display they provide a living example of democratic praxis which can serve as a model for and thus infiltrate the wider community. This habitualisation of democratic behaviour that arises from structural forms grounded on the negotiation of collective identity and that is believed to provide the basis for self-help groups' civic role, is a central theme of both Habermas and new social movement theorists and will be examined more fully below.

The view of self-help groups as driving civic behaviour is also found within much voluntary sector literature and policy commentary which commonly portrays self-help and mutual aid as the most appropriate tool with which to effect democratic regeneration in today's society (Harris 1998, Nash & Paxton 2002, Daly & Howell 2006). A stronger focus on the principles of self-help is deemed necessary to counteract the perceived decline in the civic effects of traditional voluntary sector organisations (Hedley & Davis-Smith 1992, Whelan 1999, Fyfe & Milligan 2003). However, it should be noted that these claims are made largely without the support of either empirical evidence or thorough theoretical analysis and that their authors have given little consideration to the ways in which the abstract principles on which they believe self-help to be based, such as egalitarianism or inclusivity, actually manifest in practice within groups. Likewise they have no framework against which to differentiate between self-help groups with different aims, methods or structures.

2.2 Health citizenship

A small number of authors have however begun to undertake detailed analysis, occasionally coupled with empirical study, in order to develop a democratic theory of self-help groups that is able to properly account for their contribution to the regeneration of the public sphere (Kelleher 2001, Scambler & Martin 2001, Scambler & Kelleher 2006). This work relies heavily, but not solely, on Habermasian ideas about identity, unconstrained communication and personal autonomy as the ways in which self-help groups can affect discursive processes in civil society. These concepts will be dealt with more fully below as part of the discussion of Habermasian theory. However an outline of these authors' main propositions will be included at this stage, as a central part of their work involves the conceptualisation of self-help groups as a type of new social movement; and the theorisation and classification of new social movements is a core concern within the burgeoning field of "health citizenship" (Zoller 2005 p341).

Reviewing the literature in this area presented a challenge due to the blurred conceptual boundary that exists between self-help groups and other types of lay and member-led health organisations such as health social movements, patients' groups and service user groups. However as the thesis is concerned with those more outer-focused aspects of self-help groups, such as their involvement in consultation and advocacy, which are typically associated with these other types of health citizenship organisation it was necessary to include literature that was primarily located in this broader field. The aim of the literature review was to study a wide enough range of this work to provide a good understanding of the types of activity in which these categories of organisation were participating and to be able to make comparisons between them and self-help groups. However as the focus was primarily on the latter I did not engage with these bodies of literature to the extent that I did with that of self-help groups.

There were two strands to my literature review strategy in these areas. Firstly, I conducted electronic searches of relevant terms, including 'new social movement,' 'public and patient involvement' and 'mental health user group.' I

then followed up the studies that the initial searches threw up with a more incremental approach, accessing referenced papers that seemed to be most relevant to the particular focus of the thesis.

The subject matter of this growing body of literature overlaps extensively with that of the current thesis and it shares much of its conceptual focus. It thus provides the opportunity to enhance my findings by giving a broader context within which they can be located. At the same time the current research provides empirical data, which is acknowledged to be greatly lacking in this field (Scambler & Martin 2001, Dahlgren 2002, Zoller 2005), against which its propositions can be more thoroughly tested.

The policy context of health citizenship

Academic interest in linking health behaviours with democratic activity reflects concerns at the political level, where, over recent decades, there has been a pervasive belief that civic engagement has been in decline (Habermas 1989, Alexander 2006, Daly & Howell 2006) and that a broad range of social problems, from community dysfunction to voter apathy, are symptoms of this trend (Anheier 2004, Rogers 2004). Such views are apparent in the constant stream of cross-party rhetoric in which notions of 'democratic renewal' and 'citizenship' have been heralded as being in urgent need of action by successive governments (Rogers 2004, Williams 2004, Daly & Howell 2006). This political attention has grown in parallel with the philosophical position that holds that the concern of Western political economies has been moving away from broad emancipatory and redistributive questions, towards a focus on individual identity, ways of living and personal services (Giddens 1991, 1998). The perceived need for democratic regeneration, within the context of such "life politics" (Giddens 1991 p228) has stimulated a search for new channels through which citizenship and democracy can be bolstered and the public sphere revitalised. Whilst activities, notably participation in charitable organisations, which have traditionally been seen as supporting civil society, are deemed to have largely lost their ability to fulfil this role (Nash & Paxton 2002, Lewis 2005), a plethora of government policies has been initiated as a means of countering this trend (Daly & Howell 2006).

The common thread running through these policy agendas is the broadly cast aim to "encourage citizen engagement" in order to "revitalise democracy at the neighbourhood level" and thereby "build democratic renewal at the national level" (Blears cited in Rogers 2004 p. ix) through civic action within the community. And the methods through which these aims are to be achieved frequently entail ideas and practices that operate at the heart of self-help (Bowles 2010). Initiatives ranging from the voluntary sector Compacts in the 1990's to the Coalition's Big Society are, at least according to the rhetoric, grounded in the core idea of encouraging local, grassroots, associational activity (Daly & Howell 2006, Parry, Alcock, Kendall 2010). This activity can take a number of forms in order to produce various outcomes, the most prominent of which are citizen participation in decision making and governance processes, and voluntary and community groups' increasing role in service provision (Daly & Howell 2006, Hewes, Buofino, Ali, Mulgan 2010).

Health policy

Within this broad policy agenda there has been a growing tendency to make explicit links between health behaviours and citizenship, and consequently, in using health policies to address the dual aim of improving health whilst at the same time stimulating democracy (Baggott 2011). This emphasis on health as a catalyst for civic activity brings these policies even more explicitly into self-help group territory. At an individual level, initiatives such as the personalisation of health and social care budgets and the Self Care programme purport to recast the identity of the 'patient' as an active agent, in control of the management of their own condition. Through actively taking control of their treatment, it is suggested they will be empowered to take greater command over their lives and hence be better equipped to contribute within the civic sphere (DH 2006a,b, Daly & Woolham 2010). The Self Care and Expert Patient Programme also promote participation at a more collective level through their emphasis on peer led training courses and community based services. Through these they offer opportunities for both voluntary activity and also for peer based sharing of information and experiential knowledge. Their outcomes are thus articulated not only as affecting individual health, but also in civic terms whereby it is claimed that involvement in such programmes can

result in enhanced citizenship through which "socially aware individuals contribute to community action because the health of all is a public good" (Greenhalgh 2009).

Successive governments have promoted the idea of community, and particularly patient, involvement in decision making through participation in consultation forums, planning processes and Public and Patient Involvement initiatives (DH 2006a,b, Mold 2010, Baggott 2011). Such processes are said to contribute to civic renewal through giving individuals and communities a greater say in services and processes that affect their lives (Daly & Howell 2006). Unsurprisingly these procedures have made use of self-help, service user and patient groups as a convenient means of obtaining lay input into their discussions (Hodge 2005, Godin, Davies, Heyman, Reynolds, Simpson, Floyd 2007, Baggott 2011). Similar claims are made about the civic impact of the diversification of service provision through the use of third sector organisations in service delivery, and again this is an area in which it is believed self-help should play a key part (Daly & Howells 2006, Bowles 2010).

Effects of policies

Whilst these policy developments undoubtedly appear to open up new opportunities for self-help and other types of health group, they may also bring certain risks in terms of groups' impact in the public sphere. On the positive side, agendas such as the Expert Patient and Public and Patient Involvement might serve to legitimize peer support and lay knowledge and thus enhance perceptions of the value of self-help groups. However, in being brought under the aegis of the state, it is possible that the concepts, language and practices of self-help can be coopted to further the government's own agenda and in doing so emasculate the voice of lay health groups. Such a process has been observed as having undermined the autonomy of the US service user movement (McLean 1995).

Recasting self -help groups as an integral part of public provision raises a number of fears that are widely believed to have come about within the UK voluntary sector, affecting the latter's ability to meaningfully promote

citizenship and contribute to civic dialogue. Through the dependence on state funding that their role as service providers has necessitated, these organisations are said to have become increasingly homogeneous, reluctant to engage in activities that challenge the status quo and susceptible to demands for accountability and preordained performance outcomes that diminish their autonomy (Hedley & Davis-Smith 1992, Fyfe & Milligan 2003, Lewis 2005). It is in response to the risks that arise from this policy agenda, and as a means of disentangling its rhetorical claims from its actual effects, that theorists have begun to advocate the practical application of Habermasian ideas to policy and practice evaluation. Concepts such as communicative action, ideal speech and deliberative democracy, all of which are discussed below, have been used over recent years as analytical tools with which to uncover hidden and overt cooptation, true levels of representativeness, and impediments to inclusivity in public engagement initiatives and health and social care policy more broadly (Houston 2002, Hodge 2005, Godin et al 2007, Hayes & Houston 2007).

Overview of the scope of health citizenship

It should be noted that whilst it is used by some commentators (Zoller 2005), there is no accepted body of theory unified under the heading of 'health citizenship.' The term was chosen as that which it was felt best describes the growing academic interest that mirrors the political trends referred to above. The term is used to encapsulate the increasing number of studies that equate health focused activity with democracy, and citizenship with patienthood. Its subject-matter includes the array of organisations that mobilize around health issues and are said to play a democratising role at the political level (Brown et al 2004, Blume 2006, Chamak 2008). These organisations are defined as belonging to numerous categories including 'embodied health movements,' 'health activism' 'health consumer organisations' and 'self-help groups.' They have a range of immediate aims including the provision of mutual support, service delivery and influencing policy; and they employ a variety of practical methods in order to attain these ends. However, they are all stated to be grounded in shared values, including egalitarianism and inclusivity that give rise to common processes of grass-roots participation, deliberative democracy and self-help (Jones, Baggott & Allsop 2004; Zoller 2005, Landzelius 2006).

That any political activity undertaken through these organisations arises in response to concern stemming from the individual body and participants' exclusive focus on their own health condition raises questions about whether these democratising claims have been accepted too readily. At first sight they appear to sit uncomfortably with the Habermasian requirement (discussed more fully below) for civic communication to be grounded in a concern with universal issues. Indeed even critics of Habermas' emphasis on 'the universal' acknowledge the need for "enlarged mentality" (Benhabib 2002 cited in Karppinen, Moe, Svensson 2008 p11) in democratic discourse, in which the effects on and views of others are taken into account in the course of civic conversations. And it could be argued that this is unlikely to take place in organisations with a singular focus on their own condition. Those who defend the civic status of these types of association however, claim that the health related causes that they adopt incorporate the gamut of "pressing political concerns of our day … [such as] debates concerning rights and responsibilities …[and] the linkages between citizens and governance" (Landzelius 2006 p529). Similarly, in their resistance to negative labels and stigmatised identities (Hodge 2005, Chamak 2008) health focused groups are believed to contribute to broad questions of power, social justice and inclusivity that are relevant far beyond members' own condition or situation (Epstein 1995).

Classifying health citizenship organisations

A wide variety of health based organisations are believed to provide the opportunity for active civic participation and the promotion of citizenship. This includes new social movements (Kelleher 2001, Brown et al 2004), health consumer (Jones et al 2004), service user (Hodge 2005), health advocacy (Zoller 2005) and, at times, self-help groups. Due to their extensive similarities and overlapping aims and methods there is little clarity or agreement as to where the boundaries between these groups lie or regarding their relative contributions to democratic discourse. Consequently the main focus of much of the literature is on the development of new theoretical tools which can account for the similarities, differences and unique effects of different types of association (Brown et al 2004, Zoller 2005, Blume 2006, Landzelius 2006, O'Donovan 2007). In order to do this, most commentators advocate the use of

an eclectic approach to theory building, borrowing from many of those frameworks discussed above, such as social capital, organisational, social movement and Habermasian, that have begun to be employed in the study of self-help groups.

Despite the use of theoretical models that have been shown to be relevant to the explanation of self-help groups, as well as broad agreement that health citizenship organisations are grounded in characteristics and values typical of self-help, such as shared personal experience, mutual aid and identity reconstruction (McLean 1995, Crossley 2006) there is disagreement as to the extent to which self-help groups are deemed to act as health citizenship associations. The lack of clarity regarding the role played by self-help groups may owe something to the tendency in some literature to define a whole range of health citizenship organisations as types of social movement and to explain them in terms of social movement theory. Yet there appears to be some unease about the extent to which such terminology is able to capture the essential characteristics of self-help groups. It should be noted that this is not the case for all authors, with some being happy to use the titles 'self-help group' and 'social movement' interchangeably (Katz 1981, Troman 2003, Chamak 2008) even at times conflating them into 'self-help movements'. These authors' definition of self-help groups / social movements entails a role in "challenging extant authority" and a shift "from self-blaming to structural blaming, from victim-blaming to system blaming" (Chamak p76). As such they are clearly being credited with a political element that acts as a means of converting an individual's sense of misfortune into a collective sense of injustice.

For others however self-help groups are perceived as an evolutionary stage on the way to becoming a new type of organisation that "surpass[es] the scope" (Epstein 1995 p427) of traditional self-help groups, such as a social movement, health consumer or activist group (Zoller 2005, Blume 2006). This view implies that at the stage of operating as a 'pure' self-help group they may lack some characteristic that is possessed by fully fledged health citizenship associations. This deficit has sometimes been conceptualised as the absence of a "politicised" dimension that is "linked to a broader social critique that views structural inequalities … as responsible for the causes and / or triggers of the

disease" and results in individuals who "no longer focus primarily on treatment access [and] support groups but on seeking structural change" (Brown et al 2004 p60-61).

The lack of clarity around the relationship of self-help groups to social movements is indicated by the fact that whilst Brown et al themselves see self-help groups as lacking the "politicised collective identity" (ibid) that is at the heart of their model of "embodied health movements," (ibid) Scambler and Kelleher (2006 p227) refer to self-help groups as "amongst the most radical of NSMs in the health field … [that] approximate most closely to Brown and Associates' (2004) ideal of EHMs."

In an attempt to account for both their differences and extensive similarities Kelleher (2001) offers a compromise. Whilst he sees self-help groups as social movements this is only in limited ways, meaning that they are better defined as "part of the culture of new social movements" (p138). His conceptualisation of self-help groups draws heavily on the work of Habermas as well as on social movement theorists such as Offe and Melucci. And his construction of self-help groups as new social movements and the political role they thus play certainly seems to resonate on a number of levels with what is known about self-help groups in the UK.

Following White, Kelleher sees Habermas as providing the best framework for understanding the democratising behaviour of new social movements / self-help groups in terms of their defence of the lifeworld against its colonisation by the system, and groups' consequent effects in ensuring the lifeworld is able to maintain its "socially integrative functions" (p122) of creating and communicating values and identities. Through such strengthening of lifeworld autonomy individuals are able to legitimise their experiential knowledge and incorporate their illness into the context of their whole identity, rather than allowing it to be subsumed under the technical aspects of their condition. At a broader level, self-help groups' 'political' nature reflects that which is typically ascribed to health social movements, in that they are said to act as sites of resistance to medical power, from which to mount challenges against "the individualisation of disease and the power of professionals" (Vincent 1992

cited in Kelleher 2001 p131). However despite the undoubted value of Kelleher's work in furthering understanding of self-help groups' role in bolstering the lifeworld and sustaining the public sphere through providing the conditions for communicative action and identity creation, the reasons for their distinction from, or being seen only as a limited form of new social movements remain obscure. Self-help groups, he suggests, do not fully qualify as new social movements as they are "not political" except in oblique ways (p138) and yet he concedes that neither are health social movements political "in a direct sense." (p122)

A couple of possible, and perhaps related explanations for the lack of clarity regarding the conceptual boundary between self-help groups and new social movements, and in terms of self-help groups' particular contribution to civic discourse suggest themselves from the available literature. Firstly, the range of organisations under discussion may simply be too wide to allow for generalisations. Much of the literature in this field moves freely between, on the one hand, discussion of global, anti-capitalist type movements, national or international environmental movements, or large, overtly political movements such as the main AIDS organisations in the USA, and on the other hand, 'self-help groups' (Scambler & Kelleher 2006). And from what is known about the latter in the UK, from studies such as Elsdon *et al's*, or from agencies such as Self Help Nottingham, these will often bear very little obvious similarity to the larger, more overtly political associations, in terms of their immediate aims, structure, activities or ways of communicating.

Further evidence of this conceptual disparity arises through the frequency with which new social movements are said to be grounded in "the culture of challenge" mobilising around "conflictual issues" and using "frequent … forms of protest" – (della Porta & Diani cited in Scambler & Kelleher 2006 p 220). They are similarly said to mobilise transnationally, forming broad-ranging alliances united by a critique of economic growth (Scambler & Martin 2001) none of which seem to reflect the priorities of self-help groups. If self-help groups are therefore to be attributed with a role in the public sphere it seems necessary to theorise it according to different parameters that those that are used in accounting for new social movements'. The reason for collapsing

conceptual categories in this way may lie in part with the dearth of empirical research - especially at the small, local self-help group end of the spectrum - which has adopted the frameworks of deliberative democracy, collective identity or the public sphere. This may have resulted in certain classes of group being squeezed into models empirically tested on very different types of organisation.

Scambler and Kelleher (2006) and Scambler and Martin's (2001) analysis of the spectrum of 'sectors' that constitute the lifeworld offers an interesting and potentially useful tool with which to begin to unpick this issue and gain a more nuanced explanation of the particular ways in which this vast range of associations is able to sustain communicative action in the public sphere. They draw a path from the 'enabling' sector, in which needs are initially identified and articulated, through the 'protest sector,' in which social movements take up these needs, in order that they can then be transmitted to the attention of governments in the institutionalised section of the public sphere. They refer to the former sector as including "families, pubs and other meeting places" (Scambler & Kelleher 2006 p222) and the latter as populated by new social movements. There are currently few data available that allow us to locate self-help groups on this spectrum, but the findings in the current study aim to go some way towards doing this.

One area in which there appears to be a particular lack of empirical research and yet which is of fundamental importance to understanding self-help groups or new social movements in terms of both communicative action (Habermas 1984, 1987) and collective identity (Melucci 1989, Habermas 1989, 1996), both of which are discussed at length below, is with respect to their internal, organisational structure. Although frequent references are made to the non-hierarchical nature of self-help groups / new social movements and the democratic nature of participation within them (Zoller 2005, Scambler & Kelleher 2006) little evidence is available with which to substantiate these claims. And yet Melucci (1989 pp 45, 60) in particular emphasises the essential function of groups' structural forms as "constitutive parts" of their substantive purpose and methods and the networks of relationships to which they belong. Furthermore a properly collective identity can only be formed

through the process of open, unimpeded "negotiation and renegotiation" (p44) that, like Habermas' communicative action, includes all interested parties within the conversation. Asking questions about the extent to which health citizenship associations' structures promote this type of inclusivity and participation within collective negotiations may also help to produce a richer understanding of the variety of ways in which different organisations promote, or indeed impede, democratic behaviour. And again this is something, with respect at least to self-help groups, to which it is hoped the current findings will be able to contribute.

2.3 The Habermasian perspective

The thesis aims to build on the small number of studies that have made use of Habermasian concepts in order to construct a democratic theory of self-help groups' impact in the public sphere. In doing this it is, prima facie, accepting the continued relevance of Habermas' ideas as a means of both theoretically accounting for modern social phenomena and, at a more practical level, evaluating social policy and public service practices. Having said this it is acknowledged that numerous criticisms have been levelled against his work over the years, and so the justification for these critiques will be considered in the course of its discussion and they will be taken into account where they suggest inconsistencies in his position or appear better able to make sense of the data. Similarly the findings themselves may be used as a means of critique where they reveal shortfalls in the explanatory potential of Habermas' framework.

This section will provide a brief explanation of the main concepts used in the analysis; namely; communicative and strategic action and rationality; consensus and collective identity; and the system and lifeworld dichotomy, that are key to understanding an association's democratising effects. It will exemplify these by reference to the existing self-help group literature and the current health and social policy context.

2.3.1 System and lifeworld

According to Habermas the closely related concepts of civil society and the public sphere constitute a part, albeit an institutional one, of people's private relationships, alongside family and friendships, that form what he referred to as the 'lifeworld' (1984, 1987,1996). This is contrasted with the 'system' that comprises the formal political and economic spheres of activity. The components of civil society and the public sphere, as well as the democratic processes that take place within them, cannot be "manufactured" (1996 p364) through system interventions but rather must emerge "more or less spontaneously" (1996 p366) through individuals' private communications. It is through such unimpeded dialogue and the free flow of ideas within the lifeworld that individuals are able to develop the moral agency, autonomy and unique, individual voice that allows ideas and opinions formed therein to become politicised through people's coming together into, and interacting within, associations in civil society. It is essential therefore that system and lifeworld maintain some degree of separation (1989, 1996), as, without defending its independence, the lifeworld will inevitably, due to the far greater power of the system, be encroached upon and 'colonised' by it. Such colonisation results in domination by the impersonal, technical, bureaucratic imperatives that guide the system, over the ethical, moral norms and emotional responses through which human relationships are formed. In the ensuing "cultural impoverishment" of the lifeworld it becomes less capable of performing its "socially integrative functions" of creating and sharing values (Kelleher 2001 p122). Thus as individuals become dissociated from their ethical moorings, their ability to make a unique contribution to public discourse will clearly be affected. This in turn will mean that competing conceptions of the good life, that is the ethical standards by which we should live, will give way to uncritical acceptance of the status quo, as defined by the state or market economy.

Failure to defend the lifeworld against colonisation will also affect its cultural and ethical creativity through allowing private matters and relationships to succumb to the process of juridification. This occurs when demands for

protection or support from the system, for example through the law or welfare agencies, are satisfied in ways that encourage recipients to act as passive 'clients' instead of engaged citizens, content, as long as they are being administered with their due material or clinical benefits, to allow the state to determine their needs and the solutions to them. In effect social issues come to be judged according to "hyper-rational[ ]" criteria that require the type of "immediate returns" (Scambler 2001 p13) that are within the power of the system to bestow, rather than citizens to negotiate.

Thus, in order to claim to have a positive impact in the public sphere, self-help groups should be working to bolster relationships in the lifeworld among those people who may otherwise be more dependent on, or making demands of, the state for welfare or support. The majority of the literature suggests that this is indeed a common outcome of participation in these groups. Self-help groups are described as personal and 'intimate', providing friendship, and even family type relationships to their members (Radin 2006). It has even been suggested that they can act as a substitute for broken relationships caused by the fragmentation of society, a claim borne out by the fact that in the United States the divorced are their most frequent users (Lieberman &Snowden 1999). Members typically report effects such as increased empowerment and self-responsibility coupled with reduced dependence on professional services (Steinke 2000, Katz 2003-4).

However, it has at times been suggested that self-help groups can act in ways that increase the risk of juridification and the consequent loss of personal autonomy in the private realm. This is deemed to have come about through their role in the medicalization of phenomena such as addiction and the recasting of issues such as behavioural problems in children or normal emotional responses, such as grief or sadness, as medical or mental health conditions. In doing this, the power of interpreting and addressing one's own situation is conceded to the biomedical establishment which is thus able to exert its technical interference and control with little resistance or challenge (Conrad 1975, 2007, Rosencrance 1985 Kristian Barker 2002, 2008).

The lifeworld's relationship to the system is however more complex than may appear from the view presented above. In his later works Habermas came to believe in the fundamental necessity of the system and lifeworld, whilst upholding an element of separation and independence from each other, remaining at the same time linked and integrated. Without effective channels of communication between these two spheres the system would end up devoid of ethical values and thus dehumanised, as such values can only be propagated within the sphere of personal relationships, and not through the logic of bureaucratic or technical procedures. Melucci (1989) and Fraser (1989 cited in Garrett) have gone even further and suggested that the Habermasian idea of colonisation is itself flawed, as, by postulating colonisation as necessarily negative, Habermas fails to acknowledge the enabling aspects of technical expertise and procedures grounded in the system, as well as the possibility of harmful facets of the lifeworld.

The ideal locus for associations such as self-help groups would therefore appear to be at the interface between the system and the private realm of social life, from where they could balance a defence of the latter with a willingness to commune constructively with the former. And evidence from recent years that self-help groups are working increasingly closely with health and social care agencies suggests that they may be in the right position to be able to fulfil this role. Working in this way however is not without risks, namely to groups' independence and ability to maintain a unique voice - these are discussed more fully below.

2.3.2 Communicative action

For Habermas the public sphere comes to life through the process of communicative action (1984, 1987). This entails unconstrained, inclusive dialogue that is "rational" (1984 for example pp 11, 16, 75) insofar as it can be defended against valid forms of criticism. Furthermore it is not subjected to the abuse of power, but rather allows agreement to be attained solely through the force of the better argument. This focus on rationality has led Habermas' critics, many rooted in feminist traditions, to accuse him of forcing particularist or private interests out of the picture (Benhabib 1992, Graham

2008, Karppinen et al 2008). Feminists have argued that Habermas' emphasis on universal, moral questions serves to invalidate and devalue personal, ethical issues (Benhabib 1992). However, Habermas (1996 p314) states that "visions of the good life" are indeed the types of issue over which struggles in the public sphere should take place. Coupled with his emphasis on inclusiveness and egalitarianism (1989) this suggests that the type of universalism that operates in the public sphere is based as much in notions of respect for individual dignity and worth as in narrow, procedural issues of justice (Benhabib 1992) and thus it does not amount to an automatic bar to "particularity" (Landes 1995 p98). Habermas' recognition of the individual's standpoint and experience supports this reading of his work;

> The political public sphere can fulfil its function only insofar as it develops out of the communication taking place among those who are potentially affected……..systemic deficiencies are experienced in the context of individual life histories …..*assessed in terms of one's own* life history. Problems voiced in the public sphere first become visible when they are mirrored in personal life experience (1996 p.369 original emphasis)

Critics also assert that Habermasian rationality entails formal logic and tidy, disembodied, unemotional forms of speech that serve to reinforce power differentials (Hodge 2005, Karppinen et al 2008). However, Habermas supports Cohen's view of the informal public sphere as a "wild" and "anarchic" complex (1996 p307) and stresses the role of "everyday" language (1996 p360) and vernaculars as a means of combatting social status and attaining equality– indeed in the nascent public sphere in Germany, associations were said to be;

> Preoccupied with the native tongue, now interpreted as the medium of communication and understanding between people in their common quality as human beings – nothing more than human beings (1989 p34)

The key to communicative action is thus neither narrowly conceived universalism nor linguistic formality - rather it refers to the fundamental necessity of open ended dialogue. This communicatively rational speech,

unlike that which furnishes the strategic or instrumental action of the system cannot be used as a means to justify and legitimise pre-existing decisions or ends. It must reach its conclusions and outcomes solely through the quality of competing claims and arguments and never through the abuse of power or the exclusion or denigration of any relevant and interested voices. Personal histories and experiences, and colloquialisms and vernaculars should therefore be seen as a valid, if not vital, part of the debate as without them those voices who only know these ways of speaking, would effectively be silenced and equality and inclusivity would be illusory.

Speaking your own language

For communicative rationality in the public sphere to thrive, maintaining independence from powerful structures such as the state is of crucial importance (McKee 2005). Without this separation associations will struggle to develop according to their own logic or to create their own definitions of need (Habermas 1989, 1996, Fraser cited in Houston 2002) but will tend to defer instead to the instrumental aims of the system and be robbed of their ability to offer genuine or radical alternatives. For self-help groups this would mean the loss of their role as sites in which health and social care problems are reconceptualised by the people with direct experience of their effects (Munn-Giddings & McVicar 2006).

Language, in particular the use of everyday, idiosyncratic speech, is often seen as a key means through which civic associations can resist threats to their independence and develop alternative ideas about the nature of and solutions to problems (Gardiner 2004, Garret 2009). And this emphasis on the colloquial has tended to be put forward as a foil to Habermas' focus on rationality. However, as already discussed, Habermas (1996 p360) placed a high value on the use of "natural language…general comprehensibility [and] everyday communicative practice" and even regarded dramatization, through personal stories, as a valid form of civic discourse because of its ability to bring broader political issues to life and increase their relevance amongst the general population. A central function of the public sphere is to counteract the system's hegemony through unconstrained communication, and clearly, if

groups, especially amongst the disempowered, are made to use concepts and language that are alien to them, then their ability to express their needs and opinions in meaningful ways will indeed be constrained.

Self-help groups, in their guise of "narrative" communities (Rappaport 1994) are described as being grounded in their own "special vocabulary" and philosophies (Williams 1989, Katz 2003-4 p29) that come into being through storytelling and the sharing of life histories. And as such they provide a possible site for resistance to the hegemonic, technocratic language rules of dominant structures and the potential to articulate social problems or raise political questions in ways that animate and humanise the discourse of civil society - a role that Habermas (1996) saw as the key to meaningful grassroots input into political processes. Similarly, through their emphasis on de-stigmatisation and empowerment self-help groups are observed to have used these unique ways of talking about problems and needs to challenge negative labels imposed by dominant power structures within the system (Borkman & Munn-Giddings 2008) and to effect positive changes to the language rules in operation in the public sphere. For example Chamak (2008) describes how self-help groups in France have been instrumental in bringing acceptance of new models and definitions of autism that were proposed by the people with this condition themselves.

However, it cannot be presumed that all self-help groups will speak in this way and that their effects in civil society will necessarily be the same. Many groups evolve over time from small, local gatherings into large national organisations and as such will be more likely to engage in direct conversation with government agencies. When this happens the voices of grassroots members can be drowned out by a professionalised leadership (Emerick 1991, Buchanan & Walmsley 2006, Chamak 2008) whose parameters of negotiation will be limited to those defined by the state's agenda and pre-conceived outcomes. Ironically, these national organisations tend to have a greater likelihood of focusing on advocacy than smaller, local groups, and hence appear to be more engaged in political discourse and to possess that political dimension that is sometimes seen as lacking in small, local self-help groups (Brown et al 2004). And yet, in terms of the independence and communicative rationality of their

speech, they may be making a less legitimate contribution to the public sphere than those groups who retain their own parameters for discussing the issues that affect them and hence, which may provide a more accurate reflection of the real needs of their constituents.

There is broad agreement in the literature that self-help groups are working increasingly closely with public health providers. The majority of commentators encourage these practices, believing that they will lead to greater security, legitimacy and reach for self-help groups. However, little consideration has been given to how such relationships might affect self-help groups at the civic level (Stewart 1990, Wilson 1994, Adamsen & Rasmussen 2001). For some writers these closer relationships raise fears of co-optation and consequently a diminution of self-help groups' ability to present a radical challenge to the mainstream medical or political establishment (Emerick 1991, Baldacchino & Hussein-Rassool 2006). For example, the provision of publicly funded training and support for self-help groups is increasingly seen as desirable (Dunne & Fitzpatrick 1999, Elsdon et al 2000, Kelleher 2001), with policies such as the Self Care agenda and Expert Patients Programme relying on the training of peers as 'experts.' But this brings with it the possibility of professionalisation and the adoption of frames of reference epistemologically and conceptually grounded in technical expertise. It thus appears very different to self-help groups' idea of the peer role, which is to offer an alternative to the support and knowledge of experts (Munn-Giddings & McVicar 2006), being grounded in actual experience rather than learned expertise and conveyed through everyday speech rather than technical jargon. And whilst there may be advantages that come from broadening professionals' understanding of self-help philosophy and practice through working more closely with these groups, it may also serve to encourage the appropriation of self-help language and values by mainstream structures, diminishing their impact as a genuine alternative.

Similarly the burgeoning of user involvement policies in the UK and the use of self-help groups and patients groups to act as consultation partners (DH 2006b, Godin et al 2007) can pose a threat to the vitality and spontaneity of self-help groups' dialogue. Consultation processes tend to work according to the

parameters and language rules of the dominant party, and self-help groups have been observed to have had to reconceptualise the life stories that are their usual currency, into pre-defined issues (Munn-Giddings 2003) that fit the prevailing policy agenda. The typical ways in which self-help groups discuss problems tend to be beyond the remit of consultations and hence excluded from the agenda for debate (Godin et al 2007). At the same time though, incorporation of the idioms of self-help can be used to give an appearance of legitimacy and grassroots support to government policies.

Self-help groups have increasingly expressed a desire to spread the perceived benefits of what they do through the receipt of more regular referrals from mainstream health professionals, effectively moving closer to a service provision type role (Wilson 1994). This development has been widely encouraged by commentators (Jacobs & Goodman 1989, Katz 2003-4). Again, though, little attention has been paid to the impact this might have on self-help groups' civic status. It has been observed that over recent years, as service delivery has become their main function, many voluntary sector organisations have become far more subjugated to the control and bound more closely to the strategic targets of the state, thus losing their independent voice in civil society (Fyfe & Milligan 2003, Daly & Howell 2006). Similarly Dunne and Fitzpatrick's (1999) study of self-help groups revealed how it is those groups who conform to accepted bio-medical definitions of mental illness that tend to receive referrals from mainstream mental health agencies. Self-help groups may thus find themselves under pressure to conform to dominant labels and treatment models in order to gain the legitimacy that would result in their desired closer links with health services.

2.3.3 The subject matter of a rational conversation

Just as Habermas' emphasis on rationality has been the subject of dispute, so there has been extensive disagreement about what constitutes a valid topic for conversation in the public sphere. According to Habermas, public sphere dialogue should entail discussion about competing interpretations of the good

life as well as universal moral issues such as freedom and justice, as opposed to the mere claims of niche interest groups engaged in making demands for themselves (Benhabib 1992, McKee 2005). His emphasis on universal issues of the common good has led critics to infer that Habermas would proscribe discussion of intimate or personal matters (Benhabib 1992). However, Habermas acknowledges that modern politics is more interested in forms of life and identity than in the redistributive questions of the past and that "the echo of private experiences" of "diverse voices" (1996 p364) are central to the development of ethical values. This means that questions that refer to identity and ways of living (Edwards 2004), which frequently hinge on intimate matters but may exist within the context of broader moral principles, such as justice, fairness and equality, would indeed be apposite subjects for civic debate.

The focus on 'how we live' as opposed to what can be claimed seems to be reflected in the purpose of self-help groups, the majority of which are not believed to see their role as making claims but rather as providing support and knowledge that will affect members' identity and ways of living (Ablon 1981, Wilson 1994). Again though, it should be noted that this will not be the case for all groups. Lieberman and Snowden (1999) describe how some groups evolve from small supportive or educational groups into groups whose primary purpose is advocacy, which may frequently involve making claims for increased welfare resources for group members. Similarly, national umbrella organisations are likely to have a greater role in this type of advocacy. However, making claims in this way will not automatically mean that groups are not engaging in valid civic discourse. The extent to which they do will depend on how far their claims have been arrived at through a process of communicative action.

Self-help groups have sometimes been seen as entirely inward-looking, focusing on their own narrow concerns rather than the needs of the broader community (Baumann 1999, Borkman 1999). And if this is the case then their dialogue may have very little to contribute to public discourse. Certainly the fact that the largest category of self-help groups addresses single, specific health conditions (Elsdon et al 2000) coupled with smaller groups' tendency to

focus inward on providing support to their members (Wilson 1994) appears to buttress this view, and it has been noted that even when they become involved in political campaigns, group members can be reluctant to address broad issues, preferring to concentrate on individual stories (Radin 2006). However, individual stories can provide illustrations of the application of universal principles. Indeed this mediation between the personal and the political is an important role that associations should be playing within civil society in order to give more resonance to political issues and in order to give grassroots opinion an authentic means of expression which conveys ideas in ways that have direct recognisable relevance to people's lives (Habermas 1996).

Similarly some of the biggest current questions in ethics and philosophy regarding human agency and the value of human life have manifested as medical issues in the form of genetic screening, abortion time limits and assisted dying. It is therefore important that these matters are the subject of unrestricted dialogue in the public sphere in order that the right questions can be raised at the political level. Self-help groups, through their focus on experience rather than technical expertise, can provide a unique form of knowledge that may be lacking in the discussions of politicians, scientists and jurists and hence can contribute to the articulation of more comprehensive questions. Indeed following Melucci's (1989) discussion of the impact of social movements, it may be that these types of question exemplify the limits of formal politics and can only be adequately articulated and resolved within the sphere of everyday life, in which self-help groups clearly operate. However, there is currently little empirical evidence about what, if any, role self-help groups have played in these debates.

According to Habermas, discussion within the public sphere should serve to increase the complexity of the debate (McKee 2005). This is especially important in an age in which the mass media are seen as having 'dumbed down' political discourse (Goode 2005). This is an area though, in which the effects of self-help groups appear to be somewhat equivocal. On the positive side, an important function of groups is to educate their members. They are often used as a forum to augment members' understanding of complex technological developments (Radin 2006) and bureaucratic, welfare and

judicial systems. Furthermore many groups aim to educate the broader society (Katz 2003-4, Goldstrom et al 2006) about issues associated with their condition, or about broader matters connected with disability, addiction or mental health. Clearly if this occurs it will have a positive effect on the quality of public discourse, especially if groups are able to disseminate the information in comprehensible, everyday language.

The level of debate will also be raised by breaking down stigmatising and stereotypical images that allow complex arguments to be reduced to simplistic prejudice. Thus, as a central aim of many self-help groups is to deconstruct commonly held negative images (Ablon 1981, Baldacchino & Hussein Rassool 2006) these groups could again be said to increase the complexity of prevailing discourse. On the other hand, however, the very desire to decrease stigmatisation can lead some groups to simplify political debate, for example, by stressing the biological causes of mental illness (Bond 1992, Dickerson 1998) and thereby negating the contribution of complex socio-political factors.

For Habermas (1989) the public sphere should provide a space where the interests of powerful authorities are problematized and through which their "monopolisation of knowledge" (p317) is broken. Through their experiential epistemology and the development of a unique collective narrative (Rappaport 1994) self-help groups can provide a means for undermining the monopolistic interpretations of the medical establishment and challenging the "dominant cultural codes" (Melucci 1989 p75) that buttress existing social relationships. However, the contrary has also been observed, in that some self-help groups use their shared knowledge to reproduce rather than problematise mainstream bio-medical interpretations, some having gone even further through playing a key role in advancing processes of medicalisation (Rosencrance 1985, Conrad and Schneider 1992, Conrad 2007). Kristian Barker (2002, 2008), in her work with fibromyalgia groups, has discussed the depoliticising effects of groups' desire to assume medical labels which ultimately locates problems within the individual rather than the dominant power structures or broader society, and effectively removes issues from the sphere of public debate into the sole concern of technical experts. Similarly, Elsdon et al (2000) discuss how the acceptance of a medical model for behaviours such as addiction can diminish

the possibility of broader discussion over the moral and ethical issues underlying those behaviours.

2.3.4 Routes to equality

Equality and an egalitarian structure are seen as crucial prerequisites for the creation of "ideal speech situations" within the public sphere (Habermas 1996 p316) and so civic associations would be expected to operate according to inclusive, democratic and non-hierarchical principles. Any coercion or exploitation of power disparities would effectively amount to the displacement of communicative rationality by the strategic aims of the more powerful party. Of course such a situation is, as the name suggests, an idealisation that can never be fully realised in practice. However the value of such a concept is in providing both something to strive for, and a yardstick against which to judge real life phenomena.

It has been suggested that such democratic principles are also fundamental to self-help groups (Borkman 2000). Rootes and Aanes (1992 p380) describe self-help groups as a "pure form of democracy" in which domination can never occur. If this is so, then self-help groups would provide the ideal medium for communication within the public sphere. However, again this presents an idealised view. In reality these groups are seen to possess a whole spectrum of arrangements, from collegiate and democratic to individually led and authoritarian (Borkman 1999). Indeed the lack of formal structure that is typical of small groups can itself make them more vulnerable to abuse of power (Habermas 1996, Stolze 2000). Furthermore, evidence suggests that group leaders tend to have a disproportionate share of power and organisational responsibility (Chaudhary et al 2010). This means that the political learning that is claimed to take place in self-help groups (Elsdon et al 2000) may not be benefitting the broader membership. And it is this political learning, of skills such as negotiation, organisation and navigating welfare or judicial systems, which is deemed vital to the civic impact that small groups can have within the current socio-political context (Marcello & Perrucci 2000). The implementation of policies such as the Expert Patient Programme also have the potential to create hierarchy in self-help groups through the

introduction of the trained, expert peer, a status that could clearly come to be seen as holding pre-eminence within the group.

Having said this, when talking about self-help groups it is important to remember that concepts derived from standard organisational theories will have limited applicability (Medvene 1985). This is due to self-help groups' tendency towards informality, transience and lack of bureaucracy. Moreover these groups frequently comprise people with serious, life-changing health conditions or with disabilities that confer feelings of stigma and isolation. Thus equality in self-help groups may not arise at the organisational level and may be judged in ways that are different to those within other types of organisation. The disempowerment caused by ill-health, trauma or social stigma may actually require a dominant or charismatic leader who undertakes most of the responsibility for directing and running the group as well as for ensuring the inclusion of all members within its communications.

It is in this respect that Habemas' concept of "collective identity" (1996 p 305) provides a very useful tool with which to assess not only the extent but the nature of equality within self-help groups. It is through such a common, authentic identity, derived through the experiences shared amongst peers, that members are empowered to rebuild a more positive self-image that endows them with the self-worth to speak and be heard as equals (Ablon 1981, Rappaport 1994). Studying self-help groups from this perspective may thus highlight an important difference between formal, organisational types of equality on one hand and communicative types on the other.

Melucci, who has further developed the idea of collective identity, conceptualises it not as a thing to be attained, but as an on-going process of negotiation. It thus appears closely related to Habermas' view of civil society as a discursive, consensus- seeking endeavour. In both cases individual standpoints and goals are considered, traded and compromised over by all parties to the "bargaining process" (Habermas 1996 p320) until an optimal amalgamation of views is formed; true consensus over and identification with this outcome only being possible if all individual contributions are given fair and equitable deliberation and all potential participants an equal chance to be

heard. This process will be on-going as the outcome will necessarily affect and change each individual's relation to the whole. Such open-ended, self-perpetuating activity is clearly therefore in conformity with the broader principles of communicative rationality, and there is no inherent reason, especially within a small group where the practicalities allow for all members to speak, why strong, organisationally hierarchical leadership cannot support and cultivate this process. Indeed, as stated above it may be that a form of dominant or patriarchal leader is needed in order to ensure the inclusion of all voices.

Differentiating between these types of equality by focusing on how far collective identity is maintained can help to account for the extent to which groups are perceived to represent their members' voices. This factor may increase understanding of why some groups that grow into large, national organisations come to be seen as undemocratic and unrepresentative, excluding the views of grassroots members, whilst others do not. Interestingly it is often the more politically radical groups that claim to be grounded in egalitarian, emancipatory principles, which are more likely to evolve into national organisations (Emerick 1991). But it may be the case that only some of these groups are providing the conditions to nurture a genuinely empowering and democratising collective identity. And again there may be lessons to be learned from small local groups, which are sometimes seen as lacking the political credentials to contribute towards the public sphere, but which in fact might possess high levels of the communicative type of equality that fosters group affinity and democratically generated opinions.

3 Methodology

3.1 Aims and research questions

The study was designed to address the broad aims already referred to in the introduction. These are; to contribute to a better understanding of UK self-help groups by providing evidence about the aims, activities, structure and ethos of a broad range of groups; to use this as a foundation on which to develop a civic theory of self-help groups by conceptualising them in terms of their democratising role in the public sphere.

The following research questions were asked in order to address these overarching aims;

- What are the groups' goals? Why do people decide to join, start up and continue to participate in self-help groups?
- Through what types of group activity do the groups attempt to fulfil their goals? What input do mainstream health and social care services play in this?
- What types of activity do groups take part in outside the group?
- What do groups talk about and how far are they concerned with topics of a wider political significance than that arising from their own health condition or social situation?
- What ethical values underpin the groups, and through what processes do they arise? What effects do a group's relationships with public services have on its ethos?
- How are self-help groups structured, and what are the effects of their structural arrangements on their ethos, aims, activities and communicative processes?
- What effects do groups have on social relationships beyond the group and within the broader community?

- To what extent are the Habermasian concepts that underpin his model of the public sphere, in particular, communicative action, rationality, and lifeworld autonomy, able to account for self-help groups' civic role? Does the analysis of self-help groups in these terms allow us to more accurately locate them within broader health citizenship theory?

3.2 Theoretical context

Introduction

The theoretical perspective and context of the research will be addressed more fully throughout the substantive body of the thesis rather than in terms of its methodological strategy. Having said this, the Habermasian framework that guides the study does itself imply a particular methodological approach. Whilst Habermas acknowledged the effects of structure, that is state and economy, on the process of social evolution he insisted that this could not account adequately for social integration and communications (Scambler 2001). Instead his central premises, that rest on the endeavour to attain consensus and the development of the self through purposive social interaction with others in the lifeworld imply intentionality and thus demand a central role for human agency.

The methodological strategy was therefore premised on an inter-related duality, rather than a discrete dualism, between structures and individual agency (Benton & Craib 2001) as giving rise to social phenomena and bringing about social action and change. The methodological tools were chosen and used in order to elicit the views and roles of individual self-help group members, particularly group founders and leaders, as well as the broader societal factors that affect the creation and nature of self-help groups. Such an approach appears apposite to the idea of self-help groups as "narrative" communities (Rappaport 1994) whose focus is on talk, dialogue and story-telling as a means of achieving their aims, but that at the same time are believed to be increasingly closely linked to the system. Self-help groups are frequently said to develop their own unique forms of language (Katz 2003-4)

and to use these to redefine and reconstruct their members' identities and their conceptualisation of health and social problems. The research therefore explores the ways that ideas such as health, illness and disability are defined and talked about in self-help groups. It assesses the ways in which the discourses, definitions and labels that are used by the political and medical establishments are reproduced or transformed through the dialogue and interactions amongst group members, and it looks at the effects of this speech on the wider community.

Ontological and epistemological considerations

In addressing the ways in which self-help groups, their individual members and broader structures such as government agencies affect and are affected by each other, the initial ontological premise is that these entities exist as different but mutually affecting constituent parts or layers of the social world; and that each layer has the capacity to contribute to the creation of social action and social change. The interactions between these social entities have an impact on society through the creation of phenomena, such as self-help groups, and the production of social action, such as the ways in which self-help group members respond to their illnesses and life situations.

Although the Habermasian context of the thesis is essentially discursive it does not adopt the approach of much discourse theory that supposes a dualism of individual agency and the construction of meaning (Mason 2002).Instead it follows the work of Bhaskar (1979) and Giddens (1984) in which individuals are regarded as both subjects and objects of the environment and its underlying structures. Individuals' actions are grounded in autonomous agency but subject to structural mechanisms which affect the nature of their choices and actions and the ability of their choices to be put into practice. Whilst it is accepted that discourse has an effect on identity, and in this way can be said to partially 'construct' the individual actor, this ignores the role of agency in interpreting the discourse in order to either reproduce or transform it. It is likewise acknowledged that individuals and their identities can only develop and be meaningfully articulated according to available discourses, concepts and definitions; however, it is the autonomous agent who responds to these

definitions, for example by taking the intentional step of joining a self-help group, and through their actions transforms the labels they use to identify or 'construct' themselves. Such processes, through their permeation of the wider society may thus also contribute to the transformation of the dominant discourse embedded in structures.

The concept of individual agents as entities of social reality carries with it the further presumption that their actions are meaningful in that they are directed towards, either practical or value based, ends and that actions are directed towards achieving these ends through the meanings that individuals attach to social phenomena. Social reality is therefore also constituted by people's meanings, interpretations, values and desired ends. Although these meanings are generated through the entity of individual agents, these agents do not act or construct their interpretations in isolation and consequently the interactions between them are themselves seen as properties of social reality and thus as sites that give rise to social action and the creation of cultural values. In this we are again brought back to Habermas in whose theories individuals assume their importance only in the context of the essential inter-subjectivity of social life (Scambler 2001).

Theoretical approach.

In focusing mainly on the perceptions, meanings and views of groups and group members the research takes a broadly interpretive approach. It does not, however, intend to pursue a specific or unitary theoretical perspective. As the ontological presumptions on which the study is grounded are so broad, incorporating social interactions, interpretations, individual agents, discursive constructions and underlying structures within the definition of social reality, the methodology implicitly borrows from a number of approaches. For example, questions about how individuals develop or construct their systems of meaning (Benton & Craib 2001) may benefit from adopting a phenomenological perspective. Such an approach could also usefully be employed as a means of explaining how the objects of the study, namely self-help groups, appear to those who are actually practicing within and experiencing them. The phenomenological claim that knowledge and emotion

cannot be separated off from each other (Benton & Craib 2001) also reflects the ethos in which many self-help groups are believed to be grounded whereby understanding of a social phenomenon such as an illness or disability can only be gained through accepting the validity of both its technical and emotional facets. Such a perspective would clearly have value with theorists such as White and Kelleher, who used a Habermasian approach to new social movements, in order to explain these associations' reclamation of the right to bring feelings back into the construction of health and illness (Kelleher 2001).

At the level of the group however it may be that interactionist theories provide a more useful framework, allowing us to consider the ways that group members might perceive themselves, behave and speak differently when acting as a part of a collective rather than as an individual. And at a still broader level, the desire to promote rational communication across the very different cultures of self-help groups and the medical establishment, or, in Habermasian terms, between system and lifeworld, suggests a hermeneutic approach as a means of illuminating the ways that these traditions are able to make progress towards mutual understanding (Hollis 1994).

As Benton and Craib (2001) state, essentially these traditions are all based on a very similar premise that involves understanding the meanings that people give to the social world. It is therefore unnecessary to choose between them but instead to explore their relationships to each other (Benton & Craib 2001, Silverman 2000). As narrative and conversation is central to how self-help groups work, the methodology will also be influenced by certain aspects of discourse analysis. Although some theorists warn against mixing discourse analysis with interpretive approaches due to their incompatible ontological foundations, referred to above (Silverman 2000, Mason 2002) this seems to be a problem only with regard to the stronger and more politicised versions such as critical discourse analysis (Johnstone 2002). At its broadest conception discourse analysis is simply the analytical study of speech and dialogue (ibid) and consequently there is no reason not to make use of some of its techniques and insights when studying certain aspects of self-help groups; for example their role in shaping personal and social identity, in defining life processes

such as illness, ageing or disability and their impact on public discourse through processes such as 'medicalization' (Conrad 2007).

Although the research is guided and framed by Habermasian concepts it is not bound by these and thus remains essentially inductive. It has therefore allowed the theory relating to the substantive body of the study and that in which the methodology is loosely grounded to develop alongside the processes of data generation and analysis throughout the course of the thesis.

3.3 Methods

The nature of the research questions coupled with the ontological presumptions in which the study is grounded lend themselves to a qualitative approach to data gathering. The methods were selected as a means of fulfilling both aspects of the study's aims – that is to build a comprehensive picture of a broad range of self-help groups at the same time as providing enough depth to subject them to a meaningful theoretical analysis. Such an approach cannot of course claim the levels of generalizability or external reliability and validity that would be expected within a positivist, quantitative paradigm. It can however be used in a way that gives it trustworthiness (Lincoln and Guba 1985) and authenticity (Silverman 2000) in presenting an honest and accurate representation of the views of the respondents.

In developing the research strategy I consulted with staff at Self Help Nottingham, as well as a broad range of group leaders and members. This was invaluable in helping me to decide upon my choice of methodological tools and in drawing up my interview schedules.

Interviews

The research is premised on the belief that individuals' perceptions, experiences and interpretations are constituents of social reality and are a central property of the phenomenon being studied. Self-help groups are frequently very small and informal, and so the views and perceptions of their members are likely to have a marked effect on the way a group develops and

the impact it has on its members. The research is concerned with the ways that the language, narratives and philosophy of the groups develop and how far this is down to the action of individuals and their interpretations of labels and definitions that occur in the wider society and within structures such as the biomedical establishment. It also focuses on the development of the internal structure of the group, which, in small groups, may be strongly affected by individuals' personalities, backgrounds and experiences. The research is also concerned with the ways in which groups interact with health and social care professionals. It therefore aimed to explore members' opinions of their and their group's relationships with professionals and with their interpretations of how these relationships have affected both the group and themselves as a group member.

The interviews were loosely structured to take account of the different experiences and backgrounds of the self-help group members and the different stages of development of and nature of the self-help groups themselves. This flexibility allowed respondents to discuss topics in their own ways and to focus on issues which they perceived to be of the most relevance to them, whilst at the same time ensuring that the interviews did not stray too far from the research questions.

Interviews are believed to be a valid way of uncovering the meanings that respondents attach to their and other peoples actions and to the meanings they attach to social reality (Mason 2002). The type of actions, interactions and circumstances, in particular those related to the shared health condition or social situation, that give rise to self-help groups and that affect their characteristics are likely to be highly complex. The meanings that are attached to these actions and interactions are embedded in and expressed through language (ibid) and hence a method that allows for respondents to articulate these meanings and perceptions through their own choice of words is likely to give a deeper understanding than a quantitative or overly structured or standardised approach.

However, as with any method of data generation, there are drawbacks and limitations with interviews and it is acknowledged that the data they produce

can provide only a partial picture of the phenomenon under study (Silverman 2000). Interview respondents will clearly act in their own interests in presenting a particular version of their experiences and will themselves have a limited vista and understanding of the issues about which they are talking (Miller & Glassner 2004). Consequently, the interview should itself be treated as an observational site that is 'read' within the context of broader evidence (ibid) and it is important that the respondents' stories are not simply 'bought' unquestioningly (Silverman 2007). Similarly, people tend to have multiple identities that are served by different priorities at different times, and an interview is unlikely to be able to capture all of these (Silverman 2007). This may be especially relevant to the current study as individuals may behave and see themselves differently when being addressed as a 'group member' or 'group leader' rather than as an individual when they are away from the group.

People also differ greatly in their ability to verbalise their feelings or to accurately remember past events and experiences (Mason 2002). And, as the current study is concerned, in part, with events and processes that occurred in the past such as members' decisions to instigate or join the group, this is likely to affect the data that is produced. Such issues may be exacerbated by changes in respondents' state of health that make it difficult to recall past feelings or events. However, even though memories may in fact be inaccurate with regards to the actual events that occurred, the way that people choose to recollect a story is itself a valid artefact of evidence that illuminates the processes through which they create and give meaning to their present social world.

Observations and group interviews

The research aims to explore how far the goals, philosophy and language of self-help develop through interactions between individual group members. Therefore in addition to interviews I had initially planned to undertake observations of self-help group meetings.

Observations are regarded as more naturalistic than interviews (Mason 2002, Silverman 2007) and hence provide a better opportunity to hear the language and idioms of the group. They appeared to be particularly suited to the study of

self-help groups due to the widespread belief in these groups' tendency to develop unique vernaculars which may be more likely to be used in the real life setting of a meeting rather than in a formal individual interview. Observations can also provide the opportunity to see how groups' structures affect their dynamics and communicative processes, for example their levels of inclusivity and the extent of domination by individual members or leaders. Of course my own presence as an outsider would be likely to have some effect on these internal processes and so the data would not be a perfect representation of the groups' usual behaviour, however they were still seen as a way of gaining valuable additional insight. The use of observations also allows for the sequential analysis of conversation, which, as Silverman (2007) shows, can give a very different interpretation to the meaning of what is said compared to the analysis of an isolated 'snippet' taken from an individual respondent. Again this is particularly apt in the current study which aims to explore how far groups' values develop through the interaction of the members.

Following consultations with group members and Caroline Bell at Self Help Nottingham it was felt that the majority of groups would expect me to participate in their meetings rather than to merely passively observe and that as such I would gain a more natural view of the groups. It was therefore left to each group to decide on the manner of my participation. In all cases the members were keen to take a direct part in the research and so my observations of group processes, communications and dynamics took place mainly through the medium of group interviews. This consequently provided me with the benefits I had hoped to gain from observing the meetings, as well as additional interview data that gave a different perspective to that of the group leader.

Follow up interviews

During the first round of individual and group interviews it became clear that some groups were at particularly interesting points in their evolution or were in the process of changes, the direction of which was not clear, even to group leaders. They were therefore asked, or in three cases themselves offered, to participate in further interviews at a later date.

3.4 Sampling strategy

In line with much qualitative research, the aim of the thesis is not to produce data that are generalizable but that give a deeper more nuanced understanding of a complex social phenomenon (Mason 2002). Consequently the sampling strategy was purposive or theoretical (Mason 2002, Silverman 2000) rather than representative. The sample was selected for its relevance to the research questions, the theoretical position and the analytical framework that the research is attempting to develop. It should be noted that the sampling strategy employed in self-help group research, including the current study, means that it is limited to making claims, in particular with respect to the benefits to individual members, which apply solely to those who elect to participate. The groups' informal nature means that it is not usually possible to access those who choose not to take part or not to remain members (Dadich 2003-4).

The 'wider universe' (Mason 2002) from which the sample was selected is the population of self-help groups, therefore the individual participants were selected specifically in their capacity as members of self-help groups. The research is thus less interested in accessing a range of individuals' characteristics, such as their ethnicity, age or gender, but rather with a range of self-help groups. The aim was to access groups that addressed a wide variety of health conditions and social situations; that were at different stages of their evolution; that had a range of membership constituencies in terms of ethnicity, age and gender; and that were either independent, affiliated to national organisations or had charitable status in their own right. The intended size of the sample was guided by the research aims, and thus new groups were contacted until it was felt that the range of categories outlined above had been represented and that the point of data saturation had been reached.

The groups were included in the study if they fulfilled the definition of a self-help group discussed above at Chapter 1. The fact that all the groups that were contacted were affiliated to Self Help Nottingham and thus saw themselves and were seen by Self Help Nottingham as self-help groups meant that they were prima facie accepted as falling within the inclusion criteria. In fact questions only arose with respect to one group that was led by a professional

and another that was run by volunteers. After discussion with Caroline Bell and informal conversations with the leaders of the groups at Self Help Nottingham both were included. This was because it was clear that the membership, coming in one case from an extremely marginalised section of an ethnic minority community, and in the other, suffering severe physical and mental debilitation, would not have been able to maintain the group without such leadership. Furthermore the intention of the leader of the ethnic minority group was to eventually pass control to the members and thus they were encouraged to take a lead in decisions about its direction, purpose and activities. There were no firm requirements with respect to a group's age beyond their having reached the stage of holding meetings, even if these were still preliminary meetings amongst founding members with the purpose of getting the group established. Similarly in terms of size, as long as groups had enough members to hold regular meetings they were accepted for inclusion.

3.5 Ethical considerations

The participants were recruited in their capacity as members of community based voluntary associations rather than as NHS service users or patients. It was therefore not appropriate to use the NHS ethical approval system. Instead the ethical review was carried out and approval granted by the University of Nottingham Medical School Ethics Committee (see Appendix 1). The study adhered to the key ethical principles and requirements of the School Committee such as ensuring the informed consent and anonymity of respondents and the confidentiality of all data.

Potential participants were initially advised about and invited to take part in the research through Self Help Nottingham's newsletter. A number of groups were subsequently contacted by letter or telephone on my behalf by a worker at Self Help Nottingham, with whom they were already acquainted. Explanations about the nature and purpose of the work were given to those groups that were contacted directly. Where this was done orally over the telephone it was followed up with written information that was sent to potential respondents.

Members were not asked to make a decision about taking part until they had read this and had a chance to ask any questions arising from it.

Immediately prior to interviews participants were reissued with information forms and given the chance to ask questions. They were reminded verbally of their right to ask or refrain from answering any questions during the interview or to withdraw from the study at any time. Respondents were also asked to confirm their consent to having their interview recorded. They were reminded of the strict confidentiality with which the data would be treated and of its being anonymised in all written outputs. They were then asked to read and sign consent forms. These included the details of my principal supervisor to whom participants were advised of their right to raise any query or complaint. With those respondents taking part by telephone, information and consent forms were sent out and returned to me prior to interview. The information from these was also read out immediately prior to the interview taking place. Respondents' personal details were held securely in a locked cabinet and the data from interviews were kept on a password protected computer accessible only to the researcher and supervisors.

Ethical issues

The project involved only very low risk interventions with participants and so serious ethical problems were unlikely to arise; however there were a few potential issues that had to be borne in mind when conducting the fieldwork. Firstly the respondents were suffering from a range of physical and mental health conditions. Some of these, for example depression or epilepsy, can span a range from being very mild to very serious and details of a respondent's particular state of health were not known at the time of the interviews. It was therefore necessary to be aware of the appropriateness of questions and to be alert for any signs of stress, anxiety or physical discomfort. Similarly sensitivity was needed with members of groups that addressed traumatic social situations such as bereavement. With the assistance of Caroline Bell and a number of group key members whom I consulted prior to the fieldwork I was able to devise strategies for terminating interviews without causing offence or further distress should I suspect that continuing might have brought harm to

the respondent. These strategies did not need to be put into practice as no such situation arose.

Obtaining the members' agreement to take part in group interviews was also seen as a potential problem. Although nearly all the leaders presented the information to the group at a meeting prior to confirming their participation, this process appeared to take place informally and thus the acquiescence of all members could not be guaranteed as some may not have been present at the meeting at which the interview was discussed. And although members were asked for their consent at the meetings that I attended, it is acknowledged that it may be difficult for an individual to object to taking part under such circumstances, especially if the majority of the group appears keen to participate; again though, no such issues appeared to have arisen in practice.

3.6 Data Collection

Access

Groups were contacted initially through an article in Self Help Nottingham's newsletter that goes out quarterly to all its member groups. Two hundred and sixty groups were approached in this way. They were provided with a slip and pre-paid envelope as well as telephone and email details and asked to contact either me or Caroline Bell at Self Help Nottingham if they wished to take part or if they required any further information. The invitation to participate in individual interviews was addressed to all group members; however newsletters were nearly always sent out to group leaders or secretaries and so, as expected, the majority of respondents comprised key members, that is, members, usually office-holders, who took an active part in running the groups. Approximately three months after the newsletter had been sent a second round of contact was begun. This was done in consultation with Caroline Bell at Self Help Nottingham and was targeted at individual groups that came from categories that were under-represented within the initial sample. Contact was made either by letter or telephone with eight additional groups, six of whom agreed to participate. Group members were again given

my details and asked to get in touch with me if they wished to be included. In addition to this two groups were included, in both individual and group interviews, as a result of being contacted for a concurrent research project on which I was working[1] and after consenting to the data also being used as part of my thesis.

Interviews

At the first round of data collection, which took place between October 2008 and June 2010, 39 individual interviews were conducted with members from 33 different groups. Thirty five of these were with leaders or key members, who were usually office holders. Thirty six interviews took place at the offices of Self-Help Nottingham as this was a site with which all the respondents were familiar and which was easy to access. All had however been offered the opportunity to participate by telephone, however only three elected to do this. All respondents consented to the recording of their interviews and the data were transcribed verbatim soon afterwards. In two cases the recording equipment failed and, rather than reschedule the interviews the respondents were happy for me to take contemporaneous written notes. In both cases these were written up immediately after the interview. The interviews, which ranged from 45 minutes to more than two hours, lasted just over 90 minutes on average.

Observations and group interviews

Thirteen groups were contacted via their leader who was asked to present the details of the research at their next meeting in order for the members to decide whether they wished to participate. All the groups that were contacted accepted the invitation. Although the groups all elected to take part in group interviews, it turned out that, due to the ways the meetings were run, this was coupled with periods of non-participatory observation. In three groups this took place prior to the official start of the meeting. During this time members talked both

[1] This was the ESTEEM project that was conducted between 2010 and 2013 by Self Help Nottingham, University of Nottingham and Anglia Ruskin University and funded by the Big Lottery.

amongst themselves and as a group, about a range of group and personal matters; in two other cases, due to the informal, drop-in type nature of the meetings I was able to spend time prior to the interview amongst the members; and in nine groups I was invited to stay after completing the interview in order to observe or participate informally in the remainder of the meeting.

The initial round of group interviews was conducted between March 2010 and January 2011; all took place at the group's regular meeting session. Details were initially sent out to group leaders or secretaries, all except two of whom had already taken part in individual interviews. All except two leaders took the information to their groups before agreeing to take part. Interviews lasted between 35 and 90 minutes within meetings that lasted between two and two-and a-half-hours. I remained for varying periods after the interview but did not stay at any meeting for the full session, always leaving at least 15 minutes before the end. Consent was given for all the interviews to be recorded, however extensive contemporaneous notes were usually taken due to technical difficulties such as the size of the room and background noise. Notes were written up immediately after the meeting and recordings transcribed verbatim as soon as was possible.

Follow up interviews

Nine groups undertook additional interviews, which were conducted between March 2010 and March 2011. Inn six groups the interview was with the group leader, in two it entailed a group meeting and one group took part in both individual and group follow on interviews. These interviews were tailored specifically to each group depending on their particular situation. Six of the seven individual interviews took place over the phone, the seventh at Self Help Nottingham. These interviews, which were all recorded, lasted approximately 45 minutes. As with other interviews the responses were transcribed verbatim as soon as practicable after the interview. Three of the groups invited me to attend further meetings either in the capacity of a researcher or a visitor. I attended all three at least once more. No recordings were made at these interviews; however, the groups were happy for me to take notes throughout.

Interview schedule

The interviews were loosely structured and the research design was kept flexible in order to allow new issues to emerge in response to the information that was being generated. The emphasis of the questions necessarily varied according to the role of the particular respondents within their self-help group and the characteristics of the group. For example some of the questions may only have been addressed to group founders, to those who have had specific roles within the group's organisational structure, or to groups that had reached a certain stage in their evolution. Prior to conducting the interviews I was fortunate to be able to consult with Caroline Bell, the Training and Development Manager, at Self Help Nottingham as well as with a number of key members. The main thrust of their advice was to allow respondents to speak in their own way and to give them space to tell their own background story. The first three questions were thus used as a means of encouraging this personal history and responses to them frequently overlapped and ended up covering many of the subsequent topics meaning that the interviews often did not follow a set order.

The following list indicates the questions that were asked at both individual and group interviews:

1. <u>Joining / starting the group.</u>

- Can you tell me why you decided to join the X group?
    - How did you find out about it?
    - Did you have anyone else – friends or family for instance, or any other services, supporting you at that time?
- (Group founders) What made you decide to start the group? Was the group started with specific aims or values in mind or did these evolve as you went along? Did you have any long term goals?
- (Group founders / original members) Can you tell me about the process of getting the group going – for example where did you go for help and support; how did you reach potential members?

2. <u>The group's purpose and activities.</u>

- What do you see as the main purpose of the group?
    - Can you give some examples of the type of support, information etc that it provides?
    - Do you do any social activities?
- Do you think the NHS or other services could do what the group does? Is there something unique about what self-help groups do?
- Do group members ever take part in consultation processes – PPI's or LINks for example? Do you ever get involved as a group?
- What do you talk about at group meetings? Do you have set topics? Do you have time for informal conversations? Do you ever discuss political issues?
- Does the group get involved in any campaigning activities? Has the group ever written letters – to MP's, local government or the press? Have you ever joined with other groups in this type of activity?

3. <u>Benefits of membership.</u>

- How have you benefitted from being in the group?
- Do you think there are any ways that other people or the local community benefit from the group?

4. <u>Group structure.</u>

- How is the group organised?
- Is there a group leader? What do see as the role of the group leader?
- How many people are involved in running the group? Is there a formal committee? Do people have specific roles? Do you have a written constitution? How do you get people involved in this side of the group?
- Does the organisation of the group work well? Does the way it's organised have an effect on what it does?

- Is the group part of a larger / national organisation? – if so what is the relationship between the national organisation and your local group?
- How does the group go about making decisions? For example about practical things? With regards to its aims and ethos?
- How is the group funded? Does the way the group is funded have any effects on what it does?

5. Relationship with health and social care professionals

- Can you tell me about any contact the group has with health and social care professionals or agencies? What is the nature of the relationships?
- How do you see self-help groups in relation to public health services – do you see them as just another service or as something completely different?
- (For groups with little professional contact or members who favour less contact) Can you explain why the group does not want any / more professional input?
- (For groups with high levels of professional contact or members who want more contact) Can you explain the ways the group benefits from this level of professional input? Are there any drawbacks?
- Do you have any links with other self-help groups or voluntary organisations? Are these types of relationship valuable for the group?

6. The evolution of the group and the future of self-help

- How would you like to see the group develop in the future?
- More broadly, what role do you see for groups like yours in coming years?

3.7 Data analysis.

The verbatim transcripts of interviews yielded a very large quantity of data which it was thus necessary to subject to analysis over a number of stages. The

first part of this process began before the first round of interviews had been completed and was thus able to feed into the later parts of the fieldwork. This preliminary analysis involved reading the responses in order to highlight the broad areas that appeared relevant to the research questions and thus to begin to identify possible themes. The decision about what to regard as relevant was informed by the background self-help group literature as well as by the theoretical framework that had guided the design of the thesis and the development of the research questions. This approach to the data, which explicitly refers to a pre-existing theoretical model, may appear to be too theory led to fit within the broadly interpretive approach of the study. However, even those approaches, such as grounded theory, that claim to be data driven must rely at some level on theoretical presumptions, even if these are not always made clear, in order to begin to organise and conceptualise the vast quantity of data that is typical of qualitative research (Auerbach & Silverstein 2003).

The fact that the research questions arose in response to a specific theoretical framework does not mean that the analysis of the data was unquestioningly bound to it. The overarching aim of the work was to increase understanding of self-help groups by conceptualising them through the lens of a particular framework, but in doing so it also hoped to use the example of self-help groups to critique the value and explanatory potential of these theories themselves. In line with interpretive research design (Silverman 2000) it was therefore expected, and transpired to be the case that the emphasis of the theoretical framework, the organisation of the data and the focus of the research questions all evolved in response to the data and the different interpretations of it that successive readings brought to the fore.

The data selected as being broadly relevant were then studied in more detail in order to identify 'repeating ideas' (Auerbach & Silverstein 2003) which formed the basis of the themes into which the data were eventually to be grouped. This type of 'cross-sectional indexing' (Mason 2002) allowed for comparisons and contrasts across the data to be highlighted. The coding of the data, for which NVivo software was used, was also carried out in a flexible way. Thus as I became more familiar with the data and more convinced of the

significance of certain themes, some of which had not been considered important at the start of the study, categories were changed and collapsed together to allow for a broader view, or separated out into smaller units to give a more detailed breakdown.

In order to increase my confidence in the accuracy of my interpretations of the responses, the 'repeating ideas' and themes were referred back to a sample of respondents for discussion.

The coded data were used primarily to illuminate emerging patterns. However they also occasionally revealed atypical or unique findings that did not fit into any of the categories or themes. These 'anomalous' cases were further analysed in order to draw out the extent of variety that may exist across a range of self-help groups and hence to extend the range of cases to which the inferences from the findings may apply.

The data were also broken down and analysed according to a number of 'variables' which allowed for comparisons between the responses of members of different types of group, groups of different ages and groups with different structures. Clearly due to the small sample size and unstructured nature of the research, this was not done in order to make universally generalizable claims or to allow for accurate predictions about the behaviour of different types of groups. However, use of this method can draw attention to the possibility of relationships between groups' characteristics and behaviour, or, equally importantly, to the lack of any such correlation. It thus allows us, albeit tentatively, to apply the study's inferences and interpretations beyond the specific sample (Auerbach and Silverstein 2003) and to make suggestions for further research.

In terms of the quality and robustness of the analysis, I have followed the model developed by Rubin and Rubin (1995). Rather than trying to fit qualitative research into the standard quantitative paradigms of reliability and validity, they discuss the need for transparency, communicability and coherence. In effect this involves being explicit and clear in the various steps, such as coding and categorising that were taken in order to progress from the raw data to the final interpretation. Similarly the ways in which the data are

incorporated into the theoretical context must be justifiable and result in a coherent and comprehensible narrative.

In addition to the thematic analysis discussed above, the data were considered sequentially in ways derived loosely from discourse or conversation analysis (Silverman 2000) where this seemed a useful way of providing a fuller understanding of the findings. This was most frequently utilised in the analysis of group meetings and, following suggestions from the literature about its value in this area, with the data that emerged about groups' identity and values as well as their response to medical labels and diagnostic categories (Johnstone 2002). Following Mold's study (2010) with service user forums some basic use was made of pronoun analysis in order to help illustrate the complexity of leadership status in the sample groups.

3.8 Limitations of methodological strategy

The shortfalls of the methodological strategy and tools have been discussed throughout this chapter. In addition to these the main limitation of the study derives from the sample being taken solely from groups that were affiliated to Self Help Nottingham. This means that generalising the findings to the rest of the UK must be undertaken with caution. The existence of Self Help Nottingham clearly affected the efficacy and actions of many of the groups as a majority had had significant contact with it, through attending workshops, training or obtaining one-to-one advice, over the course of their lives. Even within Nottingham it is acknowledged that the views of groups with more radical ideologies, who thus wished to remain outside the aegis of Self Help Nottingham, may have been omitted. Having said this a recent study conducted concurrently in Nottingham and Essex (which does not have an agency dedicated to the support of self-help groups) found very few differences in terms of groups' purpose, ethos or activities between the two areas (ESTEEM 2013), which suggests that making tentative generalisations from the findings should be possible.

Findings

Overview of the self-help groups

The following five chapters present the findings from the individual and group interviews.

The participating groups addressed a wide range of health and social issues that were allocated to the broad categories shown in Table 1. Whilst in some cases, particularly with respect to the groups that dealt with physical health conditions, this was very straightforward, in others it was less clear cut. For example one of the mental health groups was initially targeted at people without a diagnosis, but who saw themselves as "stressed" or "isolated" and could thus perhaps have been conceived as being a type of 'social issue.' Similarly the 'social' group did occasionally provide information about healthy living which might thus have brought it within the 'physical health' category. Following existing literature (Elsdon et al 2000, Chaudhary et al 2010) the 'social issue' class included groups that helped members cope subsequent to a life-changing event such as bereavement.

Table 1 Categories of group[2]

Category	Physical health	Mental health	Social issue	Social group	Parents' group	Carers' group
Number of groups N= 33	18 (55%)	6 (18%)	3 (9%)	1 (3%)	3 (9%)	2 (6%)

The groups spanned a range of ages as indicated below in Table 2. The newest groups were less than one year old and the oldest had been running for nearly 30 years.

[2] These classifications have been used to attribute respondents' quotes throughout the findings chapters. Due to their small numbers some categories have been conflated as follows; 'PH' refers to physical health groups; 'MH' to mental health groups; 'S' to social and social issue groups; and 'PC' refers to parents' and carers' groups.

Table 2 Age of groups

Age of group	0-5 years	6-10 years	11-15 years	16-20 years	>20 years
Number of groups	12	7	2	4	8

N=33

Table 3 refers to the size of the group "on paper" rather than the number that regularly attended meetings, which was, on the whole considerably smaller. It refers to the number of members at the time of the group's first interview.

Table 3 Size of groups

Size of group	≥100	50-99	25-49	15-24	8-14	<8
Physical Health	5	3	5	2	2	1
Mental Health	0	0	0	0	3	3
Social Issue	0	1	0	2	0	0
Social Group	0	1	0	0	0	0
Parents' Group	0	1	1	0	1	0
Carers' group	0	0	0	0	1	1

N=33

Table 4 indicates the number of groups that were branches or affiliates of national charities, or who had registered as charities in their own right. Their internal organisational structure, for example the existence of a formal committee and officers, is discussed at length below at Chapter 8.

Table 4 Groups' organisational status

Status	Independent	Branch of national	Affiliated to national	Registered Charity	Professionally Run group
Physical Health	8	8	1	1	0
Mental Health	6	0	0	0	0
Social Issue	1	1	1	0	0
Social Group	1	0	0	0	0
Parents' Group	1	0	0	1	1
Carers' Group	2	0	0	0	0

N=33

Amongst the sample, five groups were exclusively for women; four, all of which were also women's groups, were for a specific ethnic minority and one of these was solely for women over 55 years old. The remainder of the groups had no demographic membership qualifications.

4 Providing support

4.1 Overview of groups' purpose

The groups addressed a wide range of health issues from specific long-term physical and mental health conditions and learning disabilities to broader notions of promoting a "healthy lifestyle" and general "well-being." Unlike mainstream health services they did not aim solely to treat a condition or its symptoms but rather to "learn how to live with it" both in terms of morale or "keep[ing] your spirits up" and also with regards to practical matters such as driving, working or travelling abroad. This is not to say that any group was ideologically opposed to looking for 'a cure,' where this was relevant, but that this was approached within the broader context of the members' "whole life" as a "whole person." Nearly all groups saw themselves as having a social role which could be particularly important for those whose members' condition acted as a physical or psychological barrier or to which there were practical or institutional barriers against their social participation.

Groups' purposes tended to be expressed as processes rather than tangible outcomes, for example the provision of support, which was an aim shared by all groups. Similarly their role in providing information was sometimes seen as a process of "sharing experiences" or "continuous learning." Again this is an area in which they may be differentiated from mainstream agencies whose purpose tends to be expressed through more concrete outcomes.

The objectives in most groups extended beyond their meetings, encompassing activities that promoted awareness, education, consultation, and even, occasionally, campaigning or service delivery.

Table 5 below indicates the groups' main aims and the typical activities through which they were put into effect. The table is not exhaustive in terms of the links between purpose and process, as it could be argued that all activities indirectly feed into all aims and that links can be made between all objectives. Unsurprisingly, as they would not have been used to framing their activities according to these categories, respondents defined them in a range of ways; for

example, some saw social activities as a purpose in itself, whilst others deemed it a process through which to provide support.

Table 5: group purpose and activities

Purpose	**Process / activity**
Support	Face to face meetings: telephone help-lines: email contact: newsletters: contact outside meetings. social activities
Information sharing (within group)	Face to face meetings: telephone help-lines: guest speakers: literature: leader activity / expertise
Information dissemination	Awareness days: consultation processes: giving talks to other agencies. production of literature: newsletters
Social participation	Days out / celebration meals: sporting / cultural activities: fun-days: meetings
Network creation	Contacts with external agencies: contacts with community groups and voluntary organisations: consultation processes
Campaigning / advocacy	Consultation processes: writing letters: lobbying councilors and MPs
Service delivery	Providing children's / family services: providing training: telephone help-lines: receiving referrals from health and social care services.

Apart from one group, whose sole aim was to provide support, all groups had multiple objectives and in many groups there was more than one primary purpose.

Table 6 below gives a very simplified breakdown of the main purpose of the groups in the study. As will be seen throughout the subsequent findings the appropriateness of trying to ascribe a single primary purpose to self-help groups is often limited. A number of groups were in an on-going process of evolution in response to numerous factors including members' needs, funding changes or leaders' ambitions. In addition some groups felt that a changing environment, for example, improved services, had reduced the need for the clinical information previously accessed at their meetings, or for campaigning activities in which they had planned to participate. In addition it was clear from the interviews that in practice, as will be discussed throughout the remainder of the thesis, different group members tended to prioritise different goals and were using their group in a variety of ways, which would thus affect perceptions of its purpose. Having said this, the responses to the open questions asked about groups' aims were remarkably consistent with respect to individual and group interviews. A range of views was also in evidence in the slightly different meanings attached to terms such as 'support,' which some respondents construed as more personal, but others, as more practical. For example, the support referred to by members often took intangible forms, such as "understanding" or "listening." However, it was also talked about in terms of practical matters related to living with a condition such as getting "tips" about "going on holiday" or "getting insurance" and as such indicates the blurred line between information and support.

Table 6 Groups' primary purpose

Purpose	Support	Information	Support & information	Social activity	Campaigning & fundraising	Individual growth & learning
Number of groups	8 (24%)	3 (9%)	15 (45%)	3 (9%)	1 (3%)	2 (6%)*

N=33

* These two groups' purpose had changed by the time of their second interview 10 months and 1 year later. At the later stage their primary aims were described as support and support and social activity

Orientation

The purposes of and processes and activities undertaken by the groups have been broadly divided into 'inward-looking' and 'outward-looking' categories, although as Nylund (2000) suggests, these categories reflect ideal types that tend in practice to be far more blurred. Inward-looking roles are those that focus solely or primarily on the group members whilst those that are more outward-looking aim to affect the community or society more broadly. Typically groups' supporting role and the activities, such as group meetings, that enable this, as well as groups' internal information sharing and social gatherings would be seen as inner-focused in that their main effects are orientated towards the members themselves. External information dissemination, provision of services and advocacy or campaigning would generally be classed as outer-focused activities. However, the data indicate that drawing simple conclusions about a group's orientation is not straightforward. Firstly most of the groups undertook a mixture of these activities prioritising different ones at different stages of their evolution. Secondly, the concepts of inward and outward looking can themselves be misleading and simplistic in that the very personal support processes that take place in meetings will have numerous repercussions outside the immediate confines of the group. Later chapters will discuss how far theoretical ideas, in particular, "collective identity" (Melucci 1989, Habermas 1996, Dahlgren 2002) can provide the

means by which to conceptualise the external effects of these 'inner-focused' activities.

4.2 Shared experience and isolation

Probably the most important and frequently cited aspect of the support found within self-help groups was that which derived from being with people "in the same boat" who, through their shared experiences of the health condition or social situation that the group addressed, were able to listen, understand, empathise, encourage and share practical tips.

> When you come here and speak to [group leader] or speak to the *others you feel a bit better…you know you're* not the only one who *worries about stuff like this…knowing that you're not on your own, helping each other, but you're helping yourself at the same time*. (PC1-member: G[3])

> I think I just needed to talk to people that understood how I felt because unless you *'ve got it you can't really understand what it's like*. (PH15-member: G)

The need to be with these "similar people" stemmed from a very pervasive sense of "isolation" and of being alone in terms of the feelings and uncertainty brought on by their illness that could be seen as a sort of emotional isolation rather than isolation per se.

> It was just a relief to actually talk to other people with [condition] and *think 'hey I'm not completely off the planet, other people feel like that*.' (MH3-member: G)

> *When you come here it's the first time you don't feel that isolation…after they get their diagnosis it's like 'what now', who can I*

[3] In addition to coding responses according to the type of condition they addressed (see page 76, above), quotes are identified as 'I' if they were made at individual interviews and 'G' for group interviews.

even turn to you know so it's like it feels like just you and this big wide world. (PC3-member: G)

It is interesting to note however, that this sense of isolation arose, for the vast majority of respondents, despite the existence of extensive and very supportive social networks. The members of these networks though were felt to lack the ability to understand the particular problems faced by the group members.

I did feel ….that I was totally on my own apart from my family…I relied on them a lot really…I had the back-up of my family …[so] I would say it wasn't nearly as bad for me…they stayed with me, my husband and two daughters. (PH1-member: I)

*I did have a very good support system…..I mean wonderful but I k*new *they couldn't really understand how I felt…I mean friends and family were very good, we had a wonderfully supportive church, [but it's] just full understanding which you can't understand it unless you've [been* through that situation]. (S1-key member: I)

The issue of isolation thus appears to be somewhat more complex than the existing literature suggests as there was no sense amongst the groups of the type of social ostracisation (Cameron & Birnie-Lefcovitch 2000, Adamsen 2001) or "diminishing social support" and loss of "all your friends" (Munn-Giddings & McVicar 2006 p32) that has frequently been reported. What the respondents meant by describing themselves as isolated as well as how they responded to this state forms a central part of the discussion of 'collective identity' at Chapter 9 below.

The limits of group relationships

Although other members were clearly able to provide something, with regards to respondents' feelings of isolation, that family and friends could not, the support sought from these peer networks was limited in scope –both in terms of the areas of members' lives for which it was desired – being largely related to aspects of coping with their condition –and also the times and places at which it was seen to be appropriate. Although most groups met for social activities in addition to their regular meetings this was still within the official

confines of 'the group' rather than as more personal, friendship type arrangements. Similarly despite some group leaders providing their telephone number in order for members to be able to meet them outside the group this rarely took place.

> *I'll say 'if you want to pop round for a cup of tea you're more than welcome…if you ever feel lonely, don't sit on your own' – but nobody's* taken me up on it. (MH5-key member: G)

Most respondents, especially in mental and physical health groups, appeared to see the group as discrete from their broader social relationships. In fact very few were in contact with other members outside the group. There were some exceptions to this, most notably amongst parents' groups who met for social activities for their children and thus developed relationships with other parents. In addition, within a very small number of groups members spoke of friendships developing beyond the meetings and even very occasionally of a marriage having taken place. However in the vast majority of cases the social and support activities were limited to specific, official, times and places.

> *I think if we met every week we'd get bored…honestly I co*unt them all *as my friends but they're not my best friends and I wouldn't want to see* them all the time. (PH15-member: G)

> *We're not – we don't see each other in between – I suppose they're not friends in meeting each other, they're just very supportive*. (PC1-key member: I)

On the whole the data do not therefore support the view of self-help groups as spaces in which deeply personal, friendship type relationships beyond the group are a "psychologically important" component of the reciprocal support within it (Borkman 1999, Adamsen 2001, Munn-Giddings & McVicar 2006 p33).

The extent to which close relationships were nurtured or encouraged at the actual meetings varied amongst the groups. In some, there was a lot of informal conversation about personal issues and members knew about each other's lives beyond the group. These groups were more likely to see each

other as “friends”. In others however, there was little deviation from group business, for example, one mental health group which had been running for many years but in which relationships beyond the group were not encouraged, had a rule that nobody ask “personal questions” or “ asked anyone’s job.” In these groups there appeared to be a sort of bracketing off of the illness aspect of their identity and whilst seeing this as a valid part of their persona to share with the group this did not necessarily apply to the rest of their personality and lives. In terms of social capital theory the tendency for groups to foster this form of discrete, limited relationship raises interesting questions about the nature of the bonds and the types of trust that self-help groups encourage (Putnam 1995) and their consequent effects on processes such as network formation and political learning.

Limits of broader social relationships

In some cases in addition to the perceived inability of friends, acquaintances and even family to understand the situation faced by the members, respondents reported insensitivity and unpleasantness that could be very upsetting. Some respondents described how, because their appearance seemed “normal” other people expected too much from them, sometimes implying that they were playing on or exaggerating their symptoms.

> People often give y*ou ridiculous advice…’*what have you got to be *depressed about’ ‘cheer yourself up – do a crossword!’* (MH3-member: G)

> *There’s a lot of taboo around it* – people saying insensitive things and *expect you to have got over it in six weeks , they’ve got just no idea…and then they will say really unpleasant things…..and you really don’t want to hear that*. (PH18-key member: I)

The groups helped members to cope with this type of misunderstanding and tactlessness through its provision of a “secure” and “safe” environment in which people felt “relaxed and comfortable” to relate such stories including

about people whom they frequently loved, but who could, at the same time, be a source of frustration.

> And my husband – *he's very good and he always comes [abroad to* receiv*e the treatment] with me and he said 'it was a bit of an adventure at the beginning' and I thought 'no – it's never been,' so again, it's* about having someone to share that with. (PH10-key member: I)

Group members felt safe and at ease in the fact that they were "accepted" for what they were. You could "be yourself" and did not have to put on an act, pretend to "feel well" or make a constant effort to master their "embarrassing" symptoms which they sometimes were compelled to do outside the group.

> You feel *more open…..not embarrassed now about nothing*. (MH4-member: G)

> *I just sat at the group and cried…when you're at [the group] you can do that…no one thinks you're mad…..this is other parents, they* understand. (PC3-member: G)

4.3 Group values and ethos

This atmosphere was underpinned by two very important ethical values, confidentiality and non-judgemental attitudes. Consequently members felt able to speak in an uninhibited and unconstrained way that might not be possible within other arenas. The willingness of members to speak openly itself reinforced this high level of trust within the group.

> *I didn't feel I could go anywhere* – it was too embarrassing, I was very aware – *and at [the group] people don't judge you*. (PH1-member: I)

> There is a [community re*source] but it's a lot of people there…and* some people talk about you – here you feel confident, no one will go and talk to some other person. (MH4-member: G)

The effect of this atmosphere of being at ease, trust and openness coupled with the condition or situation that members had in common, was to foster a strong sense of group solidarity and collective identity which one respondent summed up as "just being part of something."

> There is a solidarity in the group where real people have got something in com*mon and we stick together…the enterprise is more important than the individual….it's ours it doesn't belong to anyone else*. (MH1-member: I)

> *It's a four walls policy – whatever is discussed in that context doesn't* go any further and I mean you can lay your soul bare if you wish to – *that's what binds the group together, because everybody knows relatively intimate details about other members which doesn't go any* further, so the group tends to stick together. (PH12-key member: I)

> *We just feel as though we're part of a group…you know so we are really strong socially together…it's a network*. (PC4-key member: G)

Members reported a strong sense of group pride in the achievements of individual members, all taking credit for the positive outcomes of the group. In one group a member, who had suffered from long-term mental health problems, managed to get a job through the input of the group – the other members felt that

> t*he rest of the ladies in the group should have the credit for it…I think we can take credit…[it] tur*ned out to be a wonderful day for her and the group as well. (MH5-key member: I)

> *[member's condition] meant he virtually would not leave his home – but it was the group got him to go on a trip …and since then he's a different man and he's come on in leaps* and bounds. (PH17-key member: G)

This group pride and solidarity was enhanced by awareness amongst some of the members of a few groups that the condition or situation they faced could be the subject of negative attitudes and stereotypes that could result in feelings of

exclusion and stigmatisation outside the group. The resulting feeling of being an "outsider" disappeared within the context of the group.

> *We had something in common…that same problem…you always feel you're the outsider…it was a bond*. (MH1-member: I)

Through the support of the group the members were able to derive the strength to face and challenge these negative views.

> *It gives you the confidence to challenge stereotypes…gives you hope* that you can do something. (PC3-member: G)

> I mean mental h*ealth has a stigma to it…cos my neighbour says 'if you can't sort out your own problem without having to go and talk to a stranger it's a poor thing' – she don't have the foggiest idea of what problems I've got but I don't care anymore, I don't care who* kn*ows…..yes absolutely that has come from the group*. (MH5-key member: G)

> Individual autonomy within the collective

The effects of groups' support processes, discussed above, stem from the idea of the group as a collective held together by bonds arising from members' shared condition, often in the face of a society perceived as either ignorant or even occasionally hostile. Paradoxically though, this collective identity was, in the vast majority of cases, grounded firmly in an ethos of respect for individual autonomy and individual difference. This manifested in the belief that each member was in the optimum position to adjudge his or her own needs with respect to the way they wished to use the group and the investment they would make in it. So, except in a very small number of cases, members were not required to adopt any set practices or roles within meetings and in no group were the members under a duty to share any intimate or personal details if they did not wish to do so.

> *You can talk about your problems….it's entirely up to the individual…. either we're getting them to talk about it or we leave them to sit in a* corn*er and if they want to talk about it they'll talk about it and the rest*

of us just automatically go into talking about something …..do they want to talk about it or do we leave them. (MH5-key member: G)

I never push them – *I always say 'if you want to talk openly you can' ……some people who come really just for the cup of tea and who really don't contribute anything, but I don't mind that if they're comfortable, that's fine…people don't have to talk if they don't want to*. (PH18-key member: I)

This respect for individual choice meant that, at first sight at least, there appeared to be no automatic expectation for people who received support from the group to put anything back into it in terms of contributing at meetings, as illustrated by the quotes above, or in terms of long term commitment to the group. Respondents stated that members were under no duty to maintain contact with or input into the group after they had derived the benefit they felt they needed from it.

People found they'd gained enough….enough confidence to have *thought well I don't really need the group any more …which is a good thing because even though I am still committed …none of the other original members are …they've all gained confidence from the group…..and moved on…people do need diffe*rent things from the group. (S2-key member: I)

*A lot of people come but then don't come back …I think that's what suits them and it's still benefitting people just to know it's there …there was one young lad, only about 25, and he came once then didn't com*e for ages and then a while ago he came back .. I think there will be a few like that who just need to come now and then. (PH7-key member: G)

I was like that when I was young - you distance yourself from it - You *get a lot of people join when they're first diagnosed …and then …they're gone and that's fine you know…we've helped them* – you *quite often find five or six years later they return again….when they* come back a second time they tend to stay. (PH6-key member: I)

These responses appear to challenge the view of self-help held by authors who directly correlate levels of participation with benefits. Borkman, for example, states that people who attend groups "only occasionally or who otherwise do not get intimately involved are unlikely to receive much help from the process" (1999 p 14). Clearly the current participants felt that there were many ways of gaining from the group, not all of which required an active or on-going input into it.

However, on closer reading it turns out that this acceptance of individuals' choice in how they use the group may be less straightforward than first appears. One respondent's interview exemplifies some of this ambiguity. Whilst he felt it to be perfectly reasonable that a proportion of members "might stay or might not," that in the "early stages" of participation "people are more likely to take rather than give" and that individual choice had to be acknowledged through a "recognition that …not everybody has to go to everything." He added however that;

> *It's not a group wh*ere people turn up and wait for everything to be done for them – you have to contribute – *there's an expectation that if you come you'll be part of it*. (MH1-member: G)

Yet clearly those members who didn't stay beyond the "early stages" and thus took rather than contributed were deemed to be making an acceptable use of the group. Similarly another group leader stated;

> *I mean if the group folds I'll be really sorry but I will not come back* and rescue it - *because if it folds then it's not doing the job it's* meant to be doing - *it's meant to be a mutually supporting group not one* person doing everything. (PH14-key member - I)

It appears that there may be subtle distinctions made between admissible and inadmissible ways of participating. In particular there was frequent censure of those whose only or main contact with the group was for social events or outings. These people were referred to pejoratively by respondents from a number of groups as "free-riders." Their desire to attend in this way was not seen as an expression of their autonomy or as their being the person best

placed to ascertain their own need, but rather as a form of abuse of the group. This was felt even amongst groups, including some of those quoted above, that believed there should be no duty to contribute at meetings or to group tasks, or to undertake a long term commitment to the group.

> *She only seems to turn up when there's an event on and that's not what the group's about – it's there to offer support, not for people to just* come for a good time. (MH5-key member - G)

This was felt despite the fact that one of the main benefits of this group was perceived as being it's provision of the opportunity to tackle situations that members' conditions acted as a barrier against their facing. The respondents however did not raise the possibility of this person perhaps being better able to deal with a more anonymous social situation than with a small and intimate group setting. Other groups were equally as inflexible in this matter.

> We have a rule that you have to come to three meetings to be able to go *on the trips…otherwise you just get people who aren't interested in the group…..we're going to be strict about that now* (PH7-key member: G)

Similarly, another group that regarded its "social interaction [as] the most worthwhile part of it" condemned members who were "not really interested – they're more interested in the next boat trip." One group was notable in its explicit opposition to this type of view. The members here thought there should be no exceptions to people's individual choice regarding what they wanted to get out of the group.

> some people do just want to tap in for information and go away and *you might not come again for a couple of years….. it depends what* people want at the time – some people might want a quick fix and not *something to get more of a grip on…..we don't judge people by how much they contribute or how much they don't* - we just want people to come - *it's like one of the parents hasn't been for a very long time and* we actually i*nvited them to our Christmas party and they didn't come and they said 'that's why we didn't come because we haven't been to anything else for such a long time we didn't feel as though we could*

just come to the party'…. and I said 'don't be silly – we would*n't have invited you if we didn't want you to come.'* (PC4-key member: G)

4.4 Social Participation

Despite some groups placing restrictions on attendance at social activities, encouraging social participation was believed to be intrinsic rather than additional to the support that they could offer. This was because members' conditions acted as a physical or psychological barrier to "get[ting] involved in life." The social interaction encouraged by the group was thus seen as a way to reintroduce members back into "a normal environment" where they could "participate in the ordinary life that's going on around." Many members described how they had become "insular" or "introverted" because of the stigma attached to their symptoms or illness. They described being too "embarrassed" to go out into the community because of their lack of "confidence" or self-consciousness.

> *We organise day trips, we've got youth clubs, so they're getting the social interaction now…our parents are beginning to access activities* – t*o mix socially…it's just getting together…we are really strong* socially. (PC4-key member: G)

> *We give each other confidence and we have outings…and it just helps everybody because there's one or two people in the group who can't get into town, who can't catch a bus….[can't] deal with crowds*. (MH5-key member: I)

> The social element was very important – *some of these women …just didn't get out*. (S4-key member: G)

Indeed in many cases this was not limited to returning merely to "normal" life, but was a means by which group members faced new challenges and addressed their fears;

> *We've been on boats…they got through it, they couldn't get on a boat* before – *we want to go back again now…there's crowds, people with* trolleys, you know that was a problem – crowds are a *problem….you've got to do it…if you're on your own you wouldn't risk* it. (PH17-key member: I)

> One girl [had to] stand in the foyer of the theatre, she broke down, she *was bad….but we calmed her down…and we was able to go in, she was fine wasn't she…no she wouldn't have done [that without the group] – she didn't go out at all*. (MH5-key member: G)

Although they were a large part of it, events and outings were not the only way in which the groups nurtured social participation. The meetings themselves were a vital means through which group members developed the confidence to go out into and meaningfully contribute to the broader society.

> *Many of them you really wouldn't hear them speak up, some might* come to the meeting and sit in the corner, but now to see how *they've grown and developed…it's given them ….the confidence to go out and* try and do new things. (S4-key member: I)

> *It's just the meeting together with people…it just gives you the confidence to try things you wouldn't normally have tried…we did this* [loc*al campaign] but I wouldn't have done that without the support of* the rest of the group – no way! (PH14-key member: I)

> *I was very frightened of going on the phone…but now I can do a lot of things on the phone…I think [the group's] made me feel 'yes I have* got the ability to do it.*'* (PH1-member: I)

> *People who've come to the group have got involved in other groups because it's given them the confidence* (S2-key member: I)

Respondents gave examples of specific outcomes that they felt were attributable to the support and encouragement they got from the group. For example one group described how "the one who doesn't go out at all" who "only goes to the group" found a job through coming into contact with the

managers of the venue at which the meetings took place. Other groups gave numerous accounts of how increased social interaction through the group resulted in the uptake of various activities within the community that would otherwise have been very unlikely.

> *One of the mum's….she's special needs herself and watching her, she's doing a voluntary course and she'd have never done that without the* enthusiasm the group gave her and just watching these parents develop and do things is amazing and then in turn how they help others. (PC3-key member: I)

> I was five years stay in the house and do nothing – *didn't have no friends, nothing, now I do English course and TA course…because of* being in the group. (PC5-member: G)

4.5 Promoting a positive attitude

Self-help groups have occasionally been accused of promoting a negative or victim mentality (Damen et al 2000, Elsdon et al 2000). The current data however emphatically support the more common view of these groups as promoting a sense of positivity amongst their members. Indeed one of the strongest impressions to come out of the data was the importance that was attached to groups' aim of providing support in such a way as to perpetuate a "positive", "hopeful" and "optimistic" attitude to life. Many respondents talked about their lack of desire for "pity"– in fact the group was sometimes seen as a haven against the unwanted, if well-intentioned, "sympathy" of others.

> *You don't want sympathy –that's not what I want*. (PH10-key member: I)

None of the respondents complained of having themselves been the subjects of the type of injustice or unfairness which could be used to perpetuate feelings of victimhood. This is not to say that they did not sometimes criticise services,

clinicians or aspects of their treatment which were felt to be inadequate or uncaring, but that this was not dwelt upon as a cause of any personal misfortune. On the contrary it was often referred to as providing the spark that led to the positive action of joining the group. Group members, in particular leaders, also sometimes perceived unfairness or injustice on the part of others. This was usually with regards to people seen as particularly vulnerable, for example due to their age, the effects of their condition or their educational or social background which prevented them from taking effective action to address their situation.

> *There seemed to be no advice, no help whatsoever…. she seemed to be so helpless and I had to push for her to have a consultation…. her generation tended to not want to bother people and think I'm not that bad I don't want to both*er the doctors. (PH9-key member: I)

> *People are reluctant to keep going back to their GP…..people have gone home and not understood what's been said and put up with an* extraordinary level of pain. (PH15-key member: I)

Again however this was discussed very much in terms of being something that the group had the power and the means and whose purpose it was to counteract. When this type of poor treatment had occurred members were admittedly offered a sympathetic ear if this were needed, but more importantly, the practical assistance and encouragement to ensure better subsequent treatment.

> I actually went with him yesterday to the hospital as an adviser - I sort *of I'm sort of an unofficial advocate I mean I was just offering him* support – but it looks a bit more official if you do go in with somebody because I said that I was a volunteer with [national organisation] and *that I wasn't very satisfied with the support they gave him last time and that he should be taken a little bit more seriously …. and this time h*e got the help he needed. (PH16-key member: I)

> *A lot of people are too nervous to go back to the Dr…we're trying to say to people 'look you know you have a right to the best treatment*

possible – *why don't you say to your own GP 'can I be referred?' …it's* like empowering people. (PH3-key member: I)

Similarly sympathy was offered to those who were undergoing acute crises or even just "down times." Members were not expected to be "falsely jolly" and some described how either they themselves or others might "sit and cry." This was very rarely seen to undermine the group's positive outlook; instead the group was providing a space in which negative emotions arising from a health condition or life-changing event could have an appropriate outlet in order that they could be dealt with, acknowledged and validated as a means towards subsequent progress. The groups performed the same function with regards to the frustration, guilt and even anger that a number of respondents reported feeling. Some of those respondents who placed most emphasis on their own and their group's positive attitude had initially used it as a means to "get [things] off my chest."

> *The guilt is absolutely, absolutely phenomenal ….we now have the group…to get rid of this…I don't know what I'd have done…without* people to share these sorts of feelings with. (PH18-key member: I)

> I was able to sound off- *I was able to get rid of my anger…about the* condition – *I'm a retired librarian for goodness sake!* (PH8-key member: I)

It was striking how people with sometimes severe symptoms saw the group as a way of perpetuating and encouraging the personal determination that would ensure members would not slip into negative cycles of self-pity.

> *The more you try and do things the better you become and you've got* to keep *on trying….some people, they're really in a bad way, they're really introverted and they really don't want to speak to anyone…we say to them just keep on trying…but then you see them after three months and they're speaking so much better*. (PH1-key member: I)

The extent to which words and phrases such as "inspire," "get on with it," "live your life" or "make the best of it" were used emphasises this intention to ensure that the types of support given by the group serve to promote a positive

attitude. Respondents frequently referred to "inspirational" people, who had spoken at meetings or helped them when they had first joined, as being a "role model" or a "positive role model." In turn they hoped that they could perform this function with new members.

> He *sort of took me under his wing…he said to me 'you've just got to keep on going…you mustn't let this get you down…and I looked at him and I thought …'if he can do that so can I.'* (PH18-key member: I)

> *[I hope] to act as a role model …I was so inspired by the* leader when I first joined. (PH8-key member: I)

4.6 Individual responsibility

Members were keen to describe their groups as "happy," "cheerful" places that most certainly were not "all doom and gloom" and that promoted optimism and a search for the best that could possibly be found in members' difficult, challenging and at times "awful" situations.

> You end up feeling 'there's no hope and he's not gonna have a life' and then when you come to [the group] you realise that they can still have a life, they can still do stuff.' (PC3-member: G)

This "cheerful" "optimism" often appeared to reflect a set of more serious values on which the support the group offered depended. The expectation of taking a positive approach to one's condition was grounded in a strong belief in "self-responsibility," "self-reliance" and independence. Both members and leaders frequently expressed a belief in a "duty" to "take action about it yourself" and to make full use of all the resources, including self-help groups, so as to best "help yourself."

> *Some people …they don't want to know….you have to get the best out of things…that's the way I think …but people don't want to be involved*

> – there can be resentment about being dealt this hand in life. (PH12-key member: I)

Members even saw themselves as having the right, if not the duty, to criticise others within the group who were being negative, apathetic or lazy. The right to "gee up" others in this way was a very valuable product of members' shared experience. This gave a level of mutual understanding and empathy that made such criticism acceptable, unlike when it was proffered by family, friends and professionals outside the group.

> Some of them sometimes need a kick up the backside. (MH5-key member: I)

> Somebody in the group might say *'hey we heard all that last week, haven't you got anything different' then that's acceptable because it's* coming from - *you know it's your peer group*. (MH3-key member: I)

The other side of this aspect of groups' ethos was that occasionally the focus on self-responsibility and positivity could have undertones of blame or at least frustration and impatience with those people who were seen as refusing to help themselves. Similarly there could be an unsympathetic response to those who were perceived to unnecessarily dwell on their problems. These individuals were not believed to be acting in their own best interests and were sometimes seen as a drain on the group and a burden on group leaders.

> *And I think 'come on …. It's not the end of the world for goodness* sake.*'* (PH8-key member: I)

> Do you know I found her quite depressing and I thought umm this is not *what I want…I want people who want to help themselves*. (PH10-key member: I)

Some respondents felt that only a certain amount of effort could reasonably be expected in an attempt to engage others in activities that would help them. And they were seen as having little right to bemoan their situation or treatment if they failed to take advantage of the assistance, such as the expertise and information that was shared within groups, that was freely available to them.

> *They don't want to join …I personally feel that's quite a blinkered way* of going on – *I think you should join even if it's only to meet people…and gain information….you can't turn round and say 'I didn't know that'* - you should do. (PH12-key member: I)

4.7 The "holistic" person

The findings discussed above indicate the emphasis that members placed on their shared illness or situation. It was frequently so central to their persona that it was regarded as a cause of strong feelings of isolation from existing social relationships. It therefore seems somewhat paradoxical that the respondents were, at the same time, extremely emphatic in stating their desire for their condition not to be their defining characteristic They referred frequently to "the whole person" and to the unique value of the group, as opposed to many professional services, as being its acting as a means to locate the illness, on-going symptoms or situation within the context of this "whole person." In effect this formed part of the process of "liv[ing] your life" positively that groups sought to promote.

> *I don't like to be described as a [condition sufferer] – I've got [the condition] but that doesn't define my personality….I dislike most* labelling. (MH3-member: G)

> *I don't want my [condition] to be my major identity* – I want to get on with things. (PH15-member: G)

The majority of the groups organised social activities outside their meetings and these sometimes took the form of sporting or other activities, including sailing, dancing and camping, that would usually be seen as beyond the capacity of people with their condition. These types of activity were sometimes undertaken with the express purpose of temporarily throwing off the illness identity or "getting away from the [condition] for a night". Meetings themselves were also arranged in a way that aimed to provide members with a balance between getting the information and support needed to manage their

situation, with the chance to do "something normal and have a bit of fun" through quizzes, games or creative activities that bore no connection to their illness.

> *Sometimes we have a quiz night….it's a bit riotous isn't it* – it gets you *away from talking about medical things because we don't always talk* medical. (PH18-key member: I)

Indeed in a couple of the groups they had arranged activities in meetings in which people gave talks and presentations specifically about an aspect of their past or present life unrelated to their condition.

> We know each other from our [condition] – *we didn't know each other* when we were young and fit, so I said I would do a talk – mine was *funny and [name] did one about adopted children…we had [name]* who used to play competitive cricket and all these things. (PH15-member: G)

This "holistic" attitude did not of course entail a denial of their condition or an attempt to hide it from their own or others' view. Rather, as discussed above, many members had seen the group as a vehicle that allowed them to be open with others about living with it. In fact it appears that prior to this openness with others the group could be a means through which to accommodate the illness within the "whole person" in order for members to come to terms themselves with what in some cases was seen as a new self-identity.

> *Oh yes, that wasn't the problem – friends and family, boyfriends aren't* the problem – *I'm the pro*blem – *I'm not the same person suddenly…so* I wanted to find a way to ask that question - I knew a bit about self-help groups - so it was well – *it was worth a try…I had to come to* terms with this – *'who am I now'* – and the others in the group they unders*tand, that's really hard with people who haven't experienced* [the condition]. (PH2-key member: I)

Indeed some groups saw an important part of the support they offered as being to challenge some members' reluctance to accept their condition as a valid part of their identity in order that it did not, through attempting to disguise it, come

to limit how they lived their lives. In some cases it appeared that, through continuing to attend the group, those members who did not accept their condition wanted to find reason to do so and saw the group as a safe place to go through the process of acceptance.

> *You can have things like covert [condition] where people don't* [display the condition] openly, so often you get people who are covert [sufferers] come to the group *as well…and other people would say 'no that's wrong – you should always try to say 'no I do [have the condition] but you must listen to me'….be truthful to yourself …[otherwise] that's going to start playing against your confidence*. (S2-key member: I)

> One *lady she comes here, she don't accept there is nothing wrong with you know [child's name] but she knows we say and [professional] says* you have to accept this – *why you won't accept this*. (PC5-member: G)

4.8 Summary

Virtually all the groups saw their core purpose as including the provision of support to their members. This could take a wide variety of forms including sharing information and encouraging participation in social activities. Such support, derived through being with people who had undergone similar experiences, was needed in order to address members' feelings of isolation. However, as will be expanded upon in the Discussion chapter below, this isolation was far more complex than initially appeared, referring less to members' tangible social networks, which were frequently both extensive and supportive, than to their distorted sense of self-recognition and social identity.

The groups' supporting role was grounded upon a number of ethical values, the interplay between which could be highly complex and that at times appeared somewhat contradictory. Again this will be elaborated upon in the Discussion section in terms of the process of collective identity formation. In short, the groups upheld strong beliefs in the value of solidarity and the

collective enterprise of the group, at the same time as that of individual choice and self-determination. Whilst they supported the individual as being best able to ascertain their own need and advocated a non-judgemental attitude towards how this choice was manifested in terms of how members chose to use the group, they imposed certain duties on some members and expressed moral censure and exasperation with those who were seen to flout core group values. This was particularly the case with individuals who were seen to have a negative attitude or who failed to take responsibility for their own wellbeing. The support offered within the group worked in parallel with their social activities that aimed to get members back into "ordinary life" and to ensure their participation in the broader community. This reflected the groups' belief in having a positive attitude as well as the essential value of social relationships.

5 Sharing knowledge, information and ideas within the group

Introduction

Until fairly recently literature about self-help groups has tended towards a "standard perception" (Adamsen & Rassmussen 2001 p910) of them as distinct from and reluctant to engage too closely with public service providers. One of the main factors differentiating the "two different worlds" (Wilson 1994 p1) that professionals and self-help groups were perceived to occupy was the epistemological basis of their systems of knowledge – self-help groups' being grounded on "stories" (Rappaport 1994, Borkman 1999 p 20) and experience, whilst professionals' rested upon the "logico-scientific method" (Borkman p15). The results of this were said to be the frequent mistrust and suspicion of expertise (Epstein 1995, Katz 03-4). Over recent years however this view has come to be seen as too simplistic (Borkman et al 2009) with commentators increasingly acknowledging the diminishing gulf between biomedical and self-help frameworks. Groups are believed to have become "adept at …. tapping professional knowledge" (Madara 2008 p158) and technical, medical information in order to both furnish members' detailed understanding of their condition and also, through amalgamating this with their own, highly valued, experiential knowledge, become "creators" of new forms of knowledge (Williams 2004 p435). The data presented in this section will be used to illustrate the extent to which current UK groups are acting as providers and producers of synthesised knowledge.

There were a number of discernible strands to the way that the groups shared knowledge, however, as with most of the processes occurring within self-help groups, these are not mutually exclusive and tend to affect and be affected by each other. The first, and most important, way in which groups share wisdom is internally, amongst the membership. This information sharing generally takes place within group meetings, and, for the vast majority of groups, is primarily concerned with increasing members' understanding of and ability to cope with their health condition or life-situation. To perform this role the groups relied on a range of sources including members' experiential

knowledge, professional advice and a variety of literature. Secondly many groups saw themselves as informal channels or as parts of networks of, mainly but not exclusively local, information. As such the process of sharing wisdom, which could be to do with access to services as well as local political issues, entailed a two-way process linking the group and the broader community. The third way in which groups shared knowledge involved the more formal dissemination of information through participation in awareness events, consultations and professionals' training. Clearly, of course, such participation would itself result in information being brought back into the group and would thus provide a source of learning to be used within the first two processes. In addition to these roles a large number of groups had physically produced their own information resources in the form of leaflets, newsletters and libraries. These were also being used across all the types of knowledge-sharing in which were groups were taking part.

The findings in this section are highly significant to the thesis' theoretical approach. Habermas' notion of the public sphere and those concepts on which its efficacy relies, for example, communicative rationality and a thriving lifeworld in communion with the system, are essentially discursive, dialogic processes. Thus the epistemological frameworks of those participating in the dialogues will be of fundamental importance with regards to both what gets said and the extent to and terms on which it may or may not get heard. Associations working effectively within civil society should act to rebalance the knowledge differentials that have the effect of excluding poorly informed private individuals from engaging in its debates (Habermas 1989). The data will therefore also be used to illuminate how far self-help groups allow their members to regain the authority to make epistemological claims and speak about matters that are often seen to have become monopolised by experts.

5.1 Informing group members: sharing knowledge about health

As indicated above in Table 5, 18 of the groups referred to "information" as being their primary or one of their joint primary purposes. Although the

meaning of 'information' could be different for different respondents, covering things such as practical advice, in nearly all these cases it included a strong focus on medical matters.

> *It's health focu*sed – not just general chat. (PH7-member: I)

> *It's a group ……. where we can discuss [the condition]…… we have a* head to head about [the condition]. (PH16-key member: G)

Some members cited this type of technical information as being the most valuable part of the group. And even amongst those groups that placed less stress on information, such as the social and personal growth groups, technical knowledge about health conditions that could affect the membership was still sometimes seen as important and could thus be the subject of either informal conversation or formal presentations from speakers.

> The most useful thing about the group – for the parents- is the use of the resource library. (PC3-member: G)

> The main reason for joining was all the expertise, especially when your disease affects only 1 in 10000. (PH12-key member: I)

The need for groups to provide this type of advice arose from a common perception that mainstream services were ill-equipped to effectively furnish members with the knowledge they needed throughout their diagnostic or treatment processes. This was especially noticed where the shock of being diagnosed with a serious condition meant that members were unable to take in what they were being told during their short and sometimes one-off consultations.

> *You're sent away from the consultant with a million questions but just a* sheet of paper –and it can be a long time before your follow-up [appointment]. (PC3-member: G)

The groups made up for this perceived deficit of knowledge through amalgamating information from a number of different sources, all seen as valuable in different and usually complementary ways. It was this combination

of diverse strands of wisdom that was often seen as the crux of the unique quality of support that self-help groups could provide.

> *I think I've learned more with self*-help than at the hospital – because *we've all had problems and someone's always had what you've had and can tell you about it and it's nice to discuss things ……[and] we* get about every other month we get someone like a dietician or the nurse. (PH7–member: G)

The groups thus tended to see themselves as "part of the continuum" of health and social care services whereby they acted as "a back-up to the NHS" through providing information in ways that resource limitations meant would not be possible from publicly funded providers. As such they believed they were benefitting not only their members, but also mainstream services.

> *Yes they have to support this kind of thing…we can back them up you see … they can say to their patients 'there is someone out there who ….* can answer your questions.*'* (PH6-key member: I)

And it appears, from the fact that over half of the groups had at some stage had patients referred to them, that this view may have been shared by many health and social care professionals.

> Professional expertise

There is no doubt that professional expertise was a highly valued source of information for most of the groups especially those for physical health conditions. Practitioners contributed to group knowledge through attending meetings, either as occasional speakers or within an on-going relationship, in order to offer advice which could be to the group as a whole or on a one to one basis.

> [The specialist nurse] used to come regularly – *she's been very helpful…so with anyone who's been recently diagnosed, she'll speak to them on a one to one basis …perhaps every two or three months*. (PH7-member: G)

The range of professionals that had acted in this capacity included; GPs; consultants; specialist nurses; mental health workers; community nurses; health visitors; speech and language therapists; dieticians; pharmacists; opticians; dental hygienists; podiatrists and physiotherapists. A small number of groups had also had visits from private companies that manufactured drugs or specialist equipment. The groups invited expert speakers at a range of intervals, with some having them as regularly as every other meeting. Only four groups had had no professional input at meetings. In just one of these cases this was because such input was felt to be inappropriate. The other three groups believed they were currently too small to justify inviting a professional but intended doing so in the future.

In addition to hosting guest speakers many groups had developed long term links with professionals who in some cases were almost seen as part of the group. These professionals contributed to knowledge both by attending meetings and by working, for example in campaigning, fundraising or distributing charitable funds, with group leaders with whom they would share their expertise on an informal basis. One physical health group, and particularly its two leaders, for example, had worked closely with a speech and language therapist for over 20 years. During this period she had kept them constantly updated on new research and therapeutic techniques and had introduced them to colleagues who specialised in different areas of treatment. Another group had worked in a very similar way with a specialist nurse for over ten years. One group, which, interestingly, existed to provide its members with alternatives to mainstream, biomedical knowledge, had welcomed regular input for over five years from health and social care professionals. The knowledge these practitioners provided was seen as essential to a thorough understanding of members' illness and its range of treatments, which, as discussed above, allowed them to make informed choices and to be able to properly articulate and justify their decisions to others.

> Of course we want to show there *are alternatives…..[but] we want their input ….we aren't saying we can't learn anything, the more views* you have the better you, you know with a complex condition – and no

> one fully understands it, but the better you understand it (MH6-key member: G)

A small number of groups reported difficulties in accessing or engaging clinical specialists. It is indicative of the weight generally attached to professional involvement that these groups were very persistent and sometimes went to great lengths to ensure these professionals' involvement.

> *There seemed to be real friction between us ….we've invited her as a* speaker about three times now and the last time she came and seemed *much more friendly…..me and [name] worked quite hard at building* that relationship because as I say they were quite antagonistic towards *us …it took two or three years to get to this stage*. (PH14-key member: I)

The extent of the groups' links with professionals meant that many had begun to see themselves as "part of the continuum" of health and social care. Respondents referred to what they were doing as being a "complement to" or an "extension of" public services and groups frequently expressed the desire to work "in partnership," for example through the receipt of "referrals" from health professionals; indeed it could be a source of disaffection when service providers were seen to be reluctant to do this.

> Members as knowledge providers

Despite the emphasis given to expert input into the groups, it was clearly only one strand of the knowledge sharing that took place within them. The other main source of information was the members themselves. The wisdom they contributed took a number of different forms. And, as discussed above, it was often very difficult to pinpoint where "support" ended and "information" began – a fact probably reflected in the number of respondents who cited "support and information" as their group's primary purpose. This blurring of support and information suggests that the knowledge which members were bringing to groups was of the experiential type that is traditionally associated with self-help groups (Borkman 1999). And indeed the sharing of "tips and advice" that the majority of groups valued very highly was generally perceived

as an intrinsic part of groups' supporting role. Having said this, the data encourage a more complex, nuanced view of the ways in which the groups interpreted different forms of knowledge. This is indicated by the fact that such "tips" were often grounded on detailed technical information. The blurring and amalgamation of biomedical information with wisdom gained through personal experience forms a central part of the Discussion at Chapter 9.2.

Leaders' 'specialist' knowledge

The majority of groups acted as repositories of, often quite detailed, medical information. This was frequently brought to the group by its key members, a few of whom had assumed the responsibility of undertaking extensive "research" into their condition. These leaders appeared to have a good level of knowledge about the biological basis of their illness and its treatment and management.

> The Ghupta programme is much more based on neuro-linguistic *programming and CBT …that makes it sound psychological but it isn't – it's a way of altering the pathways in the brain…I think that's the best one I've come across and then of course there's loads of supplements and you know diets…… there's now a urine test that proves you've got [the condition] or there's a test you know a brain* scan. (PH14-key member: I)

For three groups this was enhanced further because the leader had been or still was a nurse and one of these had specialised in the field that the group addressed.

The key members ensured that this information was up to date by "liaising with professionals in a big way" and reading official sources of literature from clinical research, national charities and service providers as well as through media reports.

> *I continued to research myself about the disease…the bio*-chemistry, *you know, the genetics…. It's only in recent years the* science has *moved on…. at meetings at HO there's always a research update but* they get really, really technical. (PH12-key member: I)

Some had even taken it upon themselves to try out new therapeutic equipment in order to report back to the group.

> The vibr*ation therapy ….. well this specialist says there's definite evidence ……. so anything like that my husband and I get very interested in ….. We can share it …..tell them the research that's been* done on it – and tell them to have a look at it and see what they think.(PH3-key member: I)

In most cases these leaders had developed close ties with a range of specialists and were also taking part in numerous consultation panels, strategic groups, research projects and clinical trials. Again these links were being used to provide groups with a pool of knowledge.

> We drove to meetings in neurology – we go to all sorts of things and it means we are able to - I mean we get a lot of information – *there's lots* of things I feed back to [the group]. (PH16-key member: G)

At first sight these data suggest the possibility that group leaders are essentially acting as an extension of or co-opting professional models of knowledge and as such could be seen to contribute to the creation of "lay experts" (Epstein 1995 p408) acting as authorities within self-help groups. However, there was no evidence of these leaders holding themselves up as such. Those quoted above all either prioritised their group's mutual support functions and the experiential foundations on which they stood, or rated these as equally as important as its knowledge sharing role. And they generally appeared to place no greater weight on technical information than on the other types of wisdom brought by the members. One of the group leaders quoted above went on to say.

> *This was a totally different kind of information …… there's a lot of experience and expertise and value and it's not all about understanding* the bio-*chemistry ……its skills that anybody who's looked after* somebody with [the condition] acquires and passe*s on …. and what* sufferers are going through, how they think – you get to understand more. (PH12-key member: I)

Another felt that his effort in bringing clinical knowledge into the group served the purpose of allowing members to make an informed choice as to whether or not to follow a biomedical approach to addressing their condition.

> *we want to show people what options are…….there are different things* there, not just drugs, you know a medical approach – but other things, *but you do need to know what's there*, and why they want to give you that drug or that drug. (MH6-key member: G)

Members' input

The aim to furnish members with adequate information in order for them to be able to make the most appropriate choices was also seen as one of the benefits of the broader medical knowledge to which most active members contributed. As with leaders this information occasionally derived from research or literature, however, more often it was based on members' own experience of clinical procedures and treatments. Conversation often focused on the efficacy of different procedures or the side effects of drugs.

> *[the consultant] wanted to give me….photodynamic therapy…which would have cost several thousand pounds…I discovered from the self-*help group that the chairman and another member were going to *special classes for…software on the computer…and I thought that I* wanted to spend the money on [that] rather than this treatment that might not work and it turned out that I made the right choice *because…it happened to one or two* of our members who were extremely disappointed. (PH8-key member: I)

Clinical matters sometimes gave rise to broader critiques of medical practices and how these might affect patients' health. For example in one group the pros and cons and possible consequences of the increased prescription of Statins were discussed at length. At one of their meetings a number of members of this group had brought in new self-testing equipment with which they had recently been issued and a variety of sources of information about its administration. They felt that the advice from different practitioners about the optimum frequency of its use was contradictory and confusing. The members used the

meeting to weigh up the relative merits of this information based on their experience of using the equipment and subsequently to formulate a number of questions to take back to their doctors.

Service providers were sometimes said to present complex information in ways that were incomprehensible to "normal" people. Respondents reported being "sent away" with literature with no "back-up" to help them to understand it.

> You get overloaded with information when you get your diagnosis – *you get all these booklets and stuff but then you're just sent away with* it – *but the problem is it's not in English and it's really difficult to* understand and you just end up getting depressed – *you can't* think.(PC3-member: G)

This could lead to members becoming confused and frustrated and to a sense of having a lack of control over their own fate. Discussions or "brainstorming sessions" at meetings however enabled them to "put things in perspective" and "get back to reality" by ascertaining what information was actually relevant to their circumstances and by helping them to focus on the more positive or hopeful aspects rather than just "see[ing] the bad" which tended to happen when they were "overload[ed]" with information with which they could not properly get to grips. This could be especially pertinent when treatments involved complex care plans or the interplay of many factors such as diet and exercise as well as medication.

> diet is something that is complex and that you need to update on –you *can't take in everything in one go…. when [name] started he was going* really over the top when he got his diagnosis and he was reading all *the food labels and not eating anything really ….I mean [name] is a lot* better now- *and he's put a lot of weight back on since he started* coming to the group. (PH7-member: G)

The members in this group had used, often light-hearted, stories about their own learning processes and experiences to show other members that through being informed and using the group as a source of continual "learning", you

could sometimes "get away with" being selective in the medical advice you followed.

> She gave me a big hug and gave me a four-pack of beer – *that's a [specialist] nurse! I mean I still like the odd pint…you have to do* things in moderation. (PH7-key member: G)

5.2 The scope of experiential knowledge

Tips and advice

That the preceding subsection followed on from discussions about clinical expertise in self –help groups may suggest that the members saw themselves as contributing to this type of expert knowledge through the information they shared at meetings. However despite the fact that illness-focused conversations were a common feature of the groups' activities and that the membership, not just group leaders, participated within these discussions, the members, and for that matter, many leaders, clearly did not perceive their input as being in any way technical or specialist, but rather preferred to frame it as "tips and advice." The respondents emphasised that they were not in the position to offer "medical advice" even though, as stated above, meetings included extensive dialogue about technical medical matters, in particular the use of medications.

> *We just all talked …you know on a non-medical basis…… we can even discretely say 'look we know there's that medication if you really, really aren't happy with what you're on why don't you say to* your own GP what about this.'" (PH3-key member: I)

> *We can't give people medical advice – because we're not medically* trained – *but we can give them what's best for us*- you know – *we don't* comment on medication – *that's between you and your GP* - although I*'m not on any medication for my balance* – but you tell that to *someone and they say 'why am I' and so I have to say well I don't know – you've probably got a different type because there are 100's of* different sorts of problems of [condition]. (PH17-key member: I)

These respondents illustrate the subtle ways that group members sometimes differentiated between giving authoritative "comment" or "advice" on medication that was grounded on knowing about it in a detached or technical sense and broader discussion of medication stemming from the personal experience of living with a condition.

> *We can't give medical advice that would be wrong…….we bring* information here about the [condition] - *[they] say we've learn*ed more here about the [condition] than from all the clinics – *we'll say 'I'm on this or that' – then other people say 'I've had that*.' (PH7-member: G)

Groups also shared practical "tips" on how they had coped with their illness. This covered matters such as driving, going on holiday or ways to remember the dates and times of appointments. In themselves these could be small things that would be unlikely to be within the contemplation of health practitioners; however, they could have a big impact on members' ability to undertake day to day activities or to face social situations.

> *There were quite a few of us saying 'has anybody else had this problem'…….I'd not learned to use a stick, things like that* – if you *walk at night in a dark street and you've got a car behind you with its* headlights on it throws your *balance off….or don't sit on these sorts of* chairs – they move, that can affect you. (PH17-key member: I)

Broadening the application of medical information

The experiential basis of this knowledge and members' concern to contextualise it within the "whole person" was commonly perceived to be a way in which it differed from expert knowledge;

> The NHS is more sort of medical - *they can try to heal you but…*– I think self-help – *they're more for you as a person whereas the health* service is more for you as a body. (PH1-member: I)

The range of experience within the group and the collective discussion about and reflection on other members' circumstances meant that groups were able to use their medical knowledge far more holistically than health professionals. Members were able to project the effects of clinical procedures onto the broader aspects of members' lives. This often involved sharing ideas about the psychological impact of available treatments. This was seen to be of fundamental importance to a person, and indeed their family, who was learning to live with their condition – yet it was a link which practitioners rarely acknowledged. One group described how, despite comprehensive input from practitioners about the physical and educational aspects of their child's condition none had linked this to his and their mental health needs. Another group leader stated.

> In fact the link between psychologists and neurologists is very *poor….but I mean the people who have [condition]* – the rate of suicide is higher, the r*ate of depression is much higher….but that connection isn't made*. (PH16-key member: I)

One leader, with extensive knowledge about the medical side of her condition, explained how new procedures, believed by practitioners to have lessened the psychological impact of the treatment because of their reduced physical consequences, could in fact have the opposite effect.

> The techniques, not to cure it, but to treat it have changed dramatically *and there's less and less invasive surgery so people that have had a* [episode of the condition] you know now you can come out of hospital *within two days and there's no marks you know there's no scars because it's all done with coil therapy which is put through the groin* – but having said that people with the coil sometimes suffer more *psychologically because their friends and family think 'hey you're ok' yet they've obviously had a very traumatic, life*-threatening illness and *that's what some of their families find difficult to cope with*. (PH18-key member: I)

Personalising knowledge

Viewing others as "whole" people meant that the knowledge shared by groups could be used in a far more tailored way. Members were able to use their own history and experience to empathise with others and thus to make sure that advice and information was appropriate to their particular personality and needs.

> *I mean he's what 20 and believe it or not I can remember what I was like back then! You know it's hard to deal with when you're young …..it affects you differently – it's the last thing you* want to hear – so *you can't just go in with you know 'this is what it'll be like from now on – you can't do this and you can't do that.'* (PH6-key member: I)

In this way, groups' knowledge-sharing role appears to mirror their individual focus discussed in the 'support' section above.

> This chap we were telling you about – he went to see the consultant *three months later and he said 'in six months' time you'll* be back as *you were before' now of course he wasn't…. I could really get cross* about that - *why don't* they say – *'everybody's recovery is different - but don't look for miracles.'* (PH18-key member: I)

Similarly the collective input from participants, at all different stages of an illness or medical process, meant that members could be prepared both psychologically and practically for what their future held. One of the main reasons why the groups were able to provide this more personal and appropriate information was because of the long-term nature of the relationships amongst many of the members. This allowed them to build up knowledge about others' characteristics and personal circumstances that was not possible within public services.

> *But [service providers] haven't got time to read through your case notes they don't know your child individually* – you know coming along

> *to something like this and getting to know other people's children you get to know the kids……. you can notice things or maybe just suggest* something that might be good for that specific child so in some respects it can be more beneficial. (PC4-member: G)

5.3 Getting the most from services

Access and availability

Many respondents stated that an important part of their group's purpose was to provide information about the availability of services and the most effective ways to ensure access to them. This "signposting" pointed in two main directions. Firstly towards services which were specific to members' shared condition, and secondly to more universal types of welfare benefit. It should be noted though that members tended to see this as a continuum of provision all of which was relevant to their recovery or self-management and not as two distinct categories of information. This type of knowledge was seen as so vital a part of the group's work because service providers such as GPs often lacked such information.

> *My GP didn't have a clue about* – I mean he was brilliant for the fact that he gave me a diagnosis but he had no idea how to proceed from there. (PH14-key member: I)

Another member described how before attending the group;

> *you're* just banging your head against a brick wall trying to find out *about services…..you don't have any way of knowing all this when you* get diagnosed – *I wouldn't know where to go at all*. (PC3-member: G)

Information about service provision was derived from the same sources as those from which groups gathered their medical knowledge. Speakers, professionals with whom groups had on-going relationships, leaders' links and members' knowledge were all valuable sources of advice.

> To help people find out where the help is – *we've had people from the PCT and we've had people from Rushcliffe and they've pointed us in* the right direction – and outreach, things like that. (PH9-key member: I)

> So we have one person – *she's very good from the mental health trust….she might tell us what's happening*. (MH1-member: I)

Health and education professionals with whom leaders were working on an on-going basis were sometimes able to provide information about the best routes through which to secure a referral to a specialist or to ancillary services such as counselling, occupational or speech therapy. The key members in one group for example had worked in conjunction with a specialist practitioner in producing literature that addressed the lack of awareness about how to access comprehensive support for their members' condition.

> How to contact her - *most importantly how to make contact…on the back [we put] all the names of the entities…telephone numbers, contact details because when people are first diagnosed ….it's become very* obvious to us over the years that they feel totally lost – *'what kind of medical advice is available to us?'"* (PH12-key member: I)

The quote above illustrates that the role of professionals in supplying this type of information was elicited in response to the broader knowledge gained "over the years" by group leaders and members through hearing about and discussing each other's experiences of services. Another leader described the different obstacles her members had faced in trying to obtain referrals. She had attempted to address this by merging members' shared stories and experiences with her own knowledge of the system along with that of an allied professional.

> *She's now trying to get counselling but it's very difficult to get the right kind of help…the after-care is not available because it's not part of the* hospital system – *we'd have to be passed to the primary care trust* – which then comes under mental health. (PH18-key member: I)

She intended therefore

t*o phone my lovely [consultant] and say 'please can y*ou give me a pointer to point her in the right direction.'

Key members and a small number of regular members were also able to address the need for information about services through their input into consultation forums, strategic planning bodies and self-management and Expert Patient courses. In some cases group members had been involved in the planning process through which specialist services had been set up and hence had extensive knowledge about where they were located and how they could be accessed. One leader had even participated in a council run audit of adult social care services. He and his co-key member stated.

> *There's a lot of activity going on for carers, a lot of government initiatives……we'll go to the meetings, we'll find out what's going on, we'll share it with the others*. (PH12-key member: I)

Utilising services

Members' experiences were a particularly important source of knowledge with regards to making the best use of services. They provided the means through which to make informed comparisons between different routes or different providers, and, by presenting the full range of options, meant that members were better equipped to address their own individual needs in terms of accessing the most appropriate support.

> You get regular suggestions and advice and you know everyone accesses different parts of the service so if a parent has an issue *another parent can say to them 'well my son's had SEAL or CAMHS or* you know this or that - have you tried contacting so and so. (PC4-member: G)

Their information was often based in their local knowledge of who's who and "what's going on" in their community.

> We know the district and the area and we know the doctors. (PH9-key member: I)

> *I also find it's an interesting source of information from th*e more *experienced members…..what mental health services are available ….[and] there's a lot of talk about* doctors and psychiatrists – who sees who and why, who gets referred to who and why. (MH1-member: I)

Sharing ideas within the group was also seen as a means through which to maximise the effectiveness of contact with service providers. This tended to be seen as something very constructive rather than potentially confrontational and thus in the interests of practitioners as well as members. Members described how medical professionals outside the group appeared to be supportive of its role in equipping members with information about treatments and referral procedures because the "time limited" constraints under which they saw patients meant that it was not always possible to recommend the most effective or efficient route and hence patients were sometimes not able to "get the most out of" their appointments. One respondent stated that group discussions.

> Give them a chance between visits to chew over the stuff and other people chime in and give people the chance to extend ideas and to clarify what perhaps they want to say to their GP when they next see him – so you get more out of it and hopefully the services get something out of it because they get a better patient. (MH3-key member: I)

In another group, sympathetic professionals were even enlisted to furnish the members with the information to take back out to their practitioners.

> We have a couple of professionals who relate to the group – *they don't* tell us what to do – we tell them, if anything we tell them what we want them to do for the group um so I see that as a strength of the group – it can help people well to stand up to professionals you know people who *are cowed really, afraid to say 'well I don't think I'm getting what I* really need you know.' (MH1-member: I)

A number of groups also acted as a focal point for information, often from local councils or 3rd sector organisations, about training and workshops in areas that would enhance service outcomes. In one group members had participated in events aimed at getting more out their children's Individual

Education Plans and statementing processes. Others provided information about empowerment and basic skills courses that would give their members the confidence to better be able to "speak up" and "stand up to" service providers.

A few groups also helped ensure better and speedier outcomes for their members by giving practical assistance with filling in forms and applications. This could involve formal help from group leaders and professional visitors or collective discussions at meetings. One group member described how this type of informal conversation about such procedures was "always going on" at the group and was helpful not just in terms of completing applications, but also in preparing members for and ensuring they knew what to expect at interviews, examinations and other eligibility procedures.

Welfare and wellbeing

A number of respondents felt that one major difference between their group's approach and that of mainstream services was that the latter generally had very poor links with and information about other welfare agencies and the services they provided. In part this stemmed from their narrow focus on patients' health condition which, according to the group-members, tended to result in their failure to connect this to broader aspects of welfare. Group leaders however tended to see issues, in particular relating to housing and finances, as a crucial part of overall well-being and hence of effective recovery and self-management.

> *'How do we claim benefits – are there any benefits?'…… [group* leader] and myself and others have been preaching on about this for so long now *– it's still disjointed – it's not joined up so you don't* necessarily get *referred on …you may within the clinical bit, but that won't necessarily cover you for benefits or for carers allowance...it* needs to be joined up somehow it all needs bringing together. (PH12-key member: I)

Because of this disjuncture members often relied on the information shared within their group.

> Information about other services and entitlement – *it's this type of stuff that's so valuable for parents*. (PC3-member: G)

A few respondents appeared to relate this need for knowledge to even broader concepts of empowerment – improving levels of information in order to increase members' self-efficacy, confidence and control over their own fate in the face of the greater power of the mainstream system.

> *Maybe it's not just mental health patients, but you're very* vulnerable actually because they have all the information – *you're just sitting* there and asking – *it's the same at the job centres and it can be the* same with health I think. (MH1-member: I)

As with other types of information, groups addressed this need for knowledge about ancillary services through a number of channels. Leaders used their "years of experience" to build up a reservoir of knowledge about, for example, "how to get yourself fast-tracked" for allowances and benefits that were of vital importance in light of their members' particular condition. Others knew where to access relevant leaflets and magazines that would provide the group with the knowledge it needed. In some cases leaders had even produced their own literature containing extensive information about welfare benefits. However again this type of resource became most valuable within the context of group discussion and reflection;

> *People can swap information about benefit entitlement ….it's very* much about exchange of information and it can be from anybody not just from the one or two [leaders] who bring in the leaflets and *magazines but you know because it's a very informal group people s*ay *'well I heard that so and so - do you know anything about it' and* somebody might or might not, somebody might at least find out about it. (MH1-member: I)

Personal links with other agencies were a very valuable route to accessing this sort of information. Leaders referred in particular to their contacts at local councils and in 3rd sector organisations as a means through which they could find out what members needed to know.

> So we have vast amounts of information and links now with a lot of organisations you know for signposting. (PC3-key member: G)

> Framework and Open Door organise meetings about benefits with someone who knows all the ins and outs and we exchange *information…… I know that Open Door are going to get one of their workers to come and give a talk and I've heard him talk before and he's very good*. (MH1-member: I)

As discussed at Chapter 4 above, groups placed a great value on social participation and its relationship to members' well-being, and as a result of this they valued information about the availability of and eligibility for transport services. A few groups had invited speakers to advise them about transport issues and in at least four groups, members participated in council run disability transport forums which provided a useful source of knowledge to be brought back and shared at meetings;

The vast majority of groups also perceived "continuous learning" as part of their broader, more holistic conception of health and well-being and to this end saw their role as providing information about educational and training opportunities as an important resource for members to tap into. In some cases it was the venue itself, in particular for those groups that met at community centres or community organisations such as Self Help Nottingham, through which they were able to access this information. And again this was an area in which leaders had developed links that enabled them to find out what was available and accessible for their group. A number of members had used this information to take up courses in various skills including volunteering, personal empowerment, English language and IT.

5.4 Summary

The dissemination and sharing of knowledge was part of the primary function of the majority of groups. Key to this role was the range of sources from which groups obtained their information and its subsequent amalgamation into a

unique form of wisdom ideally tailored to the fulfilment of the groups' goals. The theoretical implications of this fusion of different forms of knowledge are given full consideration in the Discussion chapter below and so only a brief summary of the key findings is included at this stage.

The respondents placed great value on expert knowledge with only one group seeing professional input as inappropriate. Groups made use of both one-off and long-term links with practitioners and had relationships with a wide variety of service providers including those from welfare, social service and local authority bodies as well as specialists in their own condition. In this they reflect their broader approach to wellbeing than that generally followed by health services and illustrate their responsiveness to the actual needs of patients which went far beyond the need for information on clinical matters.

The information that was obtained from professionals was not simply reproduced or uncritically disseminated by the groups but, through a process of conversation, reframed and applied in light of the knowledge that arose from members' own experiences of their condition, local services and available treatments. Respondents tended to conceive of their own knowledge, even when this was highly technical in nature, as qualitatively different to that of professionals - frequently making subtle distinctions between knowledge that was arrived at in different ways, that was being used to serve different ends or that furnished the same ultimate goal but via a different route or method. Knowledge brought to the group from any source was reinterpreted in light of all the available strands of information thereby giving rise to a process of knowledge creation. The groups could then apply this in ways that reflected the difference in emphasis between themselves and mainstream providers. This was most notably in terms of the groups' concern with the "whole person" as an individual as opposed to the more disembodied view of treatments and symptoms that tended to prevail within the medical establishment. By feeding this knowledge back into health care agencies through helping members to gain the confidence to better articulate their needs, the groups' unique form of wisdom was also seen as benefitting the system and bringing practitioners into a more communicatively rational dialogue with patients.

Members' were encouraged to bring up individual experiences of services and treatments at group meetings and at times this contributed to wide-ranging debate about health and social care policies and practice. In this way the groups were fulfilling the Habermasian idea of grassroots associations' role in civil society as making use of personal stories and experiences as a means of bringing life and meaning to broader political issues and thus promoting engagement in their debate.

6 Sharing political information

Introduction

The information sharing discussed above examined that which concerned members' health and general well-being. In this section the focus will be on self-help groups as sites of broader political communication. Over recent decades there has been a pervasive sense of decline in the quality of political discourse that is, or should be, the life-blood of the public sphere (Habermas 1989, Benhabib 1992, Alexander 2006). Habermas in particular has observed how phenomena such as the mass media, consumerism and the domination of experts have tended towards a depoliticised culture and dumbed-down political discourse in which people are concerned only with their own fate rather than with the communicative rationality entailed in the search for consensus about broader ethical issues or universal moral principles. The findings will be used to examine the extent to which such a view applies to self-help groups or whether, on the contrary, they have something positive to contribute to political debate in the public sphere through augmenting the quality and complexity of information on which political opinion rests, stimulating the discussion of new ideas and encouraging the participation of a broad range of voices.

6.1 The politics of health and social care

The majority of groups did not describe their purpose as entailing political activity and neither did many see themselves as being engaged in political conversation or information-sharing. Indeed three respondents specified that their group was not an appropriate forum for discussion about "politics or religion" and others stated that they tried to avoid "anything too political," an attitude especially prevalent amongst groups affiliated to national charities. It appears however that they may have been referring to "Politics" rather than "the political." Mouffe (cited in Dahlgren 2002 p13) distinguishes these concepts, defining the former as being concerned with government institutions

and the latter as a far broader notion encompassing the complex of social relations and ethical choices which directly affect people's lives. And most groups, including some of those referred to above, did indeed act as channels of information about such ethical matters as well as about the political issues underlying both the treatment of their condition, and health and social care services more generally. This ambiguity reflects the complexity and ambivalence in groups' attitudes towards political conversation. Whilst in some groups there was no express prohibition of any topic, in others, group leaders stated that sharing political ideas at meetings was acceptable as long as it was directly relevant to the members. And in a few groups it appears that whilst some types of subject were up for discussion this could be coupled with a reluctance to engage in party political arguments or controversial and topical ethico-political debates.

> *If it's relevant to what people need to talk about you know if they say 'I'm worried,* am I going to be forced back to work*?'* That sort of thing well that is relevant - *it isn't politics as such, politics we really regard* as you know, oh this government is this or that, rather than things that *actually affect you….how it's going to affect them personally*. (MH3-key member: I)

A few group leaders saw it as part of their role to gather political knowledge in order to share it at meetings. Leaders often gained their understanding of the political issues underlying their members' health care through both their own research and their extensive involvement in meetings, conferences and consultations;

> There was a lot of legalese, a lot of government initiatives – so if I go to a PPF conference - *and there's lots of them going on* – and I go to *the next [group] meeting .....I'll say .... You know 'did you know that* so and so*.'* (PH12-key member: I)

Most members appeared to appreciate the opportunity to access this type of information, which, without the group, may not have been available.

> And the changes – *there's always some act coming out…I don't know where I'd hear about it if it wasn't through, they are able to bring in publications, things like that …changes in the laws for benefits that's a* big question – there are big changes looming. (MH1-member: I)

Whilst there was no wish for political discussion to become their core purpose, members across a range of groups were often keen to use the knowledge shared at meetings to engage in this type of conversation. They appreciated the group as a resource for a variety of political knowledge, which could enhance their understanding of processes that affected them and that at times could "get you thinking" about their condition within its broader socio-economic context. In one of these groups, following a lengthy discussion, in large part made possible by the leader's extensive knowledge and the on-going input of professional visitors, about local welfare and education processes, the members went on to debate public spending cuts, their effects on local services and the disproportionate impact they had on "deprived communities" such as their own. In another group a key member who participated on a NICE committee stated.

> *It's a chance to get to learn what's going on, behind all the closed* doors – why the decisions get made - because otherwise how do [the members] get to hear about why this or that is happening – why these changes are being made. (PH14-key member: I)

Group leaders generally seemed to have high levels of awareness about current political ideas, priorities and terminology in health and social care. This was especially so with regard to patient and service user involvement.

> *Now they've got to be aware* – with Lord Darsai – *everything's got to* be patients – we can get in there. (PH17-key member: I)

> Activity which is forcing councils to put people first which is going to *change, transform …the way carers are funded …how they implement* the PPF, how they should implement direct payments. (PH12-key member: I)

There appeared to be an awareness of the importance of labels and definitions and the types of bodies that may play a part in shaping these. Some leaders saw the group as a way to increase members' understanding of the subtle ways in which a condition's classification could affect the attention and resources it received, and through gaining understanding of the political structures that were responsible for such processes this knowledge could be an additional source of empowerment for groups.

> The WHO has designated it as a major neurological illness – even the British government have designated it as a major illness that has a *severe impact on people's lives*. (PH14-key member: I)

> Health are way behind City Council in *consulting with carers … and there's a very fine line between health and care…… people might need all the care in the world but there's no funding for that* - so you need to really understand the health issues to tailor the health issues to the questions on the questionnaire - but the panel will all say *'that's not health that's care' and so unless you're crystal clear in your mind and* can say *'no it's health because x, y, z'.* (PH12-key member: I)

> Public funding of health and social care

A number of group leaders had extensive awareness about both national and local funding issues that could affect services for their condition.

> I was having a dig at the underspend on [the clinical area] in Greater Nottinghamshire in comparison with other parts of the country. (PH16-key member: G)

The groups shared ideas about the ways in which funding levels had an impact both on local services and also on the input professionals were able to have in groups such as theirs. In fact this information sometimes came from the professionals with whom they were linked. Their discussions about the effects of reductions in services' funding incorporated topics such as welfare benefits,

prescribing, after-care and diagnostic practices as well as more strategic matters such as changes in staffing levels.

> *Losing things like carers' allowance at retiring age – we think it's absolutely dismal…nothing supplements it* – they are taking away *nearly £50 in carers' allowance*. (PH12-key member: I)

> The specialist team now works very differently and they have to *account for all their time … there's just three nurses now covering 64* clinics - *one has gone on maternity leave and they're not filling her* post. (PH7-key member: G)

A few group leaders had also equipped themselves with statistical information that was relevant to the treatment of and funding for their condition.

> I mean the people who have [the condition] the rate of suicide is much *higher, the rate of depression is much higher ….there are 1000 deaths* a year in [the condition] which is more even than diabetes deaths and *yet it isn't recognised ….it doesn't go down as [the condition as the* cause of death]. (PH16-key member: I)

And whilst this type of knowledge may have been primarily utilised in political or consultation forums it was also clearly a topic of conversation within groups where the quantitative data were buttressed by stories of members' own experiences.

> There must be at least 500 people in the country with it, but a lot still go undiagnosed and will die or end up in mental hos*pital…my sister* had [the condition] but her death certificate just says liver failure –and I think that happens a lot – *I've heard that a lot - 'that happened to my* mum or my dad or my cousin.*'* (PH6-key member: I)

Groups provided the means by which to make comparisons between different facilities, practices and public services. This was frequently at a local level with members using group meetings to discuss different doctors, hospitals or procedures within their area. This provided a greater insight into the justification and rationale for professionals' diverse practices.

> *From the group's point of view it's hard to see where the prioritisation, how the prioritisation is made …how that's decided….there's a lot of* talk about doctors and psychiatrists and who sees who and why – because things are not usually explained – *there's a reason but it's not* normally communicated. (MH1-member: I)

Furthermore they were able to build a picture of the national and even international health and social care context. This was firstly through their membership which, for many groups, extended way beyond their supposed boundary to include participants from the entire East Midlands and even South Yorkshire and Lancashire. Secondly some were linked via their own, or others' websites which often gave rise to discussions with people throughout the whole of the United Kingdom and even internationally. This gave members the chance to compare the availability and quality of services which at times might feed into broader, high profile public debates.

> *Talk about a postcode lottery…..the list of people who can get free prescriptions was drawn up in the 30's* – really! –it depends on what *part of the country you live in …. I think all the members would tell you* something totally different. (PH6-key member: I)

This type of idea was often shared through participation in conferences, events and workshops organised by or through the national charities to which the groups were affiliated. All the national organisations funded regional and national meetings at which key members were able to learn from each other and gather information that could furnish local discussions about the respective quality of services and the extent to which national policy was being implemented locally.

> I think the main t*hing is when you go to be diagnosed it's a one*-stop-*shop whereas in Nottingham you have to go to your doctor … you have* to do it yourself. (PH8-key member: I)

> *Some areas have specialist [condition] units but we haven't got one here …even though the NICE guidelines came out, it's still patchy*. (PH14-key member: I)

6.2 Broader socio-political debate

Discussions about the adequacy of provision and funding for condition-specific services could occasionally lead to more general critiques of economic, health and social policies. At one group's meeting changes to the ways in which a member's treatment was being provided resulted in a wide-ranging conversation about imminent developments in the NHS. Members weighed up ideas such as the need for "efficiency in the NHS" against the dangers of introducing "profit as a motive" for providing services. Members discussed their fears and anger with certain policies, but also raised issues about which they felt positive, for example the possibility of increased "local control." Members' individual stories could at times reveal a concern with far broader values underlying health and social care policies. A member of one group for example had been continuing to claim free prescriptions when his condition was no longer covered by this entitlement. The group had talked about this in ways that clearly had a bearing on universal principles such as justice and fairness. In the same group another member's situation raised issues about power disparity in health structures.

> The girl I told you about down South – she got so badly disabled - the opticians, two years ago, saw Kayser –Fleischer rings and the *consultant said 'I'm not having any optician tell me my job*.' (PH6-key member: I)

A few groups also talked about broader political and economic issues. Again this usually followed on from members' narrower concerns, either as individuals or in terms of the group's functioning. For example discussions about the loss of funding for their own groups led members to reflect on the national political economy.

> I think in October government is cutting, cutting money – everything will be cutting – *pensions…benefits is very big problem*. (MH4-member: G)

The groups talked about a plethora of issues including the fairness of museum entry charges, fuel duty increases, inflation and public transport. One leader described how the members of her group, who until attending it had lacked the confidence or knowledge to speak up about political issues, were now "like sponges" in their keenness to absorb the information and ideas being shared. They discussed a "really wide range" of political issues from local government to the role of the state in welfare provision. Issues related to "youth," in particular crime and unemployment, were a particular concern.

> The real issue for the kids these days aint gangs and that, well yeah I *know they are a big problem in some areas, but it's jobs, it's all down* to jobs, if these kids aint got jobs - *my son in law, he's worked all his life, he's a hard worker, but if he don't get something soon you know* you give up hope. (MH5-member: G)

> W*e're trying to clean up the area with the youths and everything….criminal things, graffiti and gangs and that … so I read [the information] to them and this old woman says 'well that's it t*hen watch your purses.*'* (PH11-key member: I)

A few groups also acted as forums for discussions about the fairness of broad political priorities, in particular the pressure on groups such as their to attract ethnic minority members when this was not necessarily something over which they had control, and the perceived elevation of ethnic issues over disability or other areas of need.

> *There wasn't much emphasis on disabled people* – it was all channelled *towards the ethnic, BME and we started saying 'and what a*bout all the *disabled people' and I mean not just us there were other disabled* groups as well. (PH16-key member: G)

Cultural politics

Ethnicity and community relations, in particular between Asian and white populations, were a concern for some groups at a broader cultural level. A

number of groups had tried to engage local ethnic communities, but been largely unsuccessful in doing this.

> *There's a fair amount of Asian people with [the condition] …they tend not to get involved…we meet at the clinic but they don't really speak to us, don't discuss anything*. (PH12-key member: I)

This had resulted in group discussions around Asian culture that led in turn onto ideas about freedom of expression and the right to speak about issues connected with race. One group, whose small core of regular members included one Asian and two black people, had gone to great lengths to engage the local Pakistani population. They believed that their failure to do so was due to this community's regressive cultural traditions.

> There are a lot of Asian people with [the condition] but the women in *particular won't come to the group – we think it's their culture…a lot of Asian men aren't happy for their wives to go to a group like this… they don't mix, even their children don't mix*. (PH7-member: G)

Furthermore they felt that ethnic minorities could at times "use political correctness" to maintain their separation from the mainstream community and that groups like theirs were "put into the position where you can't say anything" about these issues due to the "fear of minorities and of a racism slur." Interestingly the ethnic minority groups themselves discussed similar concerns with regards to the internal politics and power structures on which their culture was based. There was felt to be prejudice against conditions such as disability and mental illness which meant that women in particular were reluctant to be open about them. This was compounded by the close-knit nature of the community.

> *There is Muslim women's centre …[but] some people talk* about *you…so we don't want this…. [they] will go and talk to some other* person – *others they might talk to some neighbour or to some family …. In our community they don't understand our situation like 'mental health' – even the husband don't understand*. (MH4-member: G)

In one group the members similarly described how they could be reluctant to act in their own or their children's best interests for fear of community censure.

> What will others think, what will family think. (PC5-key member: G)

They described how it was usually women who were blamed for the problems associated with their child's disability. And they felt that there was prejudice against disabled children who were not accepted as full members of the community. Coming to the group clearly gave these respondents the freedom to discuss these issues in ways that would not have been possible in their own community forums. And through recasting members' condition as "mental health" or "disability" rather than maternal deficiency the group had given them a whole new conceptual framework through which to understand and talk about their condition, thus providing the means to effectively articulate a challenge to the entrenched attitudes within their communities. These findings not only contradict views such as that of Borkman (1999 p.ix) that dichotomise "logic-scientific knowledge" and "personal experience," but go further even than those authors who acknowledge the use of technical information within self-help groups as a means to managing the physical aspects of a condition (Kush-Goldberg 1979, Radin 2006, Madara 2008). In the cases discussed above, scientific, biomedical knowledge was being used by members not only for practical ends, but in order to reinterpret their own subjective experience and reframe their personal, self-identity.

Broadening Horizons

Many of the groups talked about their meetings as spaces in which members were "broadening [their] horizons". The information and ideas discussed in this section were not generally approached from a political angle, however they included subjects such as environmental conservation and international poverty that have great political significance and their diversity was said to expand members' "worldview" by exposing them to knowledge and ideas that were beyond their usual experience.

> *Interesting meetings about subjects that you'd never heard before*. (PH9-key member: I)

> *Things you wouldn't hear about or even think about if it wasn't for the* group. (PH17-member: G)

Groups' conversations about novel topics came in some cases from members themselves who gave talks about different aspects of their lives.

> *People have got other life experience you know… …we have other interests…[name] did [a talk] about adopted children*. (PH15-member: G)

They also arose from the huge variety of invited speakers that groups employed. One of the most popular subjects was history – this was frequently local, but also included national and international themes. Speakers had talked about World War 2, the history of the theatre and the history of Africa. In addition groups had visited a number of historical sites such as Newstead and Calke Abbey and had followed these with related articles in newsletters, for example about Lord Byron and DH Lawrence. One respondent described how these historical talks helped the group to contextualise and reflect upon their current situation.

> *We had a speaker …she talked about the differences between then and* now – pointing out the different attitudes and what we have to cope with now *that we didn't then and vice versa – what's better now*. (PH9-key member: I)

Groups had also participated in numerous cultural activities. They had visited art galleries and museums and taken part in art and writing groups or creative activities in meetings. In some cases this could introduce them to new ideas from different parts of the world such as African drumming and Chinese brush painting. A few groups had given rise to off-shoot book groups and others had had prose and poetry reading, as well as talks from poets, at their meetings.

A number of the talks and activities that groups shared were given by people who had very different backgrounds to and experiences from the majority of members. For example in one group a member spoke about her years working amongst extremely impoverished communities in her native India. In another group a guest speaker, who had travelled throughout Somalia as a volunteer,

came to a meeting to talk about her work, and one respondent described how the Gypsy background of one of their members had inspired an "eye-opening" group visit to a Romany museum. Other topics at meetings included Fair Trade, animal welfare, wildlife conservation and the role of religious faith in wellbeing - topics which the members admitted they would have been unlikely to have given any thought had it not been for the group.

6.3 Group ideology

Self-help groups are believed to be guided by ethical principles and ideas at a number of different levels; for example, with regards to the types of support they offer; the group's inclusivity; its structure; or its relationship with paid practitioners. The literature has tended to focus on these more inward-looking aspects of groups' culture and has therefore only occasionally discussed them in terms of a politically oriented ideology (Emerick 1991, Hatzidimitriadou 2002), preferring instead to talk about their ethos, values or "meaning perspective" " (Borkman 1999 p16). The current study's theoretical approach however entails the examination of groups in light of political concepts such as citizenship, democracy and the public sphere, and attempts to locate them relative to new social movements against which they have frequently been compared, as well as to mainstream, public services. It therefore seems apt to ask questions about the extent to which the knowledge and concepts shared within groups contribute to the formation of a politicised ideology with regards to health and social care policies or social justice more broadly. When discussing a group's guiding beliefs there can be a tendency to refer to 'an' ethos, ideology or meaning perspective in unitary terms (see eg Borkman ibid) however as the findings in this section indicate this can be misleading – firstly because of the profound differences within groups and secondly because of the complex relationship between competing sets of ideas sometimes held simultaneously by individual members.

'Oppositional' and 'emancipatory' ideology

Perhaps unsurprisingly, in light of both the current post-emancipatory, lifestyle-focused political context (Giddens 1991), and the groups' aforementioned aversion to being seen as "too political," there was little evidence of a coherent or overtly expressed ideological "stance". Amongst the mental health groups, where the history of anti-psychiatry movements (Crossley 2006) may have led to the expectation of a more politicised ideology, only one group was to any extent self-consciously ideological in this way. And even this group could by no means be described as 'radical' in that it worked closely with psychologists and other practitioners and welcomed a range of views. The members did however speak in more politicised terms than the rest of the respondents and were clearly claiming to have developed a unique approach that was philosophically distinct from the bio-medical model and stood, if not in opposition, then at least as an alternative to it.

> There are other options there, not just one way of looking at mental health or mental illness –*it doesn't have all the answers, you know* doctors, psychiatrists - *it doesn't have all the, it doesn't have the knowledge to say 'we hold all the answers' ……..there are a lot of other things at work when you look at [mental illness] so it can't be as simple as psychiatrists would like to say, it's more complicated than just 'take this pill'….there are a lot of political issues going on*. (MH6-key member: G)

The remaining mental health groups displayed no intention to create a similar type of manifesto. Although some other group leaders were aware of the oppositional history of mental health activism they saw this as just one idea to be discussed and weighed up amongst others.

> *I don't think it has a collective view* – [the range of views] is talked about - *alternative therapies and whether it's good to take drugs at all – that's also discussed* – most people do but I know at least one member who is determined to stop taking drugs – *but we don't have a* collective view. (MH1–member: I)

Some groups explicitly distanced themselves from being seen as grounded in the type of emancipatory ideology that has been associated with social and activist movements.

> *We are not a parent power group……the way we work takes the pressure off schools…I mean I'd love to change the system [but] it's getting what's reasonable…where schools are concerned we would* never take a stand. (PC3-key member: I)

> *There's an* issue about being black, because, well you need to have a *boundary with a group….but there's no issues in the group about being 'Black' – the members aren't interested in that sort of thing*. (PH2-key member: I)

These quotes reflect the wider observation that none of the groups for traditionally marginalised populations such as disability, ethnic minority or women's groups raised the issue or adopted the discourses of discrimination or equality with regards to the mainstream society. Where discrimination was raised this referred to prejudice within ethnic communities, as discussed above in the section on cultural politics. To some extent these ethnic minority groups were promoting, at least implicitly, an emancipatory type ideology in their calls for greater equality and inclusion in relation to dominant structures within their communities. Indeed one member had framed this explicitly in terms of "power."

> *If women had more power …. then things will be different …I will show them everybody is the same……becau*se the mother understands these things. (PC5-member: G)

Indeed far from adopting an oppositional stance, the majority of the groups saw themselves as working in close complement to the health and social care system and thus presumably in broad agreement with its underlying values.

> Related to it, not separate – a development from other services. (PH9-key member: I)

Social justice

With the exception of the mental health group discussed above very few respondents talked in terms of social justice. Only a small number of groups referred to phenomena such as "deprivation" and "inclusion." One of these group leaders stated that she was in part motivated by the desire to help parents in the "deprived area" in which she lived "get access to things" that were available in more "affluent" communities. The membership of this group also discussed the effects of deprivation and social exclusion on the availability of local services. And, as a reaction to the perceived unfairness of some of the exclusive services provided by local schools, one of the group's fundamental principles, adopted as its official motto, was its inclusivity.

> [Group name] is for everybody. (PC3- members: G)

However, despite these references to ideas of social justice, the group only aimed to address them narrowly, in terms of "access" to services and facilities, rather than through action for wider social or structural change.

> So one of the aims is to help people to get access to things – *I haven't* achieved it all yet but – you know what I mean – even things like books and resources – I want parents to have access to them at the lowest possible cost, if any – what I can give away for free I will. (PC3-key member: I)

This appeared to be the same for those few groups that used "empowerment" discourses. One leader stated that group meetings were a forum for equipping members with the confidence to exercise their.

> *Right to the best treatment possible ….I know it sounds very political but it's like empowering people*. (PH3-key member: I)

Whilst another believed that the "empowerment" that the group promoted was a means for patients to take control of their health rather than be treated as mere "passive recipients." Other groups also talked in similar terms about their meetings helping members to be more assertive and confident and hence more equal in their relationships with health and social care practitioners.

Individual responsibility for health and well-being

This concern with access to services and with equality only insofar as it manifested within the practitioner / patient relationship rather than at a broader societal level reflects more basic assumptions in respondents' perceptions of health and illness. It was notable that, apart from the mental health group quoted above, none of the groups raised the issue of social factors as causally affecting their condition or well-being more generally. This was despite many of the groups operating in areas of severe deprivation and memberships that sometimes belonged to marginalised populations. Even the parents' group in which "deprivation" was an issue did not relate this poverty to the prevalence of the condition in their area or the ways in which it manifested or was treated. When asked whether their group ever discussed such issues, two mental health group leaders stated.

> No people are just concerned with their own personal – I mean there *are people who say 'it would be better if my depression had been* diagnosed earlier.*'* (MH3-key member: I)

> Its [about] positive psychology, around goal-*setting …it's all abo*ut *working on yourself not working for change…..I wouldn't have any* stance on [mental health] other than the emphasis on self-care. (MH2-key member: I)

This attitude is in line with the emphasis, discussed above, that many groups placed on self-reliance, self-responsibility and the need to "help yourself" as a means of coping and recovery. And whilst groups also acknowledged the huge importance of social networks as a factor in personal well-being, it was down to the individual to garner these networks by getting involved in activities such as self-help groups.

> *It's self-help from a collective point of view but it's also self-*help from an individual point of view because as an individual you start off going there because you want to get help – *so it's an act*ive step – *well it's an* active step in fact to keep going – *so as long as you keep going it's self-*help. (MH1–member: I)

Although the self-help group literature often refers to groups as the product of community breakdown (Jacobs & Goodman 1989, Katz 2003-4) none of the groups, interestingly even those few based in ex-mining areas, raised this as a political issue or as a reason for their starting the group. It appears therefore that these groups were working in line with dominant biomedical frameworks, which, despite over recent years having begun to place far greater weight on social factors (Scambler 2008), still emphasise individual rather than social aspects of health and illness. The groups' conceptual framework was thus able to slot easily into mainstream political agendas whereby attaining good health was a matter of individual action and personal responsibility.

> *There's this big drive at the moment for the over 50's to watch their* diet and take exercise – so it fits into that agenda. (PH9-key member: I)

> Hopefully [the members] will take control of their health – I mean *we're passionate about exercise and as a group we may try to push* forward the exercise aspect of it as well as the drugs. (PH3-key member: I)

Indeed in one mental health group a conversation took place about how attending the group should be welcomed by health practitioners because discussions at meetings meant that practitioners "get a better patient out of it."

Having said this, groups' views could at times be complex. Whilst seeing their condition as something within the ambit of personal responsibility, about which it was the individual's duty to "do something about", one group also felt very angry that their condition was sometimes portrayed as being the fault of sufferers.

> *They're saying people just get [the condition] because they're fat….like it's your fault for having [the condition]*. (PH7-member: I)

Another respondent described the heterogeneity within his group that had resulted in "endless…argument" about the difficult ideological issues inherent within the different ways of addressing his condition. The members of this group were divided between those who felt it was for them, as individuals, to

mask or control the condition's effects and those who felt that the problem lay in society's response to it.

> *People's views were very different …….some people would say 'uh I [have the condition] but I'm quite confident and if people can't put up with it then that's their problem it's not my problem' and other people* in the circ*le would say 'now come on you know that's not quite possible in practice' ….. other people say 'no I'm not doing that if I [display symptoms] and they can't accept it that's their problem, I just don't have a problem with it*.' (S2-key member: I)

Addressing stigma

The concept of health and illness as an individual rather than social problem was also in evidence in some groups' attitude towards addressing stigma. Even amongst groups for traditionally stigmatised conditions such as those for parents of children with learning disabilities, mental health and physical disability, some were either unconcerned with this issue or again tended to conceive it in individualised terms.

> *Stigma's been discussed …but in an individual sense - I feel if it's on* top of somebo*dy's agenda* – but not as a general political thing. (MH3-key member: I)

Rather than confronting this stigma a couple of groups chose to avoid using terms such as "mental health" in their group's name or avoided premises with connections to mental health charities or services.

> *I've tried to make it very explicitly not have mental health in the title……I don't have anything like depression or anxiety in the title*. (MH2-key member: I)

In fact far from making a stand against the process of stigmatisation a small number of physical health groups appeared themselves to contribute to or at least implicitly accept the stigmatisation of mental illness by their desire to

dissociate themselves from it - perhaps wanting to deflect any stigma attached to their own condition.

> *People think that you're not quite normal – that it's a mental health problem ….people think you're not normal*. (S2-key member: I)

> *I think as well it's the stigma of a brain illness* – you get these *misconceptions that it's a brain illness or injury so people aren't going to be all there….. I don't think our members would want to be put in* [the mental health] slot quite frankly – *I wouldn't have wanted to be ….. I don't want to sound awful – but that's not for people like us*. (PH18-key member: I)

The majority of the data thus appear to challenge the traditional idea of self-help groups as acting explicitly as sites of resistance to stigmatised identities (Ablon 1981, Borkman 1999, Goldstrom et al 2006, Chamak 2008). Having said this, such an attitude was not apparent in all cases. A small number of groups problematized and felt it was their obligation to challenge negative social attitudes. A few groups also saw it as their duty to stand up against negative media images of people with their condition. Although in some cases this may only have entailed discussion within meetings, this clearly gave members greater confidence to challenge such portrayals, if only through the fact that it vindicated their feelings of upset or frustration in response to them. In one group though the members had gone further and in addition to a long and angry discussion about a media story in which their condition had been presented, by both a politician and the leader of a national charity, as being the result of the unhealthy lifestyle choices made by sufferers, formulated and sent off letters of complaint outlining their concerns with and the inaccuracy of how this condition was depicted.

6.4 Labelling and terminology

The groups were generally happy to adopt or be conferred with medical labels including in areas such as mental illness, depression, autism, anxiety, ME or ADHD in which questions have been raised about the appropriateness of 'medicalisation' and excessive diagnosis (Barker 2002, 2008, Conrad 2007). Indeed in a few cases, one of members' main issues was with healthcare providers' reluctance to diagnose a specific condition.

> *There's a certain amount of criticism probably usually about GPs who haven't understood and diagnosed the problem* – but then those people move on to a different GP. (MH3-key member: I)

The majority of members of groups for these conditions were keen to obtain diagnoses and to come within the aegis and nomenclature of health services, indeed they often saw their group as a means by which to help others secure a diagnosis and subsequent access to services.

> We can give people like a checklist which is something called the Canadian Criteria – *which if you've got any one out of some of the groups of questions then you've almost certainly got* [the condition] so yeah we can help people with that. (PH14-key member: I)

> [The group] can help you say the right thing and ask the right questions - then the health visitors have to accept something is wrong with the child. (PC5–Member: G)

Interestingly, in the group quoted above, it was the professionals in attendance who argued against hasty diagnosis, feeling that this could "label the kids and set them on a path" that might not appropriately reflect their real needs.

One group had even amended its title, against the instincts of its leaders and members, in an attempt to fit more closely with mainstream services.

> We added the [additional title] – it started out as just [original title] but we changed it just because the medical profession insist on calling it [additional title] even though all the patients call it [original title]. (PH14-key member: I)

However attitudes towards labelling could be complex and could even differ amongst members within the same group. One leader described how it was not the assumption of a label that was the problem but rather the reluctance of some people affected by the condition to accept it.

> *Sometimes they either don't accept it or they haven't told the child or they haven't told family and friends but the rest of us we h*ave all accepted it. (PC4-key member: G)

Another group leader was a little more ambivalent. Whilst he acknowledged that some of the members "wouldn't see themselves as ill as such" and would be "put off by [mental health] labels" he appeared to see this as a lack of acceptance of having a clinical condition. And despite his desire to work more closely with mental health services he was careful to present the group in a way which would not make this connection obvious.

> I thought people would be more open to saying that they were stressed *than admitting they might have a medical diagnosis…… the people who've approached so far they can't be open about seeking help……[so] it's not explicitly health, so it's right at the edge…. the next wave of promotion that I'm* doing is going to be in GPs and health *centres and to contact the community mental health teams…..but yeah I don't want to be visibly associated with them*. (MH2-key member: I)

Indeed as this very new group became more established over the course of the research the leader had altered his view of the members' reservations.

> *We've shifted to more of a diagnosis label…what people ask about…. [it's] about generally that they're, that they have anxiety or*

> *depression…..[they have been] given that label and they're* keen to do something about it……

However this was still coupled with a reluctance to make these diagnoses public.

> *…….But we don't want our photographs in the paper!*

Whilst most groups did not challenge medical terminology some were concerned to recast their diagnostic labels in a more positive light. One group for example had brought a poster to their meeting which the members felt suggested that their condition was fatal and untreatable. They were very aggrieved about this and believed that it encouraged a negative and defeatist attitude. Other respondents similarly felt that the group provided the means to portray a more favourable image of their condition.

> When we first started the group all of us believed that you never got better from [the condition] *but over the last four or five years we've* had about half a dozen people actually get better completely and actually go back to work so we now – our emphasis has changed and when people come we say that only 25% of people stay really ill and some people get completely better and most people get a lot better. (PH14-key member: I)

Most members were comfortable to be referred to as "a diabetic," "epileptic" or "disabled." Similarly many referred to themselves and their members as "sufferers" and "patients." Interestingly only two respondents disputed the use of the term "victim" and one of these was herself not a sufferer of the condition, but rather a helper in a very atypical self-help group that was run wholly by volunteers.

Only a small number of respondents raised the issue of labelling as a negative phenomenon. They felt that to be referred to by a medical title diminished the rest of the individual's identity.

> *I'm an awkward person I dislike most labelling – I don't like to be* described as a depressive – *I've got depression but that doesn't define* my personality. (MH3-member: G)

Another group had even changed its name to reflect the members' belief that inappropriate labelling could be stigmatising and affect members' self-identity.

> The group thought we *should change it…… it can be stigmatising to call someone a [sufferer of the condition] …… it puts you into categories….. so we wanted to change that um to make it just 'for people who [have the condition]' which is less putting you in a box if* you like so that was why we changed it. (S2-key member: I)

Some groups raised the issue of labelling and terminology beyond their specific condition, in broader areas of health and social care. This was often with regards to the use of "politically correct" attempts to re-classify "patients" as "service-users."

> *[I'm] on the committee as a service user – I don't like that* – as a patient – *I'm a patient*. (PH10-key member: I)

One group discussed the origins of this type of terminology, deciding that it was derived from "academic literature" rather than from people with actual experience of health conditions.

> *One of the topics of discussion was we didn't like being called users……[everyone] said 'we don't want to be called users we're patients' – I mean you don't call somebody a user who's diabetic- it's only used for mental health patients so it's seen as derogatory*. (MH3-key member: G)

Another group felt that the designation by service providers of one of the activities it offered as "community care" had negative "connotations" that the "members don't like." And a couple of groups even believed that the title "self-help group" was affected by political factors. One of these thought that its categorisation as such was a result of the hegemony of a local third sector organisation that benefitted from defining groups in this way.

> I think self-*help group is perhaps a term ….that has been put upon us - you could say there's been a little bit of brainwashing because of [*the local organisation]. (PH16-member: G)

6.5 The culture of heterogeneity

The groups' defence of individual outlooks, differences amongst members and the lack of a "collective view" appeared in many cases to itself be a central part of their belief system. This was evident across the range of groups in which there appeared to be no desire to create a dogma of the type that has been associated with lobby groups and social movements (Epstein 1995, Crossley 2006) especially in politically controversial areas such as mental health and the of use of special, versus mainstream education for learning disabled children. The leader of a parents' group stated.

> *Parents have different views …some of our children may be able to* access a lot of mainstream - *there are still a lot of children that can't access mainstream…parent*s talk about their own experiences with *their own children but nobody would ever think 'oh she's living in* cloud cuckoo land.' (PC4-key member: G)

Another group leader discussed how in his group there was no collective stance but rather.

> Endless, in a way *argument because people's views are very different and you have to listen to different people's opinions*. (S2-key member: I)

Even where the entire core membership was in firm agreement, attempts were made to compromise with outlying views. For example in one group the vast majority of members felt very strongly that people should be open about and accept their child's condition, however they still tried to accommodate the few parents who did not accept it by alternating their meetings between those that were overtly for children with the condition and those that were stated to be for the parents of any child.

In one case where a leader had, unusually, attempted to impose a homogeneous "evidence-based," "goals oriented" ideology upon the group at its inception, the opposing outlook of the rest of the membership resulted in this being abandoned in favour of a far more flexible and eclectic approach.

> *I think people are essentially coming for friendship ….. and I think with all the social activity that's where it's heading towards….. I think the compromise that we're trying to do is to split it so one session month is* about talking about things and one session is more about the social and *it's up to people – they won't have to attend both but its clearer one* will be more light hearted and about enjoyment. (MH2-key member: I)

Conflict

In a number of groups the culture of heterogeneity actually gave rise to regular "heated" arguments and even "conflict" over ideas and values.

> *Oh there's loads of disagreement in* fact some people come in and I *want to wear a flak jacket because people aren't slow in saying 'come on this is a load of rubbish' and yet other people will say 'don't you dare say that'….a healthy debate!'* (PH14-key member: I)

As with the above respondent this was generally not seen as a problem but rather as a positive attribute of the group, reflecting its ethos of valuing the individual and a range of perspectives.

> Well as a group we have our tensions – we are a group of people, strong minded people and *there are disagreements…differences of opinion…but they're all resolvable…it's a disparate group of people from very different backgrounds…I don't think conflict is necessarily a bad thing…I don't believe in a false type of agreement, where everyone's pre*tending. (MH1–member: I)

And despite being heated these disagreements were very rarely the cause of long-term tensions or splits within groups.

> They were fairly amicable and even though people on either side of that *argument could get very irate it didn't* stop the meeting going on and it *didn't stop them coming back in future*. (S2-key member: I)

> *But even if we've had a heated conversation we all* – one thing we all *do when we're leaving is give each other a hug and kiss – I've never* known us go out of the meeting with angry words. (MH5-key member: G)

Groups' disputes centred on a range of topics, for example one group was embroiled in an "endless" argument about the ideological issues inherent in members' perceptions of how their condition should be presented within the broader society and the extent to which their role should be to challenge negative social responses towards it. Arguments often arose from members' differing views about treatments and in particular whether there was any value in alternative medicines. Even though many groups saw themselves as non-political, conflict could at times arise about national events or news stories about which members held strong views. One group had had a very "heated" debate about both parental responsibility and the role of the media following the disappearance of Madeleine McCann. Similarly more domestic political matters could be the subject of disagreement. This could entail very personal areas such as the moral issues inherent in child-rearing practices, however, again this was seen as something valuable, giving members the means to reflect upon their own presumptions and see things from a broader range of perspectives, even if agreement was not ultimately reached.

> *We don't agree in everything* – it is good- she is saying something else, some, these young ones are too modern in thinking everything is ok but also some us old ones yes are too old fashioned. (PC5-member: G)

In some meetings group issues themselves were couched in broader ethical terms about which members held opposing views. For example in one group's meeting a member felt very strongly that self-help groups should not be funded for social trips and outings. He stated that this "wasn't right" and that it diverted money away from where it was "really needed." The remainder of the group (which had itself benefitted from such funding) strongly opposed this.

The divergence of views resulted in a wide ranging debate about the fair allocation of public resources in which the majority of the members enthusiastically took part.

6.6 Summary

The groups did not see themselves as engaged in political conversation or activity and they were keen to distance themselves from any overt ideological stance. On the whole they made little connection between their condition and issues of social justice, tending instead to see health, illness and any attendant social problem such as stigma in individualised terms. On one hand this could uphold a view of self-help groups as non-political and failing to engage with the type of universal issue that Habermas saw as an essential part of the public sphere. However, on the other hand, as is considered more fully throughout Chapter 9, their ideological pluralism and lack of an oppositional stance meant that groups were contributing to the public sphere in other ways. Firstly it enabled the groups to act as repositories of information from a variety of sources regarding changes to legislation, welfare or services that could feed individual opinion formation and hence the overall quality of public debate; secondly, it enabled them to form constructive, consensus seeking relationships with the system; and thirdly, it allowed members to engage in very open, unconstrained conversations that frequently entailed discussions about broad political issues that ranged from national economic policy to childrearing methods or animal welfare. As such they were indeed concerned with topics that went far beyond their own immediate situation or subjective need. Furthermore, the introduction of cultural, literary and historic topics often presented by members or guest speakers with very different backgrounds and experiences to the bulk of the group served to broaden horizons and presumably therefore the scope of members' empathy and understanding of others.

Respondents were generally happy to accept medical labels and to use group knowledge as a means of encouraging clinical diagnosis. However, this was

undertaken not as a means of attaining the type of 'victim status' that Elsdon et al reported as prevalent amongst the groups in their survey, and that could, as will be further considered at Chapter 9, contribute towards the juridification of members' problems. Rather it was in pursuit of the positive social relations that were a primary goal of most groups and that underpinned members' autonomy in the lifeworld. Thus if the groups were contributing to the process of medicalization, of which some self-help groups have been accused, it would be in a manner that supports Broom and Woodward's (1996) view of this process as potentially enabling rather than straightforwardly disempowering.

7 Sharing knowledge and ideas beyond the group

Introduction

Self-help groups have at times been accused of insularity and contributing to a society in which social and political problems are increasingly removed from the public sphere into purely private spaces (Bauman 1999). Similarly through their perceived contribution to the process of medicalization (Barker 2002, 2008) it has been suggested that groups have abetted the co-optation, by technical experts, of ethical and political questions, thus increasingly excluding the wider society from contributing to debate in such areas. However the groups here had a very strong focus and placed great value on activities and communications beyond the group, frequently acting as a bridge between the public and health and social care institutions as well as between local community associations. The groups saw themselves as two-way "channels of information." This provided the means to both enhance their collective wisdom, by broadening the scope of sources from which knowledge came into the group, and to disseminate members' ideas, concerns and values back out into the broader community. They undertook this information sharing role in various ways. Sometimes it could be through informal means such as casual conversation with friends and neighbours, or the development of local hubs of knowledge by linking in with other community organisations. At other times it could be through more formal processes, namely, consultation, awareness events and input into professionals' training. As well as this some groups became involved in what they termed "campaigning" although, as will be seen, it was often not clear how groups were differentiating this from the other types of activity. Indeed the groups tended to conflate all these processes and frequently used the idea of "raising awareness" to encompass any activity through which they spread their knowledge and ideas or expressed their views.

Through sharing information outside the group respondents intended to fulfil a number of aims; they hoped to have an influence on policy development and

service delivery; they wished to increase acceptance of and educate, both professionals and lay people, about their condition; and they aimed to empower their local communities through providing the means for "getting to know what's going on" in public agencies and political processes. The information shared through these channels was vast and diverse and as well as increasing members' understanding of "how things work" at a political level, there could be tangible benefits such as alerting them to facilities, resources and local opportunities.

7.1 Participation in formal consultation processes

The extent *of groups' input into consultation*

Seventeen of the groups had at least some input into consultation type activities. The range of involvement, in terms of both the type of forum in which they took part and the frequency of their participation was very wide. A small number of groups had only participated in informal ad hoc or one off procedures. Most, however were participating regularly in more formal consultation and service user panels. These included LINks, GP practices' patient participation groups, Health Action Groups, mental health user forums and PCT and hospital trust Public and Patient Involvement meetings. A number of groups were members of strategy forums and steering groups - this could be for specific conditions such as dyslexia, multi-condition organisations such as for neurological or musculoskeletal illnesses or even more broadly for pan-disability groups. A few were also involved at a strategic level including at NICE and the Care Quality Commission. As well as health based processes some groups were represented at County and City Council meetings, for example in the Carers' Advisory Group, the Disability Transport Group, the Police Authority Strategy Group and the Equality and Diversity Group as well as in voluntary sector panels. Most of the groups had taken part in a number of these bodies' meetings, with eight having been involved in three or more.

The aim of groups' involvement

The groups were involved in consultations because they felt strongly that they should "have a voice" and a space in which they could express their opinions about the services that affected them.

> *You also have a voice and that's the nice thing for me ..... if you want* to say what you think. (PH12-key member: I)

There were two aspects to this 'voice.' Firstly, at an individual level, in providing the means to express a view and "say what you think" it gave members a greater feeling of self-worth and control and as such contributed to the role groups played in promoting a positive, pro-active outlook.

> Having some in*fluence because in a way that's part of the thing that* gives self-respect to folk who are receiving a service – that they can give some feedback – *they're not just passive recipients*. (PH15-key member: I)

Secondly it was hoped that through stating their views groups could influence policies and services.

> *We want a better service for people with [the condition]……. you know* we are able to put a bit of pressure on the council put a bit of pressure on Primary Care Trust. (PH16-key member: G)

Consultation forums were seen as a two way process through which members could both receive information that could be taken back to their group and also share their experience and knowledge for the benefit of patients, service providers and policy makers. One described the purpose of involvement as being.

> To pass on and share information with people and gain information - and things are changing so fast now. (PH12-key member: G)

Representing the group: Key members

The findings present quite a complex picture of the weight given to consultation relative to groups' other purposes and the extent to which it was seen either as a group activity or the individual pursuit of one or a few key members.

In approximately half of the groups that were involved it was either the group leader or a small core of key members who undertook a role in consultations. Whilst the key members, who were all highly motivated, knowledgeable, politically aware and sometimes politically active individuals, felt that it was extremely important for those directly affected by a condition to have an understanding of and influence on policies and services that addressed it, the members were generally far more concerned with the social, support and information-sharing functions that the group provided.

These group leaders were sometimes in a position, because of having retired or being unable to work because of their ill health, to undertake extensive research and gather information from a wide range of sources which meant that they were able not only to bring the experiential wisdom of their members, about living with a condition, to these forums, but could also contribute technical data about the condition itself or about the minutiae of policy changes or funding structures and the effects these could have on services. At times they believed this information to be more up to date than that held by the professionals and service managers.

> *They didn't even know anything about it when I first talked about it –* but you know it means we often have the information becau*se we've got* it first-hand because we go to the meetings - *they haven't got the time* to go to those meetings. (PH16-key member: G)

In most of these groups the different roles and attitudes of the leaders and members appeared to cause little friction. The group meetings were essentially still there to provide support and knowledge and the leaders introduced information from external forums only when this was relevant or of interest to

the members. All the parties appeared to accept each other's different priorities and motivations.

Despite the lack of members' participation within consultation processes these group leaders still saw themselves as representing the voice of the whole membership. In many cases they endeavoured to get members' views and encouraged them, usually by simply asking at the group meeting or sending out an email, to bring up any concerns that they wished to see raised. In other cases the meetings themselves might revolve around debates about the types of issue that would crop up at the forums and hence they provided ample opportunity for members to air their views and make the leader aware of their concerns.

Whilst the majority of these groups had easily accommodated the different emphasis that leaders and members placed on the importance of consultation, in a couple of the groups the divergence in attitude had caused problems. In one of these, the two key members, who were heavily involved in patient participation and local authority forums, clearly felt very aggrieved that the members did not share their perception of the value of this input. In fact they appeared to believe that there was a duty to get involved, which may have increased the resentment of members who did not wish to do so.

> *I feel that we've alienated some people – they don't want to know ..... the ones that have closed their minds off say 'you know I haven't time for this'…….it's very difficult to o*vercome these negative responses. (PH12-key member: G)

Representing the group: wider member involvement

In the other groups a wider section of the membership had become involved in a range of consultation and strategy procedures although it should be noted that it was still only a small number of members who were regularly took part. In most of these groups the input of a greater number of members was a reflection of their very collective, egalitarian ethos, in a couple of cases coupled with the fact that their meetings were seen as a space for wide ranging debate about

health and social care services, policies and structures. These groups felt strongly that in order to be truly representative of their members it was vital to ensure the involvement of more than just the leaders.

> *I'd like to see us have voices that can be gathered together in an effective way…I wouldn't be on a strategy group unless I was in a network of some kind…because otherwise you have no two*-way conversations, you just make it up and the [process] becomes a dead loss really. (PH15-key member: G)

In order to ensure that a variety of voices were heard the groups tried to encourage as many members as possible to take part and where it was possible, some groups invited agencies that wanted to gather feedback to attend group meetings to ensure that everybody who wished to could have a say. One group in particular felt that this was a far more appropriate mechanism for ensuring representativeness and to guard against consultation becoming.

> Just one person having a view. (PH15-key member: G)

Similarly these groups believed that their meetings should be used to feed back what had taken place in external forums so that the group was kept aware of what had been discussed.

> So the person goes to represent the group and then reports back to us.(MH1–member: I)

In one group, a member who regularly attended external meetings felt that the process of discussion within the group gave her a chance to reflect on and broaden the focus of her own individual concerns as well as helping her to articulate them.

> *Always I talk to all these ladies …… they say 'no this is not right'….* [then I] know more what I am talking about. (PC5-member: G)

This member was from a traditionally marginalised population that was unused to "speak[ing] out" in public, or for that matter even in private, forums. She attributed her confidence and capacity to do so solely to her involvement in the group.

> Oh no before I come here I say nothing! I cannot speak to these *people…now I say 'yo*u have to listen to this!*'*

The nurturing of voices from excluded sections of society was also in evidence in a number of other groups. One leader described the development of one member of her group.

> One of our mums – she has a sort of mild form of [the condition] *herself …she had no confidence and she really only had a basic range* of skills but you know over the last year when we were at meetings – *she's become quite, well I wouldn't say eloquent but she really puts her* point across very well. (PC4-key member: I)

National organisations

The groups that were affiliated to national charities all stated that the national was extensively involved in consultations at a higher political level that did not involve the local groups. There was no evidence though of nationals prohibiting individual branches from getting involved at a local level. In one case though the local branch felt that consultation type activities were far more appropriate at a national level, the leader stating.

> We leave that to the employed staff. (PH9-key member: I)

In another case the local branch, which took part in many strategic and consultation activities, felt that over recent years their head office had been attempting to minimise local groups' input by placing greater restrictions on the ways in which they could get involved and by imposing higher levels of control over whom they could speak to and what they could say. Branches, for example were not supposed to take part in external forums without the express authority of the national, and they were increasingly being prevented from attending consultation or strategy groups in the capacity of representatives of the national organisation. These regulations were believed to have had a very negative effect on the impact groups could make at a local level.

> *It's almost as if were not allowed to say or do as we please….. we've become a recognised group in the local community … and through* that we are able to do certain things within the community which means that you know we are able to put a bit of pressure on the council put a bit of pressure on Primary Care Trust things like that in order to *achieve things for the people of Nottingham… but if the national says 'oh no you mustn't go to a meeting and say that you are from [name of* national *organisation]' … …[it] means that there is no local* representation. (PH16-key member: G)

The group understood that accountability and risk were important considerations for large national charities, but felt that this could be addressed by providing guidance and training and that ultimately, local branches had to be entrusted to speak and act responsibly. Not to do so would simply result in local groups "do[ing] it in an underhand way," thus presenting a greater risk to the organisation.

Groups' approach and attitude to consultation

The groups generally appeared to approach service user forums from a conciliatory angle. There was very little evidence, when they talked about their activities, of members using such processes in an obstructive way or of hostility between groups of different stakeholders. Having said this, a number of groups made clear that they were there to express a point of view that may be different to that of service providers and that to this end they would "make a stand" and make enough noise to ensure they were heard.

> They do get an ear-bashing on certain issues. (PH12-key member: I)

> *We're usually pretty vocal – they may think we're Bolshie*. (MH1-member: G)

One group felt that their role was to "ask the difficult questions" and that this was not always welcomed. They believed that this was the reason why groups belonging to another national organisation that also addressed their condition were more readily asked to attend service user forums.

> They get invited to conferences and thing*s because they don't tend to ask the difficult questions and they don't antagonise – I think they're* frightened of us. (PH16-key member: G)

Clearly, although they did not term it as such, this group perceived an element of tokenism in some of these processes. They went on to say how they felt that professionals did not always gladly entertain the idea of expertise amongst patient representatives, perhaps preferring their input to be limited to softer and more subjective questions.

> *We know what they don't want us to know…..we never get any credit for anything … I mean that's embarrassing for them because we are one step ahead of them which is why we're not popular*.

Essentially though, all the groups saw themselves as working within rather than against these processes and as working towards shared ends, that is, for better services. This even included the group quoted above who, despite their sometimes antagonistic approach, believed they were on the "same side" as the service providers, even if this was not always appreciated.

> *They could take it as constructive criticism but I don't think they do ….we want a better service for people with [the condition] but that's* not always the way they see it (PH16-key member: G)

One respondent went further and stated that it was essential to be pragmatic and to work according to the rules and criteria of service providers and policy makers. He felt that nothing could be achieved by straying from their agenda or from the relentless repetition of unrealistic aims.

> [They] go *on and on until the chair has to say 'please stop – we've already said we can't help with this* – this is not in our remit.' (PH12-key member: I)

The effects of groups' input

That most groups' involvement in consultation processes was on-going and often long-term is indicative of the importance they attached to it and suggests that they perceived it as producing positive outcomes. However, despite a general feeling that they "do listen to us," few groups were able to give specific examples of how their input had affected policies, services or professional practices. It appeared that the process of being listened to was itself of value to groups as a means, as stated above, of giving patients more "self-respect" and making them more than just "passive recipients" and in the belief that being genuinely listened to may at least result in the possibility of subsequent action.

> People say thank you for coming, thank you for pointing us in the right *direction and I take that as meaning they've gained from it …you ne*ver *see any hard evidence but there is evidence and I've had people at the* highest level come and say thank you – *so they've listened at least* - whether they do anything or not. (PH12-key member: G)

Interestingly in the few cases in which a tangible outcome was achieved this had occurred through ad-hoc, informal procedures rather than at official forums. In one group it was the individual efforts of a parent, supported by the group leader, in arranging meetings at her child's school that had resulted in a change in their practices. And another group described how they were successful in a bid to secure funding for a specialist service only after a sustained campaign of letter writing to individuals in both the PCT and Parliament.

7.2 Education and awareness

Many of the groups referred to all the activities in this section as "raising awareness." However for the sake of clarity they have been differentiated according to whom they were intended to address. 'Education' refers to groups' direct input into the training or on-going learning of health and social care practitioners whilst "awareness" involves dissemination of information at more open, public locations.

Educating practitioners

Over half of the groups had been involved in education type activities. The most common way in which they did this was through contributing to the formal training of practitioners. The groups had given talks to student nurses, speech and language therapists, medical students and voluntary sector service providers. These activities were generally undertaken by one or two key members, although in a couple of cases the group had asked a number of members to get involved. The groups valued these events very highly as a means of sharing their expertise, gained through their collective experiences, and thus providing practitioners with an added dimension of knowledge which they were otherwise unlikely to encounter in their training. They felt that students and practitioners appreciated the fact that this input provided them with real life experiences of a condition about which they would otherwise only have had a theoretical knowledge.

> On a four year speech therapy course less than three weeks is taken up by [the condition] and ok the tutors on the course can tell them about [the condition] but they rarely get to meet people [with the condition] *….they're absolutely agog at being actually able to meet people who* [have the condition] and they get such a lot from it. (S2-key member: G)

They similarly stated how practitioners benefitted from stepping outside from the, necessarily narrow, focus of the acute care they provided which enabled them to see their role in broader, more personalised terms.

> They want to know how you felt at the time – the patient and the *carer….we always got a letter back from the lecturer ….. [saying] how* useful they found that interaction was - face to face - you see they *nurse that patient then they never see that patient again ….[name of group member] has always said 'please, please involve the relatives* and carers.*'* (PH18-key member: G)

A few of the groups went beyond those practitioners who worked directly with their condition and had addressed people providing ancillary services or in

other sectors. This included one group that gave talks to private employers, universities and schools. They were particularly keen to use these platforms to dispel myths about the limitations their condition placed on individuals' capacity and abilities.

> Employers need to be made aware of [the condition] as a condition where people can work. (PH16-key member: I)

> One of our main aims is to educate other people about [the condition] so professionals you know – people you know like scout leaders, *swimming instructors …make them understand a little bit about the* children they may have come through the doors with [the condition]. (PC4-key member: G)

A number of groups had also invited practitioners and students into their group in order to speak to the members. A few of these had on-going links with professionals who regularly asked for "feedback and advice" – one group describing how a specialist nurse "always says 'you're the experts.'" Another group had used the expertise it had gained through having representation at a local specialist steering group and at NICE to send out written information to all the GP practices in their area after new NICE guidelines were published. The leader of this group had been a GP practice nurse and thus was aware that such information did not always effectively filter down to practice level.

> We knew tha*t all the GPs would be thinking 'help!'* (PH14-key member)

One group aimed to address gaps in both GPs' and specialists' knowledge about their condition, with which, being so rare, they were unlikely to have come into contact. The group had invited numerous medical practitioners to become honorary members and sent out regular information and newsletters to share information about both the clinical aspects of their condition and the experiences of patients. In a few cases groups' role in sharing information about their condition led to their educating professionals about self-help groups, not only in terms of their value to patients, but also with regards to how to set up and operate them.

> Like the [practitioner].....*[she] came along and got information from the group…afterwards she came back to me and said 'we've had the* meeting and about 70 people turned up and out of that there are about eight keen active people that want to start a self-help group. (S2-key member: I)

Raising awareness

As stated above, any activity through which group members were able to use their knowledge to increase understanding about any aspect of their condition tended to be seen as awareness-raising. However this part will focus on those activities that were conducted in public arenas with a predominantly non-professional audience.

A number of respondents felt that being part of the group gave them the means by which to talk publicly about their situation. This could be due their increased personal acceptance of stigmatised conditions such as mental health, children's disability or speech and communication difficulties. Groups described how this confidence to speak out was of value not only in formal settings but also in casual encounters with friends, work colleagues or other members of their community. One respondent told how being at the group had allowed her to be "more open" about her child's condition and hence to begin to raise awareness of what was still a very taboo subject in her culture.

> Now I also talk more to different people and to family and friends and neighbours. (PC5-member: G)

Raising topics through informal interaction was also made possible through the confidence gained from members' increased knowledge and understanding of their illness which allowed them to speak to people about it in a more authoritative way. The groups were also using a range of more formal methods through which to raise awareness about their condition. Five groups had done interviews on the radio, and these, as well as a number of others, had written or been the subject of articles in local newspapers.

A number of groups had given talks in various settings including the Round Table, at Luncheon Clubs and for the WI. There was often a dual aspect to these talks which focused not only on the condition itself but also on the role of the group as a means of supporting people with it. In this respect the groups were raising awareness not just about the clinical implications of the condition but were also spreading the positive attitude on which the groups' approach to dealing with it was based, helping people to see sufferers as capable, active individuals who were still making a valuable contribution to the community. As well as these talks some groups had taken part in activities such as charity runs, and in one case had arranged a bag-packing service at a local supermarket. These groups represented members with mental illness, physical disabilities and communication difficulties. Once again they were therefore contributing to a more positive and de-stigmatised image of people in their situation by showing them as role models, capable of undertaking pursuits that might often be seen as beyond their capacity.

> *It's very positive…they can see how far we've come and they can see* what they can hope to achieve. (PH1-member: I)

The most common way in which the groups got involved in awareness raising was through having information stands in public places, including markets, shopping centres and libraries, through which they could distribute their literature and talk to members of the public. Some groups took "any opportunity" to "get [their] stall out" piggybacking onto events held by other charities or community groups. Most commonly the groups participated in these types of activity for national awareness weeks, frequently in conjunction with their own national organisation or at times working with other national charities to which they were not affiliated. The range of activities was very wide and sometimes involved working in partnership with statutory service providers.

Three groups had arranged major events in their local communities. These had been attended by other community groups, health and social care practitioners and local politicians as well as the public. All of these groups addressed stigmatised conditions and the events therefore served again to not only raise

awareness of their clinical aspects but to recast them in an extremely positive and proactive light.

> *The World [condition] Day we've planned that this year and it's even* bigger [than] la*st year…. we've got Parent Partnership, Family Information Services …we've got a Polish community group … we can* put up our [art] exhibition, our photographs and things for people to *see … I think the parents have got a passion for it so they're driven to* do something. (PC4-key member: G)

At Chapter 6 it was proposed that, in contradiction to the pervasive view in the literature, the groups did not expressly identify themselves as sites of resistance against social stigma. However the findings in this section suggest the need for a more nuanced view of this issue. These data indicate that whilst it was true that the majority of respondents did not see their role as entailing an overt, ideological opposition to stigmatising attitudes, such a challenge was, in practice, an important outcome of their actions within the community.

7.3 Campaigning

The campaigning activities raised in this section were essentially meant to refer to organised action intended to bring about change to an institution, policy or society more broadly. Unlike consultation this action would tend to be at the behest of the protagonists, albeit at times working in conjunction with others, and unlike education and awareness it would generally entail some form of activism in pursuit of a claim, request or demand and in response to dissatisfaction. However as stated above groups tended to have a very wide and fluid view of what was involved in the idea of campaigning and at times preferred to refer to what they were doing as awareness or education. Understanding the ways that the groups perceived the nature, process and aims of these types of activity can help us to clarify the extent of their similarity to and difference from health activism groups and new social movements to which they have frequently been compared and even at times analogised. It also allows us to ascertain their potential effects within the public sphere about

which Habermasian theory is itself somewhat ambiguous. On one hand Habermas (1987, 1996) supports the campaigning of social movements as a means through which to challenge to the status quo as well as to bring previously excluded populations into political debate and provide them with the experience of acting at the political level. At the same time however he warns of the depoliticising effects of interest groups whose focus on their own subjective concerns can close them off from broader arguments. Such activity can result in greater individual passivity and dependence through its demands for increased welfare benefits rather than its concern to engage citizens in public debate (Habermas 1987, Houston 2002). The current findings therefore provide an opportunity to contribute to this complex area of theory and to gain a more nuanced understanding of the range of effects that arise from different constructions of the concept of campaigning.

Influencing services and policy

Although only one group cited campaigning as their primary aim a number of others saw this as an important, if secondary, part of their purpose. A few of the groups were concerned with bringing about change in national policies; however this was generally with regard to issues that would also have a direct effect on their members at a local level. In some cases the groups' input involved nothing more than attaching signatures to letters issued by national charities.

> Sometimes it might be a letter-writing campaign – I know last year we were asked to write letters to Tony Blair – we were given copies - all we had to do was sign it and send those off. (PH4-key member: I)

However a few groups took a more active role. In one, the leader had brought information about proposed changes to legislation into the group for discussion and had drafted a letter on their behalf that was sent out to the local MP. The members intended to keep up their pressure for his active support of the changes by making further contact with him by letter and if necessary in person. A couple of groups had taken action about health and welfare issues that applied to a far broader range of conditions that just their own. Again this involved making direct contact with MPs.

> We w*rote to all the MPs…I mean how can they say 'you'll get this free if you live here but I'm sorry if you live in Leicester you've got to pay up' ….it's not just something that affects [the condition] people it can* be some really major, you know heart disease, cancer. (PH6-key member: I)

As discussed in the previous section the groups tended to view their health condition in fairly narrow, individual terms and so it is unsurprising that any campaigning in which they participated should focus on access to services rather than underlying questions of social justice. Some respondents did however display an awareness of how demands pertaining to their own condition had to be justifiable within the broader context of overall public spending. These groups presented their arguments in terms of efficiency, sometimes acknowledging the finite nature of resources in the NHS.

> As many people as possible will visit Parliament and talk to their MPs *about the money that's wasted on drugs that are unnecessary …… if there's more swift treatment then this will have a better effect …now this doesn't mean that more money should be put into [the condition]* but if [the recommendations] are taken on then perhaps more money will be saved because a lot of people with epilepsy are often taken into *A & E and this doesn't need to happen* (PH16-key member: G)

The group whose primary focus was on campaigning, whilst admittedly being concerned predominantly with their own condition, in particular with improving specialist diagnostic services, also at times advocated for broader reaching changes. This included taking action about the "postcode lottery" in service provision as well as the availability of welfare benefits and eligibility for free prescriptions. And even with regards to the services that only affected their membership there was an attempt, as with the group quoted above, to frame their case more broadly in terms of the efficiency of the whole system. Once again this group had used the means of writing to and visiting MPs in order to try to achieve their goals. A large part of this type of activity served the aim of simply "putting [the condition] on the map." In this they reflect a concern shared by a number of the groups that wanted to "raise the profile" of

their condition and which is indicative of the overlap between campaigning and awareness.

As well as addressing national policies and service delivery issues some groups' campaigns focused on the availability of specifically local services. For three groups this involved demands for funding for specialist nurses, both for the continued existence of their posts, and also in two cases for them to be able to have time allocated to work with service user and community groups. Another group was "petitioning against the cuts" in local family services. The groups had again used letter writing as their main method, this time to the PCT, Strategic Health Authority and to local councils. They had also all either attended formal, or arranged informal meetings with the relevant bodies. These campaigns had had mixed results, with those that were undertaken in conjunction with health and social care practitioners achieving greater success that those in which the group was working alone.

Local issues

A small number of groups had taken part in campaigns about one-off local issues. These issues tended to be identified and the subsequent action organised by the groups themselves rather than by national charities or public services. Although these campaigns began with very low key requests for change they occasionally resulted in members gaining a far broader platform from which to have their voices heard. For example, in one group a member had gone into a school to complain about the way her disabled son had been treated. Her success in achieving the changes she had wanted for him had given her the confidence to put forward a broader case asking for changes to the ways in which teachers were trained in SEN issues. She was also successful in this and the schools in question had subsequently asked her to act in a consulting capacity whenever such issues arose. In the same group a parent had similarly begun her action with an individual complaint, in this case to the driver of the bus on which her child had been bullied. This escalated into her and her husband's addressing not only the bus company but also the City Council who took up her ideas and consequently amended their procedures. What is particularly notable in this group is that the members who had taken

up these issues were from an extremely disempowered section of society with no history or experience of involvement in this type of activity. The parents stated how such action would have been inconceivable without the support of the group.

Another group appeared to be at the centre of a succession of campaigns about local community issues.

> We find out all different things and we can complain about *things….[member's name] has got other people interested so there's a* lot going on at the moment. (PH11-key member: G)

This group, whose membership was elderly, was particularly concerned with crime and community safety. They were currently fighting plans for the conversion of a disused shop into an amusement arcade, campaigning for better street lighting and presenting demands to the local police to "clean up the area" through dealing with the "crime," "graffiti" and "howling dogs" that were affecting their members. Their success in engaging local people had similarly resulted in their being consulted about such issues by a range of public agencies.

Language and terminology

Some of the groups whose activities have been described in this section had in fact answered with an emphatic "no" when asked whether their group took part in any campaigning. For example the parents who had achieved changes at local schools, as well as one of the groups that had engaged in a sustained series of letter writing to health authorities with regards to nurses' funding, both stated that campaigning was not a part of the group's role. These groups may simply never have conceived this type of small scale activity as a 'campaign' or perhaps, as appeared to be the case with a number of others, may have felt that 'campaigning' had rather negative connotations. Members from two groups for example felt that whilst it was extremely important to "have a voice" they had no desire to be "waving placards." In this they reflect some groups' concern, discussed above, not to be associated with overtly ideological labels such as "parent power." Others appeared to regard

'campaigning' as not in fitting with their group's positive and proactive outlook and their desire to affect services from a position within rather than extraneous to the system. One group leader, for example, whose group had responded to a lack of services by itself adopting the role of provider quickly qualified her admission of the group's campaigning role by adding that it was just "mildly…campaigning." Another group leader who had wanted to "gather a voice in some useful channels" added that this was.

> *"not so much [through] c*ampaigning about them as to try to do *something about them….it won't mean we'll be writing complaining* letters to our MP or anything like that - *I think we'd try to be a bit* more focused and useful. (PH15-key member: G)

For another group leader who again felt that it was important for the group, where necessary, to "make a stand" and had done so quite determinedly over a number of specific issues, it was their reliance on a hospital's facilities that meant that overt "campaigning," which anyway they appeared to equate with troublemaking, was not something they would wish to take part in.

> *We don't really like to stir up muddy waters – I think we're very aware of the fact that we've been given that room and we don't want to upset* too many people - we do make a stand – you know like with the *leaflet…..[but] no we don't like to stir up trouble*. (PH18-key member: I)

Whilst these groups appeared reluctant to be involved in campaigning or at least to describe their activities as such, some other groups used this and other terms such a "lobbying" quite liberally to describe a range of pursuits which appear to be far closer to education or advice than activism. One group for instance referred to their hosting of an advice and fundraising stall at an awareness event as a form of campaigning. A further couple of groups stated that they participated in campaigning through their national organisation when in fact this amounted simply to their contributing to the nationals' fundraising.

> The society does a lot of campaigns - well we do [get involved] in that we send a certain amount of subscription to [them]. (PH8-key member: I)

It appears that many groups either wanted to dissociate themselves from the 'protest' element of campaigning or no longer saw this as being an intrinsic part of it. These groups saw their role as pursuing their aims not by making demands from outside the system but by adopting an amalgam of different tactics which they could use to negotiate or work within it. One group, which had itself begun to act as a service provider, summed up this conflation of ideas.

> *I did have a vision…there's this thread that runs through where* children cannot access education – so mildly – a mild campaigning group because one of our main aims is to educate other people about *[the condition]…….it's [condition] awareness*. (PC4-key member: I)

Having said this however, there was still evidence of the existence of a more belligerent attitude within some groups. A number of respondents used words such as "fight," "fought for," "fought the corner," "fighting this" and "battled" and they spoke of being "disgust[ed]" "very angry" or "irate" with certain attitudes in the medical profession or amongst the media and policy makers.

> We had a battle on there until they made us a bit more of a priority. (PH16-member: I)

> We still need to fight for services. (PC3-member: G)

Latent activism

The discussion above indicates how difficult it can be to establish groups' attitude towards ideas such as campaigning or activism; however even this does not express the full complexity of their position. To do this it may be helpful to employ Melucci's concept, which he uses in the analysis of new social movements. He describes the activism particular to these types of association as remaining in a "latent" state for extended periods during which

they may appear to be politically inactive but through which they maintain the potential to mobilise at any time (1989 p70). Such a concept may help to give a fuller explanation of many of the groups in this study. A number of groups, that in most cases were already taking part in consultations as a means of getting their voice heard from within the system, appeared to hold the idea of more overt, oppositional type of campaigning in reserve.

> Well it depends on what emerges really – *we wouldn't [rule it out]* - oh no! (Ph15-key member: I)

> *I wouldn't rule it out, it's not off the agenda* – if there was something that people- that the group felt sufficiently strongly enough about to get *involved we could…if something* came along – if a hot issue came along that people would want to do something about – *we've got some* strong characters. (MH1–member: I)

Another group that worked very closely with and on the premises of mainstream health providers did not see this as preventing them from taking action if "something crops up that's important." Interestingly they also belonged to a national charity that had prohibited local branches from getting involved in "anything too political" and yet one of their key members stated

> If *we wanted to campaign for something we'd bring it up at the ARMA* meeting – *we'd say you know 'how do we go about fighting this*.' (PH3-key member: I)

Who was involved? Leaders and members

As might have been expected the impetus for much of the groups' campaigning type activity came from the group leader or a small core of key members. This reflected the differences between leaders' and members' priorities discussed above with regards to consultation. For some group leaders campaigning was part of their "personal motivation" and was an additional way of getting their voice heard and of having an influence over policy and services which they saw as important functions of their group. Having said

this, efforts were made in most groups to involve the membership in at least some aspects of the groups' campaigning. This might, for example, entail discussions at meetings or asking members to sign up to letters to MPs or other public agencies. However at times this input could be minimal, in particular in affiliated groups, where it was usually simply a matter of adding a signature to a "skeleton" letter sent by the head office. And even in this key members exercised an element of control over members' participation to the extent that any request for such support from the national was addressed to the group leader, thus making it their decision as to whether to pass this on to the group. In one case these requests tended to come via email which meant that only a small number of members were able to be involved.

> We do this via email - *I will send it to them…if it's a political thing you can sign up and we do that …the few who are on email are able to do that … I always leave it to the chairman to make the final decision*. (PH5-key member: I)

Other groups however did attempt to engage their members, for example by asking them to write to their local MPs or to visit Parliament. The extent to which members were encouraged to get involved might depend on the nature of the campaign. In one group whilst it was only the group leaders who visited and wrote to MPs regarding national policies, the membership was asked to take part in a local campaign regarding shops' provision of chairs.

A couple of respondents gave examples of members themselves instigating action. In one, a "young lad" wanted to assert his resistance to the unfairness that he, and indeed the group, perceived in losing their eligibility for free medications. He was determined to "fight it out" in part by continuing to sign the back of prescriptions indicating such entitlement; whilst the leaders were unable to offer him overt support because of their extensive links with health professionals and agencies, in spirit they were "with him all the way" and gave him their full "moral support." Even after the member had "ended up in court" the leadership maintained this support and was keen to let others know about his action.

> It would be great if he wrote something about it for the newsletter (PH6-key member: I)

In another case the group's reliance on the use of a hospital's premises for its meetings meant that the leader could not openly back her member's letter writing campaign against that hospital and the local PCT. Again though she provided moral support and gave the member "full rein" to pursue her demands.

> National or*ganisations' campaigning activities*

Nearly all of the affiliated groups in the study stated that their national organisation was involved, often extensively, in campaigning activities. This was generally for better services, funding and treatment for their condition, but it could also be to promote awareness of little known and understood illnesses. The affiliated groups stated that they were encouraged to get involved in these campaigns. However it seems that this was generally in very limited and rather passive ways. Most commonly the groups were asked to support the national in letter writing addressed to the government or local MPs. However this generally just meant appending signatures to a pro-forma letter or email.

> Sometimes it might be a letter writi*ng campaign…all we had to do was* sign it and send those off. (PH4-key member: I)

Indeed nationals seemed to be somewhat averse to their members developing their own ideas about any potentially controversial issue. One key member stated that the national to which her group belonged was happy for them to get involved in anything as long as it was not "too political." And one branch leader described how the national organisation only invited local involvement in low-key, parochial issues, such as a campaign to lower kerbs, leaving important matters to paid officials.

> I think possibly when they were asking for simple matters they would ask us to write and would even send a skeleton letter to fill in – but they *haven't much lately – I think because they're pushin*g for more expensive medication being available and it being sort of bigger issues *– so it's mainly down to London*. (PH9-key member: I)

In some of the groups that had supported their nationals' campaigns through writing or signing letters there seems to have been very little awareness of what they were actually putting their name to.

> *It's usually about the disabled and you know whether there's sufficient* things for the disabled – *I can't pinpoint*. (PH5-key member: I)

However not all branches adopted this passive role. A couple of the groups that were most heavily involved in campaigning, at both a national and local level, were affiliated to national charities. At times these branches and their head offices worked in partnership together, nationals for example providing advice to groups about where to take their demands, or working with them to arrange deputations to Parliament. However there could also be tensions in this relationship. One key member described how his group's campaigns were at times seen as a usurpation of the national's authority with local branches having to work hard to convince the national organisation of the benefits to itself.

> *At the moment I'm campaigning for the health service to just sponsor* [the specialist nurse] to be able to *give a short time….to …come and* talk to carers – I mentioned that to Head Office at the regional meeting - *'you're treading on toes' but they've only just realised that the Council will pay for their services ….so now I'm campaigning for the* Council to fund the national – *so I'm not treading on toes* – but they see it as a loose cannon – but having said that they do respond eventually. (PH12-key member: I)

Indeed one of these groups had even become embroiled in a type of campaign, concerning the autonomy of local branches, vis a vis its own Head Office.

> *They looked at that and said 'we're sorry but you can't use those' and we said 'why not?' And they said 'because it's not a recognised part of [the national]' …and it took 18 months'* battle – but we won in the end (Ph16-key member: G)

Developing broader alliances

As well as working with national organisations a number of groups saw their campaigning role, or potential to undertake this role, as being something that could best be done in alliance with other interested parties. These alliances might simply comprise a few local self-help groups working together in response to a specific issue.

> We had a chap from [a local self-*help group] come to see us… ….we all sort of got together and sent signatures ….I think* it was quite *successful …I know a lot of people were involved*. (PH5-key member: I)

At a more formal level another group described how it was able to increase its impact by building up networks of community based organisations

> what I found worked was to work, not as a solitary group – becoming *part of other disabled groups like Disability People's Advocacy in Nottinghamshire … I found if you worked in association with other* disabled groups you got more strength – *'united we stand, divided we fall'* – that became my motto. (PH16-key member: G)

A few groups were also collaborating with third sector service providers. They were able to use these networks to gather information to buttress their demands. For example one group that was campaigning for greater community safety was able to.

> *Find out all different things….we find out who's coming out of prison* and into the district. (PH11-key member: I)

Forming alliances of this type also provided a source of political learning, helping groups to understand how the system works and how agencies might work around issues such as accountability and confidentiality in pursuit of a joint cause.

> *So then [a third sector agency manager] said he'd heard something about it and he can't tell you what to do – but he can say 'well* if I were

> *a member of yours I'd do such and such' and then they can take it up – once it's been got up by the locals*. (PH11-key member: I)

Groups that took part in clinical advocacy networks, for example for neurological or musculoskeletal disorders, similarly saw these associations not only as a means through which they could increase the force of their voice but also as sites of political learning should they wish to take up their own cause. Furthermore, membership of such networks provided an interface and thus increased the potential for alliances between, health professionals and lay organisations.

> they are a link between ordinary people and the medical *profession…..that would be through ARMA if we wanted to campaign for something…..we'd say you know 'how do we go about fighting this'* (PH3-key member: I)

A few groups had already worked in conjunction with health practitioners. Indeed the group whose primary purpose was campaigning was organised as an alliance between medical and scientific specialist on one hand and people affected by the condition on the other. They felt that by working together in this way they strengthened the case they could make.

> *So there's not a lot you can tell us about it – you know they can't really turn round and say 'no that's not right' 'yes it is* – we know!' (PH6-key member: I)

Other groups had worked, at times very closely, with consultants and specialist nurses in their campaigns for better local services.

> We went there and had quite a good chat with the doctor, the neurol*ogist…just to ask him about the National Service Framework* – and he was asking us can we help him campaign for a [specialist] *nurse which of course we agreed with …we did quite vigorously*. (PH16-key member: I)

7.4 Local webs of knowledge

In addition to their extensive links with professionals and with publicly funded strategy and consultation forums the groups were embedded in much wider, frequently more informal, community based networks of knowledge sharing. Most groups saw themselves as operating at the heart of their local community where they could act as a nexus for the flow of information between different stakeholders. The respondents were linked to a huge range of organisations including churches, cultural and community groups, voluntary associations and other self-help groups giving them the chance to access resources, share ideas and learn from each other.

The importance of the local community

The groups were generally very keen to stress their identity as community based organisations.

> *We've* become a recognised group in the local community *...and* through that we are able to do certain things within the community. (PH16-key member: I)

Some even felt that they were at least as well if not better described as a "community group" rather than a self-help group. One respondent described how an important part of the group's evolution was when.

> We decided to bring it out into the community. (PC4-key member: G)

Up until the change of venue that this decision precipitated they had felt that they were cut off from many people who might benefit from the group and were in danger of becoming exclusive. Instead they wanted the group to be accessible to any local person, whatever the extent or nature of their need. They hoped their move into town centre premises would make this possible and would position the group as a local hub through which support, knowledge and ideas could be freely exchanged.

Groups felt strongly that they were there to serve local need - this could either be at a city level or within a particular district. The groups were able to serve their locality in this way because, unlike mainstream public agencies and national charities, they understood local people and local issues. One group for example stated.

> *We're the Nottingham branch …so the local branch…we are able to do certain things within the community ….achieve things for the people of* Nottingham (PH16-key member: G)

Self-help group networks

This sense of localism did not mean however that the groups were closed off from or had no vision or concerns beyond their own immediate vicinity. A small number of groups for example had taken the opportunity to expand into new districts; indeed it was their local knowledge that allowed them to be able to do this. Two of these groups were operating in ex-mining areas of the county and had in-depth knowledge of the different traditions, idiosyncrasies and even hostilities between geographically close communities. It was this understanding that allowed them to communicate with the different populations in appropriate ways, something which mainstream providers were not always able to do.

> *I've had a few hiccups with one school in particular but as it's very new as a venue …. what happens now with [the group] is we move* about –.... – but – *I can't explain to* you what [the local] people are like – *very weird! They wouldn't go to the community centre*. (PC3-key member: I)

Similarly the groups were very keen to develop ties and work with other self-help groups. This allowed them to pool their resources and knowledge for example in attracting better speakers or in sharing trips and outings. They were often also able to open up their facilities to other groups which made running a broad range of activities such as art or exercise groups more viable.

> We work with another group called [name] and they put on trips and *we put them on as well so we go to each other's*. (PC4-key member: I)

In providing the opportunity for a broader variety of social activities these links with other self-help groups also created a wider and more diverse pool of people with whom to share ideas and information. One group leader, whose members came from an isolated community, referred to this as "cross-fertilisation."

> There is a group that meets on a Wednesday at [place] and the reason *we're li*nked to them is that a lot of our women also go there – so if *they're doing something then our women will bring that information to* the group and also vice versa and I think some of their members come to our chair exercises – so there is a lot of cross-fertilisation. (S4-key member: I)

For many groups the possibility of learning from each other was particularly important. Experienced groups were very keen to advise and nurture new groups or groups that were having difficulties. One respondent had even shared the expertise he had gained from his role in his own group by acting as the treasurer of another until it was able to appoint its own upon becoming more established. Another group leader who had been assisted in getting up and running by an existing group was subsequently able to repay the favour.

> *It's interesting because the [name] group that I went to see and that I'm now supporting* - the person who leads that at the minute, I have to run sessions on her behalf. (MH2-key member: I)

Members had shared information about a variety of aspects of organising a group including constitutions and rules, getting feedback from members, fundraising and publicity. In addition they passed on tips to ensure that other groups were aware of and could get the most out of facilities and resources that were on offer.

> I give them ideas of where to go and what to do and what not to and silly things like - *are your group disabled and if the answer's yes, you*

> *get in for free at some places …[so] don't forget to ask*. (PH17-key member: I)

Many of the groups were able to garner these relationships through their attendance at Self Help Nottingham's networking events. These could either be for classes of condition such as mental health or based around aspects of running a group such as those for new groups or key members. These events were seen as a "really, really useful" forum in which to share knowledge and ideas.

> *The mental health network meeting…there were at least 8 other groups* there sharing how they were running. (MH2-key member: I)

Community groups and organisations

As well as their relationships with other self-help groups, the groups were frequently linked into a broader network of community associations. This included wholly informal member-led groups such as reading, art and theatre groups as well as a range of more formal organisations. A number of groups had members who were active participants in local churches and their committees, as well as in large national charities such as the RSPB, Action for Children and the Ramblers' Association. In addition members of many groups were active in more formal bodies such as political parties, tenants' associations, school governing bodies and the Guides, Brownies and Scouts. And again these were seen as two-way channels allowing ideas to flow to and from the groups

> You can find out things at one group and then bring it back with you to this group. (PH7-member: G)

> So you can share information with other groups you know. (PH15-key member: I)

This information might be of a political nature, as discussed above with regards to campaigning. Such communications allowed groups to share knowledge about "how things work." For example at one meeting, newsletters were exchanged with a local political party and a tenants' association, ensuring

that members were aware of proposed changes in the area. They were then able to feed the group's opinions on community issues back out to these other bodies. Groups had also used these links as an added means of awareness-raising through which they could disseminate information about their condition or their group's work.

> *I was at another meeting and someone said 'oh [name] what's this?'...and they said 'can we borrow it to put in our newsletter?' and* six months later *he said 'can you do a little article?'* (PH16-member: G)

7.5 Summary

Far from acting in an insular way the groups attached fundamental importance to building networks within the broader community. They were extensively involved in consultations which they saw as a means by which to influence services through raising challenging questions and to give patients greater self-respect through having a voice in processes that affected them. In addition participation in such activities provided the opportunity of gaining a better understanding of decision making and governance procedures in the NHS. On the whole respondents felt that they were on the "same side" as service providers and working towards shared goals. Consultation and advocacy forums were preferred to protest or campaigning as a means to affect services. The groups were generally keen not to be associated with overtly oppositional ideological labels and they were far more likely to engage in raising awareness about the possibility of living positively with their condition than in making demands. Their actions could thus be conceptualised as oriented to the promotion of lifeworld autonomy rather than to the types of claims-based welfare passivity that are believed to undermine the public sphere. Their choice of communicative method also helps to differentiate self-help groups from new social movements who tend to place far greater weight on resistance and protest (Brown et al 2004, Scambler & Kelleher 2006). Having said this a few groups did see campaigning as part of their role, undertaking activities

such as writing letters to MPs or visiting parliament. When such campaigns were adopted it was usually with respect to the availability of or access to services that would affect their members and it was often done in alliance with service providers or national organisations. Furthermore a number of groups, even those with very close links to health and social care services, did not rule out the possibility of more confrontational forms of action if this were deemed necessary in the future.

The groups frequently placed great weight on creating informal links with other community organisations, seeing themselves in many cases as "community groups" as much as self-help groups. These relationships acted as channels of information, giving the groups the opportunity to keep abreast of what was happening in their local area in terms of services and events as well as local politics. They were also seen as a resource, providing a breadth of skills and experience with respect to starting up and sustaining a self-help group.

8 Group processes and internal democracy

Introduction

Self-help groups have often been described as democratic, non-hierarchical and non-bureaucratic in their decision making procedures and internal dynamics (Rootes & Aanes 1992, Riessman & Carroll 1995, Adamsen 2002). This chapter discusses those factors that have a bearing upon the levels of democracy in groups, which contribute to or militate against the development of hierarchy and that affect the different ways in which power is used and interpreted by members. A key part of understanding this aspect of self-help groups lies in the relationships between their leaders and members and the relative roles they play in determining the group's direction, purpose, ethos and operation. Consequently the main focus of the chapter will be on these relationships, asking questions about the impact they have on inclusivity, equality, decision-making and perceptions of group ownership. It will also include a discussion of how far the different organisational structures adopted by groups can have an effect on their evolution and internal dynamics, as well as on their autonomy and freedom to act independently of external agencies.

The implications of groups' internal structures and decision-making processes are fundamentally important to their theoretical conceptualisation as democratising agents in the public sphere. In order to contribute to civic discourse the groups must be orientated towards the normative ideals of democratic, egalitarian communication that is neither constrained in scope, nor distorted in meaning through the abuse of power or the influence of hierarchy. Such unrestrained dialogue would also depend on groups' ability to articulate their own conceptions of need rather than serving the prescribed, strategic ends of powerful structures such as public services, national organisations or prevailing government agendas. Moreover if organisational forms and relationships are indeed a central and "constitutive" part (Melucci 1989 p45) of the process of collective identity formation, it is essential to understand how they work and their possible effects in order to properly recognise the extent to which any such identity is created.

8.1 Effects of groups' organisational structures

The groups had adopted a range of structural forms. This included two registered charities, 12 groups with little structure beyond a recognised leader and the occasional ad-hoc office holder, one professionally and one volunteer run group and 17 groups with some form of written constitution and formal committee.

Reasons for remaining unstructured

The majority of unstructured groups were in this form for practical reasons, however for a small number of groups, maintaining an informal set up was an intentional decision that reflected and was seen as a means of protecting their ethos. In a couple of cases this was explicitly a matter of defending members' equality and guarding against the emergence of hierarchy.

> *We didn't want to become a formal branch with a committee and whatever …we don't have officers, we don't want it to become a big* hierarchical agenda driven group – *we don't want to be talking to each* other formally. (PH15-key member: G)

For these and a few other groups there was an implicit fear that taking on a structure would somehow inhibit their group's freedom and independence to pursue the path chosen by members.

> *There's no structure …I don't think we want to be constrained by any* sort of structure. (PC2-member: I)

These groups had all elected to remain self-funded, suspecting again that applying to external funding agencies would embroil them in unwanted formality, effectively subjecting them to the authority of systems other than their own collective will.

> *And that's a problem with funding* – they expect a certain structure and *that could take a group in a direction it didn't particularly want to go – which would alienate the members …and then we wouldn't have* control over our own group. (MH3–member: G)

Having said this it appeared that some of these groups were willing to make subtle distinctions in terms of allowing restrictions on their members' freedom. For example one group, despite not wanting to be beholden to funders, had free use of hospital premises, which she admitted meant that she had to be very careful about "stir[ing] up trouble" by complaining about services. And another leader, whilst adamantly opposed to the personal hierarchy that may have arisen from the adoption of a formal organisational structure as well as from the undue influence of funders, was strongly in favour of having a group that was "very structured" according to the rules and ideology of a national charity to which the group had once been affiliated.

The effects of formalisation

The majority of groups that had adopted a formal structure and appointed a committee had done so as a condition of a funding application. Some of these groups had initially shared the unstructured groups' fears of formalisation as a driver of hierarchy and abuse of power; however, most subsequently acknowledged that the funding application process and concomitant formalisation had turned out to have had very little effect on the atmosphere of and relationships within their group. Indeed the groups raised a number of positive effects, in particular in terms of members' political learning, which they believed had arisen from the process of undertaking a formal structure.

> *You get to know how things work…how the system works…what the* right buzz-words are - *it was quite a learning curve…so in a way it was* quite useful. (PH7-key member: I)

In addition, some group leaders felt that conferring official titles was a way of giving recognition to and thus empowering group members to get "more involved" in directing the group.

> *To give a bit of recognition to the other people … giving them roles in* the group will allow people to get more involved. (MH2-key member: I)

Leaders' belief that titles would confer greater confidence on members to get involved was borne out by those who felt that it had forced them into

undertaking responsibilities that they would previously have shied away from. One reluctant treasurer stated.

> I took on the role of treasurer - *I didn't want the job…. But I'm doing* OK you *know….I suppose I wouldn't have done anything like this … so* in a way I suppose it pushed me into doing it. (MH5-key member: I)

Some respondents also believed that undertaking a more organised form was vital to the group's direction and identity as an entity that belonged to the members.

> *We weren't going anywhere …. It was really drifting… you need* something to hold it together, to move it on, the first thing is a *constitution but yeah I think giving some of the ladies set roles …* [making them] stakeholders. (PH1-key member: I)

The level of external funding received by the groups was generally very low, ranging in the vast majority of cases from a few hundred to a few thousand pounds. Only two groups had obtained significantly higher amounts of money. The receipt of funding was widely regarded as having had beneficial effects in terms of group autonomy and ethos, with a number of respondents believing that it had boosted rather than encroached upon their group's independence. One member described how prior to securing funding their group had been reliant upon a local health centre which had had a tendency to "end up controlling the group". Their grant had allowed them to secure their own venue, thus enhancing their freedom. Another similarly felt that members' stake in and ownership of the group was greatly strengthened by their ability to pay for their own dedicated premises.

> *I'm hoping we'll actually become more personal* – it will give us more *personal space because it's our* space. (PC4-key member: G)

Funding providers had generally left groups to spend their grants in pursuit of their own aims, with very little interference beyond their initial requirements for the establishment of committees and appointed officers.

> No *they've just left us - we've got the funding and it's up to us - they're happy with that….. I mean to be honest the people who give us the* money who say yay or nay they – *well they don't keep tabs on us*.(PC4-key member: G)

Despite the perceived advantages of formalisation it seems clear that ultimately the ways in which power is exercised in groups is far more dependent on the relative strengths of the leaders and members than on its nominal organisational status. In the cases where committees and offices were used as a means to empower and involve members this was generally in groups where it was already the leaders' intention to encourage broad participation; the titles, procedures and policies merely being employed as a tool with which to help leaders achieve this. On the other hand in some groups, either the dominance of the leaders or the apathy or lack of capacity of the members, meant that despite the existence of large, official committees on paper, all the work was done by one or two individuals.

> Wel*l to be honest although there's a big committee there is me and Mrs [name] …between us most of the organising side is done*. (S4-key member: I)

8.2 Groups' sources and use of rules

The groups differed in their attitudes towards having a written constitution as a means of expressing and enforcing their rules about internal processes. They also derived their rules from a number of different sources including leaders, members, national organisations, funding bodies and agencies such as Self Help Nottingham. However there was considerable commonality in the substance of groups' rules and the ethical values that the groups hoped to promote through their application.

> Using rules to promote group ethos

Many of the groups had devised strategies against the possibility of domination of meetings by individual members. They clearly felt that to allow any member

to monopolise discussions was a contravention of their ethos of equality and respect for each other's views. Some groups felt able to prevent such behaviour through the informal means of collective censure.

> *Nobody can really dominate …. Because the others can just say 'no we don't do that.'* (MH1-member: I)

However others believed that written rules provided greater certainty and "something to fall back on."

> *We've had a couple of people come to meetings who have tried to convert us … so [the constitution is] useful to be able to stop people if* they go off on their own particular interest or agenda too much. (MH3-key member: I)

Amongst these groups formalities such as having a written constitution were thus seen as means of nurturing a fair and egalitarian ethos where no one view or individual could hold sway.

> *People [hadn't] been trained to go to meetings* – people who butt in - and whereas they used to rule the roost in the old days, they started to become alienated. (PH12-key member: I)

One group went on to say how written rules could thus act to enhance group solidarity and unity.

> *…..it's important as well to present a united front* – when you make a decisio*n you can't have one person go off and say something and* another go off and say something else – it undermines the group if *you're not united*. (PH7-key member: G)

Formal rules could also provide the means through which to impose standards in an impersonal way that did not undermine the confidence of members or encourage an authoritarian approach in leaders.

> *It does tell you what you should and shouldn't be doing and you do really need to have that because you're not hurting people as much* – if

they're not doing something right you don't want to be like a teacher and say 'you're doing that wrong.' (PH1-member: I)

For a couple of groups the equality of members' status was protected by rules forbidding or discouraging questions about their educational or employment background.

We start the meeting by reading out the preamble …. We don't ask people direct questions about where they're from or what their position is, what their job is. (MH3-key member: I)

Regulating responsibility for the group

Although, as discussed throughout the findings, many groups were ambiguous regarding their expectations of members' contribution towards group tasks and processes, this was still an area in which some had developed or drafted specific rules. Essentially these rules were a means of encoding and expressing the central ethos of "self-help," that is, the members' duty to actively take responsibility for themselves and for the group. Again these rules had been articulated both informally, through group customs and discussions, or formally through official clauses in constitutions and mission statements.

I've known other groups where people just want to turn up and have someone do it all for them ….. we're clear from the start - it's about getting on and doing things. (MH2-key member: I)

A small number of groups had used their constitution to set out their ethical position with regards to what they referred to as "free riders," that is those people whom they saw as abusing the group through accessing trips and outings whilst contributing nothing. Groups clearly saw this as an "abuse" of the group and a breach of the principles of "self-help" and fairness on which their expectations were grounded.

*In the constitution we did say if you hadn't come for five weeks then you're not e*ntitled to things - *because it's not fair on the members – they put in all the subs, they contribute so it's not fair on the other*

> *ladies and if they don't come on a regular basis the group won't keep* going. (MH5-key member: G)

The source of rules

Although 12 groups did not have a constitution, for most of these this was just a practical matter regarding their group's size or stage of maturity. A small number of groups however saw the use of written regulations in more ideological terms, believing that it was contrary to the ethos of a truly member led organisation. These groups believed that ethical dilemmas should be resolved through a process of negotiation amongst the members.

> *If there is a problem, a disagreement, what does it say if you can't sit* down and talk it out – *no we haven't got [a written set of rules]* – we *don't need it*. (MH6-key member: G)

However, as discussed with regards to organisational structure, the methods used to articulate and enforce rules were always subject in practice to the relationship between leaders and members. In groups with less empowered members the lack of a constitution did not in itself foster inclusive discussions but coincided with rules being created and applied in a rather more authoritarian way;

> I have to bang [a *diary] on the table to make them all shut up … and I allocate three ladies each time to take turns and we can't start the meeting 'til they wash the pots*. (PH11-key member: I)

Where the groups had a written constitution and policies these had almost invariably been drafted in conjunction with or even by an external organisation, usually Self Help Nottingham but also health service providers and funding agencies, the danger being therefore that it was more a reflection of their rather than the group's values.

> [Self Help Nottingham] give us quite a lot of support – they organised the constitution – what else did they do – that funny word BME and something else. (PH17-key member: I)

This was particularly the case for some affiliated groups that had to adopt the national organisation's prescribed constitution. At times groups saw this as a challenge to their individuality and autonom.

> *There's a national constitution we have to follow – we don't have a local constitution …it's almost as if we're not allowed to say* or do as *we please…. I mean it's far easier for the national if we all work to the* same model– if we start to have different like you say a different character it is far more difficult for them to handle us I suppose. (PH16-key member: G)

Rules such as those that prohibited local branches from participating in research activities or organising their own fundraising events were seen as stemming from a lack of trust due to which groups, who had been doing such things without consequence for many years, felt deeply "insulted." Respondents appeared to believe that by imposing prescriptive regulations, nationals were acting to disempower local groups by removing their ability to decide for themselves and articulate local needs through their own processes of deliberation and discussion.

> *I said 'sorry but we're a local branch with lots of initiative and enthusiasm' but I don't think they like that* – I think they want compliant people. (PH12-key member: I)

Not all affiliated groups saw these rules as constrictive; in practice some were given a lot of leeway to pursue their own ends in their own ways.

> We have a big folder which tells us broadly - *they're just guidelines … they're not breathing down your neck* - we know a lot of [branch leaders] and they all have their own ways. (S1-key member: I)

However whilst this may have worked in practice in these groups' current circumstances, the national organisation retained the right to enforce rules that went to the heart of a group's self-determination, such as its choice of leader. The respondents quoted above who had run their branch successfully for over 20 years described how today this would not have been possible.

> *That's a situation that wouldn't be allowed to happen today because* you have to be two years beyond your grief, your loss, before you can take on that role.

8.3 Running and directing the group: leaders' and members' input

This section will consider the various roles that are played in the management and organisation of self-help groups and the processes through which decisions are made. This includes decisions about specific, day to day activities as well as those at a higher level that determine the direction, ethos and overall purpose of the groups. In doing this it will attempt to establish where power lies and with whom ownership rests. The section will begin by considering the extent of stratification within the groups and the ways in which leaders and members perceived their respective roles and differentiated themselves from each other.

Although virtually all the groups had an individual who was seen as the leader they differed in how far this person operated alone. In quite a few groups the leader worked in very close partnership with one or two others to the extent that these were sometimes co-leaders in all but name. In a small number of other groups the term 'leadership' might be more appropriate as the nominal leader effectively ran the group in conjunction with a very active committee.

> *What does 'group leader' mean anyway* – a lot of it is done by a *planning committee…so not having a person in the title of chair is not a huge setback I don't think as long as you've got other people who are* fulfilling the roles that are needed. (PH14-key member: I)

Similarly when discussing 'members' it is important to note that members of the same group differed in how far they were expected to be a part of the group's management or decision making processes. Even in some small, close-knit groups in which everybody was expected to participate, exceptions were made for new members or those with particularly onerous problems.

Furthermore many respondents acknowledged that certain types of people might want to make use of the group in ways that did not result in any duty to take part in its administration - some doing nothing more than receive group newsletters.

> *[some people] just want to tap in for information and go away … that's what we're here for …some people might just want a quick fix…we don't judge people by how much they contribute or how much they don't*. (PC4-key member: G)

In all the groups, whatever the nature of their leadership and including those that prided themselves on their egalitarian structure and "family" atmosphere, there were a number of, sometimes subtle, ways in which leaders were differentiated from the members.

The status of leaders and members

Perceptions of leaders' and members' relative status could be complex and somewhat ambiguous. At times leaders talked about themselves as part of the group; benefitting from the same support processes as the rest, but at others they spoke in ways that had the effect of separating them from or perhaps elevating them above the regular members. In a small number of cases this was quite explicit; these leaders denying their need for the type of support that the group provided.

> Oh no – *I don't think my own grieving had anything to do with the* group – that took place quite separately – *I'm not really one for going* to self-help. (S3-key member: I)

In one group, the leader had even issued the key members with official group T shirts. She clearly understood the effect this could have in terms of creating hierarchy within the group and the tensions to which this gave rise.

> *I'm already aware people are looking at us different and I put that* down to the T shirts because *recently we've had T shirts made* - only *for the five main ones … and it's changed [how people see us] so I'm telling them we're stopping wearing the T shirts because … people are*

treating us different …it makes us look like nutritionists and NHS. (PC3-key member: I)

However subsequent visits to the group confirmed that the T shirts were still being worn.

Although the data have not been subjected to a full pronoun analysis such as that undertaken in Hodge's (2005) study of hierarchy within service user groups, the responses reveal an interesting tendency for leaders to refer to members in the third party and as distinct from themselves, commonly talking about "them" and "their" rather than 'we' and 'our.'

*They're very happy…yes they do tell me what they w*ant. (PC1-key member: I)

Some of them need pushing, a big push…they've got an inner fight with themselves. (MH5-key member: I)

One leader, in attempting to portray his equality with them admitted, "I'll learn a lot from the members" - interestingly though, by not referring to the other members or to their learning from each other he did not seem to regard himself fully as one of them. He went on to describe "their" problems;

So the people who come to the group generally have got – not many *friends they're quite isolated or if they did have relationships they've* lapsed due to their anxiety and depression. (MH2-key member: I)

A couple of group leaders stated that they "took them" on trips suggesting a more active role for themselves and a more passive one for that of the members. Others talked about doing things for "them" or granting them permission to do things themselves, even at times suggesting their bestowal of the group upon the members – it being "theirs" and "yours" rather than "ours."

I said they should have a constitution that better reflected their aims.(S4-key member: I)

I think it's important if you have an idea to let them roll with it …it's their group. (PC4-key member: G)

Having said this, the complexity of leaders' identity within the groups is indicated by the fact that the very same people would at times speak in very inclusive ways about activities that bound them to the members.

> About eight of us, we all went on a two day training course for *empowering parents … that was something togeth*er as a group. (PC4-key member: I)

In one of the groups quoted above the leader even included the rest of the members in taking credit for achievements in which it was clear they had taken little or no direct part.

> *It has worked out for us, we are lucky … we've got funding* – we *managed to get a room … we've done fantastic…we negotiated the rent* – we got it half the price they asked. (MH5-key member: I)

Leaders' background, experience and skills

A number of group leaders had a professional background in health and social care. This included three nurses, two social workers, two community workers and six teachers. Other leaders had undertaken counselling and group facilitation courses. They tended to see this experience as providing them with skills that were not necessarily shared by other members and which thus gave them a unique role within the organisation of the group

> *[Leading a group is] not suited to everybody …. All our lives we've* dealt with people - *we're teachers so also you're articulate, used* to *talking to people … you've got to be articulate, you've got to have organisational skills…we've had people come forward …who clearly* are totally unsuitable. (S1-key member: I)

These leaders often derived personal benefits from and appeared to have been empowered by the ability to use the skills and experience that they had accumulated prior to their diagnosis or life changing event.

> running and being part of the committee again it just gave me some sort of focus and it gave me colleagues again – when yo*u've worked all your life you're used to a set of colleagues and that had all gone and also it helped build up my confidence because …. it's a big thing* – so to have colleagues again. (PH14-key member: I)

Members similarly felt that the leaders possessed skills, knowledge and experience that the group needed in order to thrive and develop.

> We would miss them - not only for their leadership but also for their *knowledge of the system …. [one of the leaders] does the funding applications and she's very good* at it. (MH1-member: I)

And their professional status could give groups additional prestige and provided them with contacts that allowed them to grow and progress.

> [name] got in touch with them - *and it always helps when he says 'Dr' – it's not right but it always helps … we weren't really going to get much bigger whereas [name] he's got lots and lots of contacts and he* can really get things moving. (PH6-key member: I)

At the same time the regular members of a few groups were deemed to lack certain skills or the attributes required to successfully contribute to running a group.

> Not all parents are ready – *you need confidence to run a group, it's a big step… two of the parents on the committee are special needs themselves, so I can't give them a lot … I have* to be careful. (PC3-key member: I)

In some cases members' lack of capacity stemmed from the condition, situation or characteristics shared within the group. Lack of sight, physical mobility, good mental health, speech skills and particularly old-age were all seen as reasons for members' limited ability to participate in group tasks. That leaders were still able to do so despite similar symptoms reinforced the image of them as being more resilient and better able to cope.

> The group members are too traumatised to even be involved in *anything like this … no they're not ready and even if they were ready it's too much*. (S3-key member: I)

In addition both members and leaders felt that the latter, being more "articulate" and willing to "speak to anybody" were better qualified to act as the group's spokesperson. This allowed leaders to go out and develop useful links which might include negotiating cheap prices for venues, securing funding or ensuring that national organisations were sympathetic to local groups' needs.

> *If we need a spokesperson we'll always look to [name]* – if we need someone to talk on our behalf because she can tend to put things over *where a lot of us can't*. (MH5-key member: G)

> *I was the one having discussions with [the national]…I made the links…I talked to the regional organiser to get what our choice were … [the group] wasn't keen on lots of structure and formality at that stage*. (PH15-key member: I)

Leaders' altruistic motivation

There was a strong element of philanthropy in many leaders' perception of their role. This was often in conjunction with their having themselves gained support from the group although for some leaders this support had been of secondary importance.

> *My attacks had been controlled by that time …now I feel able more to actually help the people who are still suffering …I want to help other* service users so it was a sense of vocation. (PH16-key member: I)

Of course what differs in these situations from typical voluntary activity is that these leaders' ability to offer such help stemmed from their own experience of the condition or situation that members faced. They were thus not simply acting as an extraneous benefactor but as an intrinsic part of any processes of collective identity formation that emerged within the group.

> *You feel for these people…I wanted to help…if I can help anybody through what I've been through*. (PH18-key member: I)

The need for such an altruistic approach appeared to stem, at least in part, from leaders' tendency to see members' needs as greater and as more complex than their own.

> The parents of children with [the condition] can sit in very dark *holes…I mean I must admit I'm not one of those parents … I always see* the positive side. (PC4-key member: I)

To members this self-confidence and positive attitude meant that leaders were seen as role models, providing examples of resilience and the possibility of coping and even thriving with a serious health condition. They were thus frequently held in high esteem.

> [Name] was a very strident sort of person, s*he didn't see why she* should be a second class citizen – *she wanted to be at the front … she's* a very positive person. (PH1-member: I)

This admiration was partly a response to leaders' perceived commitment to the group and their achievement in having established it, something that members felt very few people could or would be willing to do, and which hence gave leaders an additional stake in the organisation.

> *Credit to them, they've kept it going really* - because it is a problem I think with any group, taking responsibility for doing whatever needs to *be done … they personally have a big stake in it … they're very committed and they're both very competent*. (MH1-member: I)

However for a few leaders the altruistic desire to help could stray into an overtly paternalistic attitude towards group members, their own benefits coming from the members' appreciation of this rather than from their reciprocated support.

> *I feel like I'm doing something for somebody …to see smiles on the faces …some of them are like* my children. (PH11- key member: I)

At times this could thus result in leaders seeing themselves as better able than their members to ascertain the latters' needs. For a small number of group members this was positively welcomed, reflecting their desire for dependence.

> *When [name] ran it [name] did everything … she took everything on herself … she was fantastic for the group … … I rely a lot on other* people so I think [name] was good for me as a person. (PH1-key member: I)

Although neither leaders nor members generally advocated such a dependant attitude, respondents did tend to value strong leadership. This was the case even amongst groups with very empowered members and committees.

> *She's very enthusiastic … she is the power really*. (PH3-key member: I)

Even when this strength amounted to dominance it was perceived as bringing advantages to the group – indeed one respondent believed that without it the group might not have existed at all.

> *We've got one leader who's very forceful, maybe that's why the grou*p *got formed in the first place … I think the dominance that this person* has is more of an asset than a drawback. (MH1-member: I)

Interestingly one of the ways in which "dominance" or strong leadership was exercised in these groups was in enforcing the group's 'self-help' ethos according to which all members were under a duty to contribute. It was thus a means through which to foster both empowerment and members' ownership of the group.

> *She's in charge … if it don't [get done] she'll soon shout …. we are* i*ndependent … doing things our own way*. (PH15-member: G)

It should be noted that there were also occasionally attempts to minimise the stratification of leaders and members. This was expressed through a reluctance to use the term "leader." Members of a few groups were very hesitant when asked who held this role.

> [Name] I think, but um yes um yes. (PH7-member: I)

A small number of leaders also shied away from the title, preferring "facilitator," "coordinator" or "contact" instead. In a few cases they occupied the position at the head of their group very reluctantly.

> *I would call myself the contact….I tend to be the only long term member there so it's often down to me to keep some sort of order…I get landed with sorting things out … I'm the only person who kno*ws what goes on. (MH3-key member: I)

Participation in group tasks

Respondents from many of the groups shared the view that "to be a true self-help group" it was imperative that members "have to contribute." This might be with respect to the group's substantive aims of providing support but it could also involve a duty to contribute to the tasks involved in organising and maintaining the group.

> To be a true self-help group, the groups should do it themselves and get the membership of the group to organise it – to set it up – to find people that are keen to want to do it. (S2-key member: I)

Some groups had achieved a balance of input with which they were very satisfied; with a few members contributing to the organisational structure through taking on committee roles whilst others took part in more practical ways such as making teas or posting newsletters. These jobs were often portrayed as an equally valid contribution to the group's functioning.

> *I mean we've got members with limited literacy ….. but they* contribute in other ways – they get people to come on the trips and they, they do contribute. (MH1-member: I)

These groups, although sometimes admitting that greater involvement in organisational roles "would be the icing on the cake," felt that the level of member input adequately served their "simple needs." In addition to satisfying their practical needs, shared involvement in group tasks may have contributed to the "solidarity" and cooperative atmosphere in these groups.

> *And it's easy because everyone* chips in – if we say we need something *doing then everyone helps…. I can just ring anyone and say 'can you* do this or that.' (PH7-key member: G)

However whilst some groups had managed to achieve this ethical ideal of collective involvement, a range of factors affected others' ability to put it into practice. Firstly it was not always clear what was expected of members. On the one hand it was felt that self-help was about "everybody taking responsibility" rather than "one person doing everything" however some of the leaders that espoused this philosophy also felt that people had a right to use the group according to their own needs with no corresponding duty towards its upkeep.

> *People hopefully are improving and moving on ….. most move on* which I think is the healthy thing to do – it makes it more difficult to *run the group…but it's more positive*. (PH14-key member: I)

It also appears that the "self-help" ethos espoused by leaders was not always shared by the groups' members. Some of the leaders who had the most explicitly articulated "self-help" philosophies felt;

> *People in general don't seem very keen to do anything … the actual structure, the maintenance of the group, nobody wants to do it … it's* very difficult to persuade people. (MH3-key member: G)

Indeed what seemed common to a number of groups was members' reluctance to take any "actual responsibility" by adopting committee roles or undertaking administrative tasks. This meant that in many groups most of the organisational work was done by a small group of "core" members.

> *There are few people left to run these sorts of things … it's only a few* of us - I mean the whole group would be better if we could get them *[involved] … they don't really want to have to run these things*. (PH1-member: I)

Leaders addressed members' reluctance to undertake tasks or get involved in the group's organisation in various ways. In a small number of cases they

simply gave up and, for the sake of keeping the group alive, took all the responsibilities upon themselves.

> Still nobod*y's – all the work's landed on me … I've asked about you* know - does anybody want to be responsible for the money or for the application forms for the grant- but nobody did. (PC1-key member: I)

Some leaders however took a far more proactive approach to ensuring members' input. Interestingly it was often the strongest, even at times "dominant" leaders who got the best results in this regard. Their success was achieved through a mixture of carrot and stick that reflected these leaders' understanding of the factors that prevented members getting involved. Where leaders suspected apathy an uncompromising approach was adopted.

> I refuse to take that role myself – *they've got to take responsibility for the group…I'm perfectly willing to be on the committee but not* to take all the responsibility (PH1-key member: I)

However, more commonly these leaders were aware that it was a lack of confidence and experience, coupled often with the debilitating symptoms of their condition that prevented members from taking a more active part in the group. They therefore coaxed and encouraged the members to get involved in ways that were individually appropriate and reflected members' skills and personality. This might involve conferring official roles where leaders felt it would boost members' self-belief.

> *I knew they'd be reluctant to come forward for official positions …. I did it very light heartedly ….. and one of the mums was saying 'I'll look at sorting something out for the summer holidays' and I went 'fantastic* [name], put [na*me] down as project manager!'* (PC4-key member: G)

In getting members involved in this way leaders not only reduced the burden on themselves but helped to create a more collective ethos with strong feelings of ownership amongst the members.

> We all do a bit *don't we -but I think we are independent aren't we - don't you think on the whole*- doing things our own way you know

> *it's…it might take us a little longer but we get there in the end*. (PH15-member: G)

Having an input into groups' organisation and, at least some types of tasks, also provided a means of empowerment and political learning for members.

> *I'm doing ok you know …. I suppose I wouldn't have done anything like this … so in one way I suppose it pushed me into doing it*. (MH5-key member: I)

And in this way it could be said to decrease any inequality in status between members and leaders, especially in those cases where members went on to take increasingly responsible roles that might previously have been the preserve of the leader. In a few groups for example, members had progressed from helping with very mundane tasks to being trusted to take on jobs that involved the presentation of the group within the public domain.

> *Where there's been a funding crisis and the members have had to get* involved in f*undraising, that was really empowering for them….people have stepped up and researched things … they've asked to attend training here … and others have put themselves down for marketing* and promotion. (MH2-key member: I)

It should be noted that not all respondents shared the view that members should be involved in running the group or contributing to its tasks. A very small number clearly felt that their members lacked the capacity to take part and felt that this did not have a negative impact on the group's efficacy.

> *We haven't got a committee … the group members are too traumatised* to even be involved. (S3-key member: I)

For a couple of other group leaders however there was a little more tension inherent in their approach to running the group. And whilst they paid lip service to the ideal of member involvement, were unwilling to relinquish any control, not only over the group's organisation, but even trivial tasks such as making teas and opening up venues.

> With them as parents doing it - how would you manage the finances if *things went wrong….we've got a couple who always come to the AGM and say 'I want to be more involved, but you can never get hold of them and then they don't turn up … I like to know what's going off…at least if I do it myself I know it's* done. (PC3-key member: I)

Interestingly, although members' involvement in the groups' tasks and organisation was said to promote a sense of collective ownership, it does not appear that a lack of this type of input will necessarily impede such feelings. Although the members of a couple of these groups did seem to have little awareness of the group as being 'theirs,' showing little commitment to it or seeing it as a service akin to those provided by public agencies.

> People just come and go as they need the service. (S3-key member: I)

In four other groups the opposite was true. Here the members had a strong sense of ownership, referring to the group as "another family" or a "community."

> When group started as self-help group we thought we need support worker …. *other group all the time the worker doing everything and telling you what you're doing - now is a lot different…. like another* family you got here. (MH4-member: G)

8.4 Decision making

The groups were involved in making decisions of various levels of importance and about a range of matters. These ranged from steering the group's overall direction and evolution to more day to day matters such as choosing where to go on outings or whom to invite as speakers. Respondents tended not to distinguish between these levels when talking about decision making; however it was clear that in nearly all groups different types of decision got made in different ways with varying levels of input from members and leaders.

Determining the group's direction

Groups' overall purpose and the intended route of their evolution, despite being of fundamental importance, were often not determined through purposive acts of decision making. Instead they appeared to be agreed upon in a more implicit way. In many groups, a lot of which had been running for a number of years, this was because the group's initial aims, that is, to offer support, social activities and information to members, had remained unchanged, groups simply wanting to "roll on" as they always had. The continued attendance of members and the benefits they gained amounted to their tacit satisfaction with the status quo. It was generally enough to for leaders to confirm this periodically through informal questioning at meetings.

> We said look be honest is there any way we could improve it - and they *couldn't …– and if you've got something that's successful don't knock* it. (PH4-key member: I)

Having said this it had occasionally been necessary even for these groups to take a more active stand with regards to affirming their desire to adhere to their original path. This situation had arisen when individual or small groups of members had tried to redirect the group towards their own ends, and it usually resulted in attempts at compromise. For example two groups decided to alternate meetings thus allowing both the original purpose and that favoured by the minority to be pursued. The leaders of these groups felt that the decision making process had itself been valuable in clarifying the group's direction through overtly democratic means that reflected their ethos of inclusivity and "fairness."

> He was trying to take it in a direction that perhaps upwards of two *thirds of the group didn't want to go …whilst [the new meeting* arrangements] offered a compromise by allowing meetings for [therapeutic exercises] it also clearly defined the group in terms of its broader social role. (S2-key member: I)

In a few instances, generally where groups were begun by a number of individuals, the process by which their direction was decided was arrived at collectively, with all those members who were there from the start taking part in discussions about the "way forward." This was despite the fact that their

initial preconceptions of what the group was for may have differed. These groups saw the process of coming to an agreement about the group's future as valuable in itself, in terms of boosting members' confidence and developing a sense of group identity and pride.

> None of us had a clue what we were going to aim for – this evolved – we just all talked a*nd we all decided … it was very much our own ideas … we're all a lot more confident now and at first we were worrying a* bit – *what as a group we were going to do … we said we'd form a committee, we'd get involved and toss things about … funnily enough* we a*re pushing boundaries in some ways nationally … we're a sort of* flagship now. (PH3-key member: I)

Leaders' vision for the group's direction

Around a third of the groups were led by a very strong individual who clearly had a "vision" beyond the establishment of an informal support and information group. Sometimes this "end vision" entailed the group's role evolving into that of a service provider or the use of the group as a stepping stone that could provide justification for the funding of a subsequent public service.

> *I ran it as a pilot … it is really a facility that should be there in the* healthcare system. (S3-key member: I)

In other cases the leaders' aim was to change the focus of the group from being predominantly inward looking, to establishing it as a part of a network whose role was to link with agencies and organisations in the broader community.

> *I decided that our whole format for doing things wasn't really very good …. We were a group that was just dwelling on our own problems …. I started attending quite a few community meetings …that's how we* managed to get a lot more community status. (PH16-key member: I)

In all but one of these cases the evolution towards these ends represented a substantial deviation from the original purpose for which the group had been

established. And, as the leaders of these groups generally espoused democratic values, it might be expected that this transition would have occurred after a process of inclusive dialogue.

> I never do anything or take decisions on my own – *it's always the group … admin and the way forward - nothing's ever just my decision*. (PC3-key member: I)

However, in fact there was little indication of members' active participation in any decision making processes that had resulted in groups changing from the type that simply "meet for a coffee morning" into ones that were now working extensively in partnership with larger organisations and often in receipt of referrals from mainstream health and social care agencies. Indeed the leader of one group admitted that even as her group began with such modest aims she had personally envisioned something far more ambitious which she had unilaterally taken action to implement.

> *When it did start I did have a vision … my end vision is now* - and I have actually sent off a proposal to the head of [the department] for Notts County Council – *it's to have a resource centre … [into which] hopefully we'll have quite an influx of professionals*. (PC4-key member: G)

On one hand this could be indicative of a lack of internal democracy within groups, in that this type of important, higher level change was being made without reference to the members. And indeed it appears that in a small number of groups the leaders' protestations of democratic decision making were somewhat tokenistic, being limited to rather mundane issues such as the contents of information packs or the venues for outings, whilst excluding members from engaging with more important matters. However for some groups it might equally be a reflection of the differing roles, discussed above, that leaders and members ascribed to themselves and to each other and which they clearly deemed in the overall best interests of the group - leaders thus taking responsibility for decisions at a more 'strategic' level for which they were generally seen as better equipped due to their confidence, experience and ability to make contacts with external parties. In these cases members' support

for leaders' plans was indicated by their continued satisfaction with and input into the group. And that they still talked about the group's value in terms of its on-going, original functions suggests that these were perceived as entirely compatible with the leaders' ambitions, both aspects being integral to the overall purpose and evolution of the group.

However not all groups appeared to work in such a complementary way with regards to the group's development. One leader, for example, took no account of her members' wishes when deciding to allow the group to come to a close so that she could concentrate on large-scale funding applications in order to act as a service provider.

> *I'm involved now in setting up the [service] … I don't think [the group] will [survive] it's had its life, it's served its purpose, I've done my part*. (S3-key member: I)

And a couple of leaders refused to even consider the developments that members wished to see regarding the group's growth. The ostensible reason for this was that the members lacked the commitment to assist with the added responsibilities that these changes would entail. There was a sense though that in fact these leaders were doing little to encourage and may even have been actively discouraging members from developing the confidence and experience to undertake such responsibility in order that they themselves could retain sole control over the group's evolution.

A small number of group leaders had attempted to steer their group towards the fulfilment of an ideological agenda which was often the product of their professional background.

> In the longer term *perhaps I have some ideas … I would like to* introduce more educational activities – *I think there's a lot of research* that shows that this really [works]. (S4-key member: I)

This type of goal-oriented, evidence based ideology was not shared by the members, who had joined these groups largely in pursuit of building social relationships. In one of these groups, as with those discussed above, support for the leader's intention to re-direct the group was evidenced by its continued

popularity and the value that the members placed on being part of it. The members were "happy to follow" and clearly maintained a strong sense of ownership. This group provides a good example of the tension inherent in the role that these leaders took with regards to steering the group. The leader of this group who joined as a volunteer, via a third sector agency, spoke at length about how she felt that the value and success of the group were down to its being "truly grassroots" with the members themselves having determined its purpose and direction at the start.

> [It] started out from the grassroots, from these women who identified *their own need for a group for themselves …. there was no one who* came along and said this is what is needed the need was recognised and the group was started by the women themselves. (S4-key member: I)

However the fact that she had effectively taken over the role of identifying their needs, and that this had if anything increased the popularity of the group, is also indicative of the importance of taking a nuanced approach to ideas such as egalitarianism, democracy and member ownership, which appear not to be dependent on all members having an equal say in all areas of an organisation.

The other two leaders who had attempted to steer their groups according to their, initially dogmatic, ideological ambitions, ended up completely abandoning these in favour of the path preferred by the majority. These leaders claimed to have arrived at the decision to make such a change after a process of "canvass[ing] the members" and finding out "what people want." However it is not clear how far the members were successful in convincing the leaders through a process of rational debate or whether the leaders simply conceded in order to ensure the group's survival and their continued leadership of it.

Bringing ideas to the group

All groups, even those with very set formats, felt they needed at least occasional "fresh ideas" in order to prevent meetings and activities from becoming stale and repetitive. Suggestions about where to go on outings, what types of activity to provide, whom to invite to the group and what to talk about

were most commonly required. As might be expected groups differed in the extent to which leaders and members contributed ideas, although it was generally the former that came up with the bulk of proposals. Indeed the ability to do this was seen in some groups as being one of the specific qualities possessed by leaders.

> *He's great you know, he hasn't been here long at all but he's got all these ideas …. With [name] now it's like he sees things* - all these types of opportunities. (PH6-key member: I)

Having said this, in the majority of cases, leaders were keen to also elicit ideas from members as a means of not only reducing the burden on themselves but also encouraging a sense of ownership and commitment within the group.

> A*nd we're open to all ideas, to any input, any suggestions that people make … it's important if you have an idea to let them roll with it … [then] they don't just think they're coming along under sufferance*. (PC4-key member: G)

Members were not always forthcoming though in making suggestions. And whilst in a few groups this suited both leaders and members, in others it was a source of frustration.

> *They don't take the initiative themselves … I don't know- it's hard to find out … how do we get them involved … I'd like to do a lot of new things but they don't* – very little input. (PH1-key member: I)

A range of methods was used in order to encourage members to contribute ideas, some of which were more successful than others, however, as with other areas of member involvement, the success was ultimately less to do with the chosen method than with the leader's attitude to and relationship with their members.

Generally however, the use of more official means such as planning meetings or sending questionnaires out to members to garner their suggestions were less effective than informal discussions within regular meetings or casual discussions with group leaders.

> If they hear anything or got any suggestions they certainly break their necks to come and tell me. (PH11-key member: I)

The success of this less formal approach may have been due to the lack of confidence some members had in asserting their ideas.

> Some of the girls do find it hard though to actually speak up, I did, no I did when I first came- you know I m*ight be thinking 'we should be doing this' but*. (MH5-member: G)

The development of new ideas within groups could also be affected by the flexibility of their internal structure. In some, particularly very old groups, that had had the same core members for many years it could become very difficult to make suggestions or to deviate from accepted ways of doing things.

> *Now I find it impossible to talk about … how it should progress … we used to raise things and have a group discussion, but it's hard now …* nobo*dy says 'why don't we do so and so.'* (MH3-key member: G)

Similarly groups that operated as closed structures with boundaries that were difficult to penetrate by newcomers appeared to be less likely to evolve and develop new approaches – one group leader acknowledged this.

> All of us are getting older and maybe in a way getting more set in our *ways … which is another reason for having younger people with new* ideas – it had never occurred to any of us that we might have a website. (S2-key member: I)

On the other hand those groups with more fluid memberships and roles were more likely to be in a state of on-going development and tended to be more receptive to a wider range of ideas.

> *Well it has changed … as membership changed because it changes its* character a b*it according to who's there*. (MH1–member: I)

Making practical decisions

In nearly all the groups, including most of those whose overall direction was left to the leader, it was felt that members should be involved in making decisions about practical group matters. Although a few groups felt they had very "little to decide" for most there was a range of issues about which decisions needed to be made. On one hand these could be about things of significant importance that might ultimately affect the groups' evolution and purpose; for example whether or not to have links with professionals, whether to apply for external funding or what types of activity the group should provide. On the other hand there were more mundane decisions such as where to go on group outings or whether to subsidise a Christmas dinner. However, although such decisions might appear more trivial, in groups in which the leaders were trying to foster an inclusive atmosphere, members were made to feel that these too were important choices that affected the group's efficacy.

> She always will ask us – *I say 'no we already went to Leicester' then we try something new this time … then other ladies they say 'yes, this is better' so this is good … she listens*. (PC5-member: G)

In fact in a few of the groups in which a section or all of the members lacked confidence in their own opinions, having an input into decisions about group outings seemed to be a particularly important way in which they were able to assert themselves.

> We all participate and that *and make suggestions for outings … yes it's* democratic like that. (PH1-member: I)

Choices of this type, rather than those to do with the group's evolution, appeared to be what respondents were referring to when they described their group's decision making processes. Generally group leaders, even those who had assumed sole control over their group's overall direction, felt that they acted in "democratic" and inclusive ways. In fact such participatory decision making was clearly seen as something fundamental to the ethos of self-help, with most groups keen to emphasise their democratic ways of working. Respondents often stated that "all the group" was involved in reaching agreements, that "we put things out to everybody to see what people want" and

that “the decisions are shared … everyone has their say … we decide between us diplomatically.”

Very few respondents openly denied the value of democratic processes. However such attitudes did occasionally exist. In one group the leader felt herself under no duty whatsoever to involve members in group decisions, as she saw the group as her enterprise and hence fully under her control. Another group member strongly regretted both the withdrawal of the previous leader, who had made all decisions “unilateral[ly],” as well as the “more democratic” approach of the new Chair. Interestingly though, this respondent had now begun to criticise other members who would not state their preferences regarding the group’s activities. This suggests that she may have begun to internalise and value the democratic behaviour which she felt had been forced upon her. Similar results could be seen amongst groups that felt that promoting a democratic culture was so important to their identity that even though members were apathetic and content to follow unquestioningly, leaders insisted on going through the formalities of an inclusive process.

> *We tend to formally put things to them …. [but] they’re just happy to go along with things … we will try to get them involved and think about* what they actually want. (MH5-key member: I)

This approach had clearly resulted in these members’ empowerment and helped to develop a habit of participation as, during the course of the research, they became visibly more active in terms of stating their opinions and questioning the options available to them.

> Where were decisions made?

The groups used a variety of practices and forums in coming to decisions. For many there were no separate committee meetings or planning groups, all decisions being made instead within regular group meetings. This often involved a very informal process of “chatting” about options until agreement was reached.

> *It’s quick and easy* – do you want to go there? Yes? Right done. (PH17-key member: G)

This was presented by group leaders as a very democratic and inclusive method of ensuring all members' input; however, there was evidence in a couple of groups that in fact it was those with the loudest voices whose views were accepted. Having said this though, such a process clearly suited the, mostly long term, members of the groups at which this occurred. In another group the members had developed strategies to ensure that whilst such domination might occur within meetings, their views were ultimately taken into account. They did this by forming alliances that allowed them to collectively stand up to the more overbearing voices. Indeed they seemed to see this type of negotiation as intrinsic to being part of a group of "strong-minded" individuals.

> There are disagreements sometimes, differences of opi*nion … sometimes people feel pressured …* so *they'll complain to other members afterwards 'I don't think she should have said that' … [so] it doesn't dominate how the group functions or what the group decides*. (MH1-member: G)

Approximately a third of the groups held separate committee or planning meetings. The main purpose of the committee for most groups was to make decisions about the "nitty-gritty" and "the boring details," whilst important matters were to be agreed upon by everyone at the regular group meetings.

Although a number of respondents stated that their group followed this type of process, there were in fact subtle differences in the role played by committees in terms of controlling the options from amongst which members eventually made their choices. The group quoted above was an example of a very open process through which important matters, such as what to spend grants on, were first raised at the regular group meeting, members being invited to think up ideas and bring their suggestions to subsequent meetings in order to be discussed and decided upon by the group as a whole.

> *We get everyone to think about what they want to do then you've got time to talk about it and discuss it and you're not just making snap* decisions. (PH7-member: G)

Some committees used devices such as questionnaires and emails to bring members into decisions.

> If we want an opinion on anything we can just whack out an email. (PH3-key member: I)

In other groups however, although the final decision might be made by the membership, the committee's role involved analysing the available information in order to narrow down the options which were ultimately to be presented to the group.

> Well the treasurer decided that we ought to put up subs from £2.50 to £5 and we put that to the *meeting and got a unanimous 'yes.'* (PH8-key member: I)

Although these groups saw themselves as acting democratically and the members as free to decide for themselves clearly the latter would be unlikely to have the necessary information at their disposal to properly question the options being presented to them. Of course this is not to suggest that in all these groups the committees were intentionally keeping members in the dark- all members being, after all, free to attend committee meetings. And the difficulty many groups had in appointing officers and in particular treasurers suggests that members would be happy for the committee to take this role. However there were occasionally times when the group's approval appeared to be a case of rubber stamping decisions that had already been made elsewhere.

> When we [the two leaders] decided to change the constitution we brought this to the committee and after this we took it to the whole *group … once I explained to them they accepted it straight away*. (S4-key member: I)

> Who has the final say?

In most groups the leader or Chair reserved the right to have the final say regarding group decisions.

> *If it's not working right I'll have the last say and we sort it out that* way. (PH11-key member: I)

The need to assert this right had often arisen when leaders were in disagreement with their members over a specific issue; a situation that had sometimes occurred when members had taken unilateral decisions without informing or consulting with the group leader. Leaders of groups across the range of structures, from highly democratic to authoritarian saw themselves as being in ultimate authority.

> I will tackle it - this is one thing I will put my foot down with. (PH7-key member: I)

Having ultimate decision making power was not only an issue in instances of dispute and disagreement. Leaders' authority was also sought in an enabling capacity, giving members the official go-ahead to put their ideas into practice.

> *One of our members has got a bee in her bonnet and at the moment I'm giving her full rein because she's got to get it out of her system*. (PH18-key member: I)

In some cases, especially with larger groups that were working in partnership with mainstream agencies, having the final say was deemed necessary in order to protect the group's public image and to ensure compliance with legal and financial regulations.

> *If it's major things or things that go out into the community such as* things that we produce then I would tend to have it go out through me because I want it to have that professional image – I need it to have *that … I tend to let them roll with it you know provided things aren't* too expensive or too much out of our comfort zone – I try to keep a lid on financial things. (PC4-key member: G)

In a less direct way group leaders also retained an element of final authority and control through the fact that it was usually them who, after group discussions and agreement, went away and implemented decisions.

> I was organising what they wanted to do – I put [it] in place. (PH15-key member: I)

This was particularly relevant to the creation of constitutions and policies and the production of literature, where, although the general contents might have been decided upon by the group, the final wording and nuance would remain in the hands of the leader.

> Everybody had a say in it being drafted – you know put your own bits *in and we'll compile it*. (PH18-key member: I)

Group leaders often also acted as a gatekeeper. For example invitations to take part in research or consultations as well as information from national organisations or professionals were nearly always addressed to group leaders who were thus in the position to be able to decide unilaterally which of these to pass on.

8.5 Summary

The main themes that arise in this section, most particularly concerning the roles and status of leaders and different types of member, are treated at length in the Discussion chapter in relation to the groups' collective identity creation and so only a brief summary of the findings will be given here.

The vast majority of groups, despite the numerous ways they differentiated leaders and members and the elevated status that was attached to the former, saw themselves as democratic and inclusive and believed that this was a fundamental aspect of their group's ethos. Many groups feared that this egalitarian atmosphere would be affected by their adopting the formal structures required by funding bodies. However these fears proved to be unfounded as despite prescribing certain structural requirements on paper, funders did not interfere in how groups conducted themselves in practice; in fact some groups felt that their autonomy was enhanced by gaining the money required to fulfil their goals.

Groups placed much weight on rules as a means of protecting their values, using them for example to prevent domination, to preserve equality and to ensure members' contribution to group tasks.

Leaders and a (usually small) core of key members took most of the responsibility for running and organising the groups. The vast majority was very keen however to increase regular members' involvement. Leaders had most success in achieving this when they adopted a gradual approach, initially engaging members in straightforward tasks, which were nonetheless ascribed a high value, until the members had built up the confidence to take on more demanding roles. Similarly members were asked to contribute ideas according to their own capabilities and experience, with leaders welcoming input about simple matters such as where to go on outings as well as more important issues such as how to spend group funds.

The role of members was more complex with regards to decision making and is the subject of detailed analysis at Chapter 9. Although members, and in particular the committee, were routinely asked for their views, group leaders often appeared to make higher level decisions, about the overall direction of the group, unilaterally. Furthermore they tended to reserve the right to have the final say in cases of disagreement. However, members' continued support for the group enterprise implied their consent to the leaders' actions and their belief that it was contributing to collective goals.

9 Discussion and conclusions

Strengths and limitations of the thesis

The final chapter is used to draw out the principal theoretical implications that arise from the findings. Prior to this there will be a brief consideration of the strengths and limitations of the study.

The thesis makes a contribution to the understanding of self-help groups in both empirical and theoretical terms. At an empirical level it has added to the sparse evidence base about these groups in the UK. Until now the majority of research has adopted a case study design, which, whilst of undoubted value in eliciting the unique characteristics of individual self-help groups has been limited in its ability to present a broader picture of the unifying features of a diverse range of groups. The methodological approach of the current study has allowed it to build on and advance the work of Elsdon et al (2000) in developing a more comprehensive picture of the self-help group phenomenon. Having said this of course, it must be reiterated that the qualitative design does not allow for firm generalisations or broad, statistical predictions.

The findings have added to a number of important areas in which little information had previously been available. This is especially with respect to groups' structural forms, in particular their leadership and the roles of and expectations on different types of member. It has also provided an account of self-help group members' role within and attitudes towards consultation, campaigning and social network formation. The findings also update those of Judy Wilson (1994) with respect to understanding the relationship between professional service providers and UK self-help groups. And in this, as well as in a number of other areas, they have provided evidence that challenges some of the traditional and occasionally presumptive ideas about these groups.

In addition to contributing empirical data, the thesis extends the conceptual parameters of a phenomenon that is still widely seen as under-theorised. Through the use of a framework that has had little application within this field it offers new ways of understanding and explaining self-help groups – in terms

moreover that are very relevant to on-going concerns at the political level. At the same time the empirical data provide real life examples with which to animate the abstract, theoretical world of the Habermasian public sphere; in doing so making a case for its continued relevance to the study of society.

The remainder of this chapter uses ideas largely borrowed from Jurgen Habermas in order to develop a model that enables us to account for the groups' structures as well as their activities, be this, their inner-focused support and social activities or their outward-looking engagement in public forums, as intrinsic ingredients in the development of their normative culture. In addition the model allows for the framing of the groups' goals and benefits in terms of their impact at the community level.

Conceptualising self-help groups in this way allows the thesis to contribute towards greater clarity within health citizenship theory by giving these groups a more firmly grounded location within it; and it enables us to draw out some of the characteristics that distinguish self-help groups' impact in the public sphere from that of other types of lay health organisation.

Of course the advantages that have come from following a particular theoretical design carry with them their own limitations. These limitations can have an effect at all stages of the research; decisions about which literature to pursue, the types of question to ask and the selection of data to be presented and subjected to analysis, all entail options that necessarily get chosen at the expense of others. The result is that the thesis can only claim to provide a partial account of the groups – partial in terms both of its completeness as well as with respect to my own, conscious and unconscious, preferences and biases.

9.1 Discussion: collective identity

Introduction

In chapter two I examined the ways in which some of the central ideas in Jurgen Habermas' theoretical model of the public sphere and civil society were relevant to the explanation of self-help groups' commonly perceived role as drivers of democracy and citizenship. It was suggested that concepts such as communicative action, lifeworld autonomy and independence from the state were appropriate tools with which to begin to develop a civic account of self-help groups' behaviour. This framework was then employed throughout the findings sections as a means of drawing out the data that were deemed most relevant to explaining the groups in terms of their democratising effects. At the same time the application of this "theory heavy" model to a broad set of empirical data provided the opportunity to test its explanatory potential on a real life social phenomenon, something which has been largely lacking up until now in the literature (Dahlgren 2002:14).

The discussion is divided into two parts. The first will explain the findings in terms of collective identity and the second, briefer section, will consider self-help groups' occupation of that space which constitutes the interface of the system and lifeworld.

9.1.1 Self-help groups as sites of identity creation

Although the concept of collective identity was only paid brief attention in Chapter 2, during the analysis of the findings it gradually began to emerge as that which could most comprehensively explain how self-help groups were acting to sustain discourse in the public sphere. In this section I will therefore argue that it is through the process of collective identity creation that the best account can be given of self-help groups' democratising role.

One of the most important proponents of collective identity, Alberto Melucci, stresses that collective identity should be seen as an analytical tool as much as

a thing in itself to be studied. And as such, particularly when used in conjunction with other Habermasian ideas about rational communication and consensus, it will be shown to be a very useful way of conceptualising many of the aims pursued by the groups, as well as the processes they used in order to attain them. This was especially important with respect to the groups' traditional role of using members' experience and knowledge about their shared condition as the basis for providing mutual, personal support, sharing information about living with an illness or coping with a life-changing event. By focusing through the lens of collective identity it can be shown that it is in pursuit of these functions, rather than the groups' more outward-looking, overtly political actions, such as participation in consultations or campaigns, that their democratising effects primarily arise. This is not to suggest that their outer-focused activities do not contribute to the public sphere and the part they play will be discussed in the subsequent section. However the extent to which these activities act to democratise public discourse itself rests on the prior and therefore more fundamental process of identity formation taking place within the groups.

It was clear, from the extent to which respondents wished to talk about them, that the groups still prioritised these traditional functions, with the majority describing the provision of "support" or "support and information" as being their primary purpose, and the need to be with "people in the same boat" as being by far the most common reason why they initially sought out or started up the group. Thus, to fail to account for such activities by concentrating instead their outward-looking roles would risk presenting a distorted picture of groups' civic status. By refocusing attention away from some of the theoretical ideas that it had been presumed would form the basis of the analysis, for example self-help groups' autonomy in relation to the state, and beginning instead to view the data from the perspective of collective identity, it becomes clear that the groups' inner-orientated aims are at the heart of some of the key processes through which they can be said to sustain democratic discourse. Collective identity is thus proposed as the concept best able to capture and make sense of the broad range of activities in which the groups were engaged. Similarly it can provide the best explanation of the complex values that

determined how groups put their aims into practice, in particular through the development of their structural forms and the different expectations and duties they imposed on different categories of member. Furthermore it was frequently the overarching pursuit of identity creation that brought to life and gave meaning to many of the core Habermasian processes and values on which communicative action rests. For example; the groups acting as a medium of consensus seeking; the adoption of inclusive structural forms; groups' impact on relationships in the lifeworld; their constructive engagement with the system; and their consequent effects on public discourse, can all be conceptualised in terms of their acting as sites of identity creation.

It was also suggested in chapter two that a thorough analysis of self-help groups in the light of Habermasian principles, could help to locate them in relation to other types of health citizenship association. And again this is a task which will be shown to benefit by being approached from the perspective of collective identity. Collective identity has in fact played a central part in the theorisation of these types of organisation (Epstein 1995, Brown et al 2004, Chamak 2008), in particular health social movements, as well as in that of the processes, such as deliberative democracy, on which they are grounded (Dahlgren 2002, Elstub 2006). However, as stated above, this is a "theory heavy" area whose claims have had relatively little application to empirical data; fundamental questions such as what is meant by collective identity in ethical and normative terms, why it should be seen as democratising, why and how it arises and how its development is related to structural forms or leadership models have rarely been tested out in practice, most especially in the case of self-help groups. The remainder of this section will therefore address this deficit by providing an analysis of the self-help groups as sustaining communication in the public sphere through their role as sites of collective identity creation. In approaching the data from this perspective it is hoped that a more nuanced understanding of the similarities and differences between self-help groups and other health citizenship associations can be gained. And in providing the theoretical means through which to refocus our attention on the "enabling" as opposed to "protest" end of the spectrum of civil society (Scambler & Martin 2001 p183) we hope to illuminate the particular

ways in which self-help groups can have democratising effects through actions oriented to this location, and in doing this conceptualise them in their own right rather than as an embryonic or partial form of another type of organisation.

9.1.2 What is collective identity?

For Habermas personal and collective identities develop symbiotically through social interactions operating according to the principles of communicative action. What is fundamental to this process is that the parties to the communications are oriented to reaching understanding and consensus (1984, 1987) rather than the achievement of pre-ordained outcomes. As such the creation of collective identities can be construed as a bargaining process through which individuals with a plurality of backgrounds and worldviews are able to come together to articulate alternative interpretations of their needs and interests, to define and communicate new cultural meanings and values and consequently to develop mutually acceptable social goals (1996). Participation in such a communicatively rational exchange will result in a;

> circle of those who understand themselves as members of the same social group and can speak of themselves in the first person plural (1987 p60).

Melucci conceptualises collective identity along similar lines, warning against its reification, and thus, like Habermas, stressing its processual aspects, which it is essential take place within democratic structural forms. He defines collective identity as entailing "a sense of we" achieved through a process of

> active relationships between actors who interact, communicate, influence each other, negotiate and make decisions. Forms of organisation and models of leadership, communicative channels and technologies of communication are constitutive parts of the network of relationships (1989 p45)

In other words a truly "collective" identity entails far more than simply the existence of the shared condition, situation or experiences of a group's members. To focus too much on these shared characteristics risks reification which, as will be discussed below, could be used to support a view of self-help groups as deleterious to democracy through their sole concern with their own narrowly defined, personal issues (Bauman 1999). Instead, by construing collective identity as a process, and in particular as the pursuit of consensus, we illuminate its role in the negotiation of social goals and values and in encouraging democratic and socially integrative praxis. It is thus only if self-help groups are engaged in such processes that they can be said to be creating collective identity rather than merely possessing a shared identity. However in order for such an identity to augment public discourse it must clearly also have effects beyond the parties to its creation. And so the remainder of this section will address the following questions;

- Did the groups engage in communicatively rational processes as a means to developing social goals and values?
- And if so, did this have effects beyond the group that served to enhance communications in the public sphere?

9.1.3 The ingredients of collective identity

The findings suggest that there is a complex interplay between two, in some ways contradictory, forces in the development of collective identity. These are;

- Homogeneity arising from the shared aspects of the group
- Heterogeneity arising from the input of diverse individual voices

Without the creative tension caused by the co-existence of these two factors groups may be able to adopt a shared identity but this will not develop into the democratising process of collective identity creation.

Homogeneous characteristics

The fact of members' shared health condition or social situation was clearly an essential factor in bringing people to the group. Indeed by far the most widely cited reason for joining or starting up groups was to be with others "in the same boat" or who are "the same as you." And it is easy to see how this in itself could be construed as the "key mobilising force" that results in a "collectivised illness identity" (Brown et al 2004 p54). However, ipso facto, the existence of a shared condition lacks explanatory power on a couple of levels. Firstly it cannot fully account for the phenomenon of a self-help group, as many people other than self-help group members also share the same condition. Indeed one of the groups' biggest concerns was their inability to effectively communicate the value of self-help to these others and to co-opt them into the group. Secondly a shared illness or life-changing event as a basis for association does not support any claim to civic or democratising status. Something beyond the mere fact of the health condition is clearly necessary - and this was the belief in addressing it in a certain way. This belief was shared, and its importance emphasised, by virtually all respondents in the study. In other words the shared, homogeneous aspect of the groups consisted of two strands, one physical and one normative or value based, and it appears that the latter may be equally as important as the former. It was the acceptance of the fundamental, core value of "self-help," which involved taking the "active step" of joining and participating in the collective enterprise of the group as a means to "helping yourself" and "taking responsibility" for your own well-being, that differentiated group members from others with their health condition. The centrality of this core value was indicated by the fact that although, as will be discussed throughout this section, the groups championed the value of members' diversity in terms of their views on broader social, ethical and political issues, a failure to accept this core belief acted as a boundary of acceptability for participation, with those seen not to subscribe to it being referred to pejoratively as "free-riders" and in some cases excluded from the group.

The need for heterogeneity

The existence of a core belief, shared by members, moves groups slightly closer towards the idea of creating a democratising collective identity in that it is the development and communication of values and cultural norms that is the basis of the socially integrative function of a communicative lifeworld (Habermas 1987, Kelleher 2001). However, the data suggest that this core belief, acting as it did to bring people to the group, preceded their participation, and thus it could be argued that it had not been developed through communicative processes within the group, but, as with their shared condition, was something that members simply happened already to possess. The presence of a unitary shared credo would thus fail to account fully for groups as drivers of democracy and would still leave them open to accusations of looking inward and fencing themselves off against communicatively rational engagement. Groups could still thus be seen more in terms of possessing a shared identity rather than participating in a process of collective identity creation.

Therefore these two strands of group homogeneity must co-exist with characteristics that transform this shared identity into a communicative process of "negotiation and renegotiation" (Melucci 1989 p44) through which the search for consensus over shared social goals and values becomes a constitutive part of the groups' purpose. Clearly such a process of negotiation can only take place in a system in which different voices and viewpoints are competing and contributing and which is taking place over time, rather than as a one-off or time limited event.

For Habermas such a process of socially integrative communicative action is facilitated by the use of the dialogic medium of personal narration. He clearly saw this as a means of authentically anchoring personal identities in a way that enabled them to make a legitimate contribution to the subsequent development of collective identity;

> *Narrative practice … serves … the self*-understanding of *persons….they can develop personal identities only if they recognise* the sequence of their own actions from narratively presentable life

> histories; they can develop social identities only if they recognise that they maintain their membership in social groups by way of participating in interactions (1987: 136)

In other words through the use of narration as the medium of conversation the input of each party will necessarily be unique, being grounded as it is on the individual "life histor[y]," no two of which can be the same. Thus narration serves to ensure the heterogeneity that is needed in order to perpetuate the process of negotiation of the social goals and values that comprise the collective identity. Furthermore it helps to ensure that those social goals and values are not abstracted from individual life stories and personal experience in the lifeworld as may be the case with the instrumental goals developed within the system. The vast majority of groups indeed appeared to be operating through such narrative practices. Meetings were clearly being used as a space in which to discuss the specific ways in which a condition had affected particular members. And the variety of ways that members with different backgrounds and personalities responded to their illness and treatment were a central topic at group meetings. Their frequently extensive technical knowledge about their condition was almost never framed in abstract impersonal ways, but rather as "tips and advice" that arose through living their day to day lives. Despite the fundamental importance of being with people "the same as you" respondents were determined not to be "defined by their condition," sharing stories, for example, about their lives, achievements and hobbies through which they had identified themselves prior to their diagnosis. The acceptance of the unique histories, characteristics and abilities of different members was evidenced by the fact that people were welcomed to use the group in different ways and to serve different ends. And whilst many clearly wanted to have an on-going involvement and a say in the group's development, others, particularly the young, might just want to "dip in and out" for specific information or advice. Similarly there was no expectation placed on members to disclose personal information or even to speak at all at meetings, each person being acknowledged as best placed to ascertain their own individual needs with respect to what they got out of the group.

Using the idea of collective identity creation illuminates how a group's shared core belief about taking control of a shared problem is addressed through its contextualisation in the heterogeneous backgrounds of individual members and the negotiation of social goals arising from taking account of these different contextual histories. We can thus begin to make sense of groups where, at one and the same time, people are encouraged to "use the group in different ways" but where this could only be made possible through the medium of the collective whose importance was thus paramount; as one respondent, from a group of "strong minded individuals" expressed "it's not about the individual – it's about the group."

Heterogeneity of structure and roles

In Chapter two I discussed the fundamental need for inclusivity and equality as the bedrock of communicative action. By extension, such principles will also be essential to the formation of collective identities and social goals, which themselves can arise only through communicatively rational processes. Abuse of power or the exclusion of voices will clearly result in the imposition of an identity and the instrumental, individual goals of the dominant party. Of course it should be reiterated that this is an idealised concept which has never been fully achieved in reality (Habermas 1996 p316); its value lies in its use as a yardstick by which to measure the communicative processes through which an association reaches its opinions. Despite the importance of structure to the creation of collective identity being such that Melucci actually postulates it as an intrinsic part of a group's social goals, there has been very little empirical research on this relationship, most particularly in the case of self-help groups. Yet, as will be seen from the following discussion it may provide an illuminating means of addressing one of the key themes in health citizenship theorisation by accounting for the range of effects that different types of lay health association may have in sustaining public discourse.

Organisational roles

Members' personal histories, in particular their educational levels, professional background and personal ambition had led to their prioritisation of a range of group functions. As a result of this they took on a variety of different roles

within its organisation. In most groups the leader (or occasionally a small group of leaders) appeared to have an elevated status that was reflected in the high esteem in which they were held and their greater say over the 'strategic' direction of the group. At first sight this appears to be at odds with the requirements of communicative action and thus to be an impediment to the development of collective identity. However the data indicate that the way power was perceived and used within the groups was more complex than the leaders' ostensible status may suggest. By using collective identity as a tool with which to explain the leaders' role and the consequent levels of democracy within the groups, a number of inter- related questions arise; were power or status differentials within the group used to further the more powerful parties' instrumental aims or the group's collectively negotiated social goals? How collective were these goals? Was power used as a means of silencing voices or bringing them into the group's negotiations? By asking such questions it is possible to make sense of why in many of the groups, leaders' strength or even "dominance" appeared to foster collective ownership and a strong sense of solidarity and to encourage members' input into the development of group codes, customs and practices; whilst in a very small number it resulted in a detached membership with little "sense of we."

As stated above the leaders in many groups had a disproportionate say in groups' higher level decision making; for example in developing the group's capacity to act as a service provider, to work in partnership with professionals or to forge links with broader advocacy bodies or community organisations. And steering the group towards these ends often seemed to take place in the absence of any discussion with members. However, in most groups this did not seem to affect feelings of collective identity and ownership as the leaders' ambitions were clearly seen as running in parallel with those of the members; these tending to focus on more day to day ways of maintaining the group's original support functions, which the members in general still saw as being fulfilled. Respondents were happy to take a pragmatic view of the different contributions that individuals with different narrative histories and consequent priorities could make to the group. Leaders were seen as providing the motivation, technical knowledge and ability to speak confidently and

articulately, skills that were frequently lacking amongst regular members due to their health condition, educational, professional or cultural background. What was key within those groups with well-developed processes of collective identity creation was that all contributions served the collectively agreed goal of sustaining the group in order that it could fulfil the individual needs subjectively decided upon by each of the members. The fact that these needs were in part addressed by being "part of something" indicates that the process itself, that is of taking part in a joint enterprise of decision making in which "we all get involved," albeit in members' case generally at a more quotidian level, was a constitutive part of the group's purpose and the identity to which its members agreed to subscribe. A tangible example of how regular members' and leaders' different roles served the same ends was that a prime concern for many groups was their inability to reach potential new members who they felt could benefit from the support functions to which the regular members contributed and from which they themselves most benefitted. Thus when leaders, through their ability to make links with professionals or to increase the scope of the group through identifying and securing funding, took the group, albeit at times unilaterally, in a direction that helped to fulfil this, it had the effect of bolstering rather than impeding the group's identity and collective goals. Furthermore it could be argued that the disparity between members, who generally prioritised and contributed more actively to inward-looking activities, and leaders, who tended to take the impetus for developing outward-oriented links, supports a view of self-help groups as sustaining the public sphere in broader Habermasian terms; thus whilst it was usually the leaders that ensured the group did not become closed off from both communications within the broader society or from its integrative links with the system, the members tended to ensure that, despite these links and the groups' consequent growth and formalisation, they remained anchored in lifeworld values, articulated through the medium of narrative histories and reciprocity.

Who is the "we" in a self-help group?

The groups' structures were not only differentiated along the lines of leaders and regular members. There was also evidence of different categories or levels of member. Respondents frequently spoke about the existence of; a "core,"

which was the category with the highest levels of commitment and most closely involved in running the group; ad-hoc members, who only attended occasionally; transient members, who "move[d] on" when they had gained what they wanted from the groups; and peripheral members who only took a limited part in group activities and in its organisation. The result of this stratification was that in virtually all groups it was only a proportion of members that was included in the negotiation of group goals, rules, practices and customs. This therefore raises questions about how collective groups' identities really were, who was "part of the circle … [that spoke] of themselves in the first person plural" and how inclusive this circle was.

What is of particular interest in understanding the normative culture that bound the groups is why certain categories of member were accepted as having a legitimate part in the group, whilst the "free-riders" referred to above, as well occasionally, as peripheral members, were not. In answering this we are again drawn back to the tension arising through the groups' shared and heterogeneous values, reinforcing the hypothesis that however strongly the groups claimed to celebrate diversity and autonomously reached, individual interpretations of need, there must be some core value without which the formation of a "we" would be impossible and hence that the breach or failure to acknowledge the value of which will set the boundary for acceptance within the group.

The transient, ad-hoc and (sometimes) peripheral members in nearly all cases were believed to be using the group to "help themselves" in line with the core self-help ethos and purpose. Members who "moved on" for example were seen to have used the group as a means to having helped themselves. Ad-hoc members, in particular the young, were also seen to be gaining something in terms of their own self-management and efficacy by their occasional attendance; in some groups the fact that their benefit arose merely through "knowing the group [was] there" if they needed it was enough for the rest of the members to see them as subscribing to and hence legitimating the core purpose and ethos of the group. Thus neither of these categories was subjected to opprobrium for their failure to take on any duties with regards to sustaining the group or contributing actively to its process of collective identity

negotiation. In this they provide further evidence of the importance to the groups' collective identity negotiation of respect for each individual's autonomous choice, which would necessarily allow for the option of not taking part in such negotiations. These members, whilst wanting to benefit in practical ways, appeared to have had no need or desire to gain from being "part of" a democratic collective, neither may they have needed the group in terms of their own self-recognition or personal identity (discussed below). However, such practical benefits, especially when the group was seen as a means by which these passing members returned to work, appeared to fulfil the core normative requirement of taking an "active step" and using the group as a means to "help yourself."

Of course this presumes that these members' decision not to participate directly in the group's identity creation was freely taken. An alternative interpretation would be that whilst these members wanted to help themselves in line with the group's core value, they nonetheless did not subscribe to its wider norms, goals or ways of working, but felt powerless to affect or change them and hence removed themselves from the process of their formulation. Clearly only under the former conditions could groups be said to be engaging in the type of communicative action that gives rise to collective identity and sustains civil society. However even taking into account the methodological bias inherent in interviewing largely core and long-term members, the evidence from nearly all the groups suggests that the former was indeed the case; ad-hoc members were welcomed back whenever they "turn[ed] up," sometimes becoming more settled members upon their return; short term members were consistently referred to without hostility or condemnation; and some respondents spoke about the evolution of the "core" membership itself and the ways that the group had changed in response to this – the implication therefore being that in the vast majority of cases entry into the bargaining process was open, fluid and inclusive. Thus, although these categories of member did not seem to take a direct part in the negotiation of group identity, their welcome participation can be seen as democratising in two important ways; firstly, in supporting each member's right and capacity to ascertain and define their own need it reinforced the importance of individual autonomy as the basis of the

group's collective identity; and secondly by providing open-ended communication channels to and from the broader society that would help to foster mutual understanding beyond the group by allowing group norms to be exported and ensuring that the group's collective identity did not become an unchanging, closed system but remained in active contact with values and ideas from a range of different sources.

The attitude towards these transient participants provides an illuminating contrast with that shown towards long term members and again illustrates how the core "self-help" ethos acted as the keystone on which the communicative processes and structural forms that supported the group's collective identity creation rested. Unlike those participants who were just passing through or dipping "in and out", members who stayed on in the group became subject to additional duties and responsibilities that contributed both to the social goal of sustaining the group as well as to the creation of its collective, normative culture; the former being through the expectation of taking on organisational roles and practical tasks and the latter through actively contributing ideas and participating in decision making procedures. It was through this diversified attitude towards different types of member that the group displayed their respect for individual choice as being manifested through the core "self-help" value; help yourself through moving on, or help yourself through being "part of something." And this provides an explanation of how the same groups were happy to see "the vast majority of people move on" at the same time as emphasising that "you have to contribute – there's an expectation that if you come you'll be part of it."

Viewed from the perspective of the lifeworld it is clear that in both cases the groups' overriding aim was to encourage personal autonomy and to prevent passivity and dependence. In other words, with the exception of a tiny minority of groups, what was not allowed was to simply be helped. With regards to long term members the groups were not always successful in achieving this aim but leaders and core members dedicated a lot of energy and imagination to the task of getting these individuals involved in group responsibilities and where members persistently failed to respond to this they became subject to moral disapproval akin to, if less intense than, that shown towards the "free-riders."

In a couple of groups leaders did not impose these types of expectation on any category of member. In these cases the leaders' domination of the group was clearly not used as a means of furthering the group's collective goals or of ensuring members' input into their development. Instead it was the result of a paternalist attitude that denied members' basic capacity to be involved in the group's structure and that ensured the leader's control over all aspects of its functioning. The result was that the members of these groups displayed very low levels of ownership or collective identity, and it is interesting that since the completion of the study neither is still in existence.

9.1.4 Whose voice is being heard?

As well as responsibilities towards sustaining the group through having an input into its tasks and organisation, long term members were subjected to a duty to contribute to the creation of the group's normative culture and the development of its collective goals. Interestingly, and in support of Melucci's ideas, the need to sustain such an inclusive process and the structural arrangements on which it rested, that is, fulfilling members' aims of "being part of" a democratic body, appeared itself to be a constitutive part of such social goals; a factor that helps to explain why some leaders and core members stayed on in groups despite having already addressed "everybody's problems already." Thus any leadership model, as long as it fed into these ends could be seen to sustain the negotiation of a collective identity. As might be expected, many of those groups with egalitarian structures and collegiate leadership tended to have the types of open communication with high levels of member input that would foster the creation of collective goals, with these goals and structural forms perpetuating each other. However, perhaps more interestingly, there was, once again, extensive evidence of groups in which the members' background, health condition or circumstances acted as a barrier against their willingness or confidence to "speak out" and where it was thus only through the encouragement and even coercion of a strong leader that these members gradually came to be included in the conversation. Some of the most dominant leaders were clearly using their power in the group to ensure that "everybody

has a say." In fact such a process had occurred to perhaps the greatest extent in a professionally led group. This group, whose membership came from a traditionally very repressed section of an ethnic minority culture, had developed an extremely strong "sense of we" which they were aware would have been impossible without such leadership. Similar evolution of group identity had occurred in dominantly led groups that contained members with learning disabilities, speech difficulties and limited literacy. Using collective identity as an analytical tool thus warns against thinking in hard and fast terms about what constitutes an 'ideal' grassroots association in civil society, or an ideal structural form or type of leadership in self-help groups. Both sociological theory and self-help literature has a tendency to idealise democratic structures and shared leadership (Maton 1988, Rootes & Aanes 1992) without necessarily giving thorough attention to the different forms these might take and the various ways in which democracy might arise. Similarly the Habermasian requirement for the "spontaneously emergent associations" in civil society (1996 p366), which has at times fed the idea of professionally instigated or "astroturf" groups as being somehow less civic than 'true' member – led organisations (O'Donovan 2007 p713), if accepted uncritically might obscure the unique modes of democracy taking place in other types of group. By focusing on processes of collective identity formation, as being effected through the ethos of "self-help" coupled with the inclusion of all interested voices in a process of on-going negotiation, it becomes clear that similar democratising effects may come about in groups with different structural forms, these forms themselves being negotiated as part of the collective identity in response to the needs of the parties to its creation. Thus groups, in which apparent status differentials, arising through the leader's professional background, educational level or strength of personality, exist, may still provide an ideal milieu in which to foster the type of communicative equality postulated in Chapter 2.

This does not imply that group leaders would never use their knowledge, ability to articulate their point of view or the esteem in which they were held in order to influence members. It is notable that in a number of groups, including some of the most democratic, with the strongest "sense of we," leaders

reserved the right to have the "final say." However the evidence clearly indicated that members of groups with all types of leader saw themselves as speaking as equals and as such contributing equally legitimately to a social identity to which all members, including group leaders, subscribed. Indeed the idea of shared identification with the outcome of group communications, or rather the lack of it, may help to explain the low levels of collective identity and member ownership in a very small number of the groups. The leaders of these groups, either through tangible symbols, such as wearing official T-shirts, which put them on a different communicative footing to the rest of the members, or through their denial of ever having needed or benefitted from the group's "self-help" function, differentiated themselves from the membership in ways that meant they were not personally buying into a common identity. In most groups however, the fact that members' contributions might not be of the same nature or made at the same level as those of the leaders did not invalidate such input forming a constituent part of the "we." Many respondents felt a sharp awareness of being an essential component of this, despite it transpiring that they were only contributing ideas about "where we go on trips." It could be argued, especially in light of the leaders' disproportionate role in determining the group's strategic development that this amounted merely to tokenism. However such input in a small, informal setting can actually have an effect on its overall purpose, ethos and atmosphere and in fact social events and outings were an extremely important part of how most groups realised their overall aims.

In addition there was evidence that many leaders would use opportunities such as this to build members' confidence so that they would begin to undertake increasingly responsible roles and have input into more important group decisions and ideas. This often involved allocating duties and official titles that had the effect of equalising the status differential between leaders and members, in particular through involving members in communicative processes outside the group; through encouraging them for example to speak at consultations and awareness events or to run websites or Facebook pages. Clearly an implication of 'training' members to project their voices thus,

would be its feeding back into the ways they would subsequently be able to involve themselves in dialogue and debates within the group.

9.1.5 Conflict and ideology

The complexity of the interplay between the homogenising and heterogeneous forces at the heart of the groups' collective identity creation was also evident with regards to their ethical and political ideology. The discussion so far has illustrated the profundity of the groups' attachment to the ethical values that underpinned their construction of "self-help", with deviation from this normative code leading to censure and even exclusion. Such a position could thus be deemed highly ideological; and yet the groups did not see it in this way. A possible explanation for this may be because such an admission could undermine the majority of groups' almost equally important belief in respect for the individual and support for a diversity of views. The groups, including those with the strongest adherence to a "self-help" ethos, frequently referred to having "no stance" or "no collective view" on what they saw as political or ideological issues. It appears therefore that the 'core' value that bound the groups might have been endowed with an elevated status that in some ways resembles a latter day version of the "sacred" or transcendent component that united more traditional societies in a collective identity in the past (Habermas 1987 p71) and without which such societies were seen to lack the means to maintain their cohesiveness and stability. It may be therefore that groups are tacitly aware that without such a shared, fundamental value that defines the "we" and its boundary, there would be no possibility of sustaining the collective. As such though it remains conceptually problematic in terms of its compatibility with unrestrained communicative action as it suggests that perhaps any, otherwise democratic, grassroots association, in order to maintain its integrity, will indeed be constrained in its freedom to debate, deviate from or amend the group's 'core,' binding value. It is unclear as to how far Habermasian theory is able to find a way around this thorny issue. On one hand Habermas appears to accept the necessity of certain elements of "background knowledge" in the lifeworld as being so "anchored that I cannot

touch them" (Wittgenstein 1969 cited in Habermas 1987 p336). However Graham Scambler (2001 p3) interprets Habermas' work as meaning that these "background assumptions" are only taken for granted in this way within the process of instrumental rather than communicative rationality – the latter acting as a means through which to reflect upon, question and reinterpret such knowledge.

Leaving this difficulty aside however, the groups unanimously upheld a view of themselves as ideologically pluralist. And such a lack of a political "stance" was especially notable, given the history of radicalism in this area (Emerick 1991, Crossley 2006), amongst the mental health groups, none of which advocated a particular standpoint with regards to the use of drugs or psychiatric practices. All groups felt that, whilst such things were often "up for discussion" they were ultimately choices that had to be made by the individual depending on their own circumstances and personal history. The group's role was therefore to provide a forum in which these issues could be discussed and justified and through which choices could thus be better informed and taken with greater confidence. The groups were similarly keen to distance themselves from identification with overtly political ideologies such as "black" politics, "parent power" or disability rights which might have stifled the members' freedom to contribute their own opinion about treatments, policies or ethical questions, to the group's negotiation processes.

The result of this ideological pluralism was that "conflict" was not only a fairly common occurrence in meetings but was seen by some groups as an intrinsic part of their collective identity. It was therefore to be welcomed and encouraged rather than avoided. In this they provide an interesting counterpoint to those health activist movements that similarly claim to be grounded on collective identity and that are sometimes seen as having a greater impact on political discourse in the public sphere than self-help groups. These organisations, for example, the anti-psychiatry or AIDS movements, have been observed to draw sharp ideological boundaries between activists and others, to the extent that they may at times have excluded the voices of those who do not share their political outlook (Epstein 1995, Crossley 2006). Many of the groups in the current study therefore, through their "endless … argument,"

"heated debate" and "conflict" that were an integral aspect of their social goals and through which compromise was nearly always attempted, appear to be more paradigmatic examples of the negotiatory / consensus seeking process at the heart of collective identity creation than some forms of new social movement. Thus, whilst self-help groups' voices may not sound as politicised as activist organisations', this lack of an overt "politicised collective identity" may reflect a more communicatively rational process, more oriented to understanding than to pre-ordained ideological ends. In other words whilst self-help groups' identity may be less "politicised" it may be more genuinely "collective" in terms of the range of political views it draws into the conversation.

This is not intended to suggest that all self-help groups' and all new social movements will have the same impact on public discourse or to suggest that one type of association is inherently superior to the other in this respect. Indeed it is possible that the activist / non activist boundary around new social movements is simply performing the function that the 'core' "self-help" ethos is doing in self-help groups. However by focusing on the processes that give rise to collective identity development it allows for a more nuanced view of the range of effects that organisations with different structural forms and political outlooks can have, and the location on the spectrum of civil society at which they are likely to be felt. It thus provides us with a set of useful questions that can help in the task of unpicking the democratic implications of different health citizenship groups.

9.1.6 Identity as recognition: the self beyond the group

The internal processes discussed above form a crucial part of the collective identity creation taking place within groups. Members were clearly articulating their own needs and negotiating their own roles according to their individual priorities in ways that would contribute to the social enterprise of the group. However, it could still be argued that to do this solely through the device of being with people "in the same boat," however democratically they behaved

amongst themselves, amounted to a withdrawal from the broader community and hence to the diminution of civil society. Of course it would be expected that the level of internal democracy in an association would correlate with its democratising effects in the broader society. And we have already suggested that those groups with open, inclusive and fluid structural arrangements would be in communication with the wider society and hence in the position to take the group's democratic ethos out into their other social networks. This section will look more closely at the ways in which the groups' support role, grounded on both the shared experience as well as the "self-help" ethos, can have an effect on communications in the lifeworld and civil society.

One of the most puzzling observations upon first reading the findings was the frequency with which respondents referred to their or other members' "isolation" as a reason for needing the group, despite it transpiring that virtually all belonged to extensive, strong and supportive social networks. This isolation arose due to others' inability to offer "understanding" to members who thus sought out the group as a means of obtaining such fellowship. Such a retreat into the company of others who shared the cause of the isolation appears to be at odds with the Habermasian concept of the public sphere acting as a space in which to nurture social integration through communicative practices oriented to mutual understanding; instead of contributing to such processes, members' actions could be fostering social fragmentation by denying those who do not share the condition the opportunity of attaining understanding. Thus any collective identity that closed off communications in this way, whatever the means of its creation within the group, could not claim to be sustaining the public sphere more broadly.

However, closer reading of the data allows such a negative interpretation of the groups' role in addressing "isolation" to be wholly dismissed. In fact the groups were using both their shared condition and normative culture as a means of enhancing the quality of public discourse in a number of important ways. At an overt level, evidence of this case came from the limited ways in which the respondents used the groups. The lack of desire to form friendships that went beyond group meetings and periodic social events clearly indicates

that the groups were not being used to replace existing relationships or in a way that encouraged dependency on either leaders or other members.

At a more subtle, communicative level the data indicate that the shared experience and the inter-personal understanding this gave rise to were acting as a means of reforming and reframing self-identity and self-recognition. This identity could then be carried out beyond the group to form the basis of the dialogue through which a more authentic social recognition could be achieved. This section will therefore consider how the groups were addressing the "self-understanding" that Habermas regarded as a necessary precursor to the development of "social identities" and the subsequent ways that this can affect the lifeworld and public sphere.

Mandiberg and Edwards (2013) summarise the extensive literature on the concept of self-recognition. Their overview can help us to understand the role of self-help groups in augmenting communication channels in the lifeworld, and it is hoped that their framework may itself be enhanced through its application to the current findings. Self-recognition is conceptualised as entailing three aspects, the individual self, through which we compare and differentiate ourselves from others, as well as the relational and collective selves. They explain how

> *Individual self and identity is influenced by the reactions of others …* When others do not confirm an identity that is salient to the individual *… the salience of that identity is reduced …. [thus the] positive sense of* self will *be disconfirmed … [and] … [this] may lead to less* involvement in the broad community and more dependency related inter-personal relationships with mental health staff (p24)

With regards to the individual self as formed through comparison with and differentiation from others, the groups were acting as a way of accommodating the changes that had been forced upon them as a result of a diagnosis or life-changing event. Members frequently referred to previously held jobs, roles and responsibilities which had socially located them and formed the basis of how they saw themselves in relation to others and without which they clearly felt adrift. The groups provided the opportunity to use old skills, albeit in a

different setting, and to take on new duties and commitments that allowed them to recreate a self that could still be compared to others in a favourable way. In order to achieve this, the members were clearly relying on lifeworld resources as opposed to dependency on impersonal, professional relationships. However, the data indicate that the groups' role operated at a deeper level of the individual self than that outlined by Mandiberg and Edwards. Members' adjustments to their self-recognition arose not only in response to their comparison with others, but crucially in relation also to their past self. A number of respondents indicated that it was their own inability to recognise and understand their new self in relation to a salient previous self that preceded others' inability to understand them. Mandiberg and Edward's conceptualisation of self- recognition may therefore benefit by being extended to include an on-going process through which individuals, particularly after a life-changing event, assess their current self through its comparison to and differentiation from past selves.

The need to address "isolation" through being with people "in the same boat," far from driving social fragmentation, was therefore the first step towards achieving mutual understanding within the broader society. Being with others who could vindicate or offer insight into members' situation allowed them to begin to answer the question "who am I now" and address the dissonance within their own self-recognition, the existence of which would inevitably have undermined others' ability to understand them. Without this, all subsequent communications, be they within institutional, personal or intimate relationships would necessarily be distorted. Likewise true consensus and social "comprehensibility" (Habermas 1996 p359) would be impossible due to the erroneous premises on which attempts to attain them were based. In using members' shared experiences through the process of narration of individual life histories in order to nurture the development of a new self that is a coherent continuation from the old, groups were performing the most fundamental function in terms of identity creation, which provided the basis on which all subsequent relational, social or collective selves could be negotiated and understood. It appears therefore that in stressing their sense of "isolation" despite being embedded in extensive social networks, the groups were not

encouraging members to adopt a 'status' of 'isolation' akin to the victimhood of which self-help groups have been suspected of fostering in the past, as a means of making dependency inducing claims on the system or withdrawing from social relations. This positive approach to the process of identity formation is again indicative of the centrality of the groups' "self-help" ethos and its demands for "self-responsibility," active steps" and "a positive attitude." The respondents' ability to "be themsel[ves]" and to "work out," through the validation of other members, how to live as a person with their condition, but still within the context of their own personal history, allowed them to rebuild social lives, "get back into normal life" and form new connections and networks in the community.

What is interesting about approaching collective identity in this way is that by focusing on self-recognition as a means to social recognition the effects that take place in the lifeworld assume a slightly different slant to those that are usually attributed to new social movements and hence to self-help groups when they have been cast as a type of such. In new social movement theory associations are said to sustain the public sphere through their defence of the lifeworld by "reacting against its increasing colonisation" by the system (White cited in Kelleher 2001 p121) and "challenging" system imperatives, in particular biomedical expertise and individualised models of health and illness (Zoller 2005, Chamak 2008). The symbiotic processes of self-recognition and collective identity formation taking place in the current groups however did not arise through the desire to challenge or as a means of disputing biomedical knowledge or definitions. Instead they were oriented primarily to relations in the informal, private sector of the lifeworld. This is not to say that members did not use the group to enhance their status in relation to health professionals but this was rarely, if ever the reason why members joined or started groups. Although authors such as White and Kelleher undoubtedly appreciate the ways that self-help groups affect members in the most private spheres of their lives, their and others' emphasis on "challenge," disaffection and reaction risks underestimating the effects that this role of self-help groups can have on the quality of public discourse. In order to support any subsequent challenge to the system, or indeed to encourage the effective integration with it, it is essential

that the lifeworld itself is functioning properly. This not only depends on its being defended against system colonisation, but on the proper grounding of dialogue and relationships within it. If individuals wish to have an effective voice in the public sphere it is of paramount importance that this voice is heard by others as the speaker intends it to be, and this can only be achieved when it is a voice they properly recognise as their own. And far from challenging the individualist model of health, many group members chose to incorporate aspects of it into the process self-recognition and collective identity formation, using the technical information shared within the group as a means of increasing the likelihood of diagnosis or of reconceptualising their situation in biomedical rather than social or cultural terms. Respondents' frequent willingness to incorporate medical labels into their self-identity could perpetuate the view of self-help groups as encouraging medicalization, a process generally believed to diminish the public sphere through removing complex social and ethical issues from public debate and into the exclusive arena of technical, specialist knowledge systems. And in one way groups did appear to be upholding such a view, constructing their conditions solely in individualised, corporeal terms with very little direct concern for broader issues of social justice. However, medicalization is also usually associated with deleterious effects in the lifeworld through its tendency to encourage passivity and welfare dependence. And this is not something to which the groups could be accused of contributing despite their readiness to adopt clinical labels. Members' overriding concern to help themselves meant that they saw diagnosis not only as a way of attaining self-understanding that helped them to reframe their identity but also as a means to better services and treatment and hence to being better placed to "do something about" their illness. This reframed, positive identity was then communicated to the broader society, both through members' reengagement in "normal life" and through groups' extensive awareness and education activities, in ways that encouraged people with their condition to be recognised and treated as competent, capable participants in community life.

Understanding identity and recognition

It is important to understand the ways in which self-help groups address questions of recognition and of individual and collective identity, as a lack of clarity about such concepts and the ways they are related to each other, could have practical as well as theoretical implications. Kelleher (2001 p140), for example believes that "leaders of groups need to be trained in identity reconstruction … [and] how to move from chit chat to challenge." Such a recommendation raises a number of issues. Firstly, the members' focus on shared experiential knowledge conveyed through personal narrative as their primary resource in the reframing of their identity does not sit easily with the idea of formal training. Secondly, the institutional basis of training leaders would carry with it implicit notions of ideal leadership, which could thus impede the process of negotiation of the group's structural form as an inherent part of its collective identity creation. And lastly, steering groups too hurriedly towards "challenge" risks undermining the communicative foundations that they are building through "chit chat." Indeed to refer to groups' communicative methods as "chit chat" simply because they are not framed as overt political challenge could itself be seen as devaluing their work and as a symptom of the academic bias in this field towards the "protest" rather than "enabling" end of the civic spectrum. This is not meant to suggest that training group leaders or other types of institutional support for self-help groups can never be helpful, but rather that it should be undertaken with caution and in light of the best possible theoretical understanding of self-help groups' goals and their means of attaining them.

9.2 Discussion: "Part of the continuum." Self-help groups at the interface of system and lifeworld

Introduction

The majority of the groups clearly saw themselves as "part of the continuum" of public health services, and yet at the same time strenuously defended their independent status as "separate" from them. They were very reliant on health practitioners as sources of information, were happy to receive benefits such as free rooms, felt they should be in receipt of referrals from health providers and yet would brook no "interfere[nce]" from them. This ambiguous position - simultaneously claiming to be within the private sphere and linked to but separate from the state – requires further examination and invites analysis from the perspective of the system / lifeworld boundary. Using this conceptual space as a tool with which to analyse the findings we can begin to account for why the groups perceived themselves in this seemingly equivocal manner and in doing so can throw further light on the ways in which they were sustaining communication in the public sphere.

As discussed at Chapter 2, Habermas conceptualises the system and lifeworld as two distinct spheres of social life. According to this model the system, encompassing the state and economy, is grounded in the technical knowledge of experts and specialists and defines and responds to social problems according to an administrative logic that prioritises efficiency and effectiveness over communicative, socially integrative ethical values. The lifeworld, on the other hand, elevates the normative, emotional and personal aspects of need, in the articulation of social goals, and expresses these through everyday language (1989). Through the system's greater power, which derives from its control over information and resources, there is a natural tendency for it to 'colonise' the lifeworld and subject it to system imperatives. Defending the lifeworld's autonomy is thus essential if citizens are to maintain an independent voice that is capable of developing genuine alternatives to the instrumental aims of the system.

It is now widely believed however that the most effective way of defending lifeworld autonomy is not to attempt to uphold total separation between the spheres but rather to ensure that they remain 'integrated' through mediation and open communicative channels that allow lifeworld values to permeate the system (Habermas 1996, Scambler 2001, Houston 2002). Part of the role of associations in civil society should thus entail the defence of the lifeworld against colonisation through the provision of a communicative interface at its boundary with the system. Indeed both Kelleher and White believe this provides the best account of the unique way that self-help groups / new social movements sustain the public sphere. The literature offers many further examples of the ways in which new social movements, service user and self-help groups are working in alliance with the system and how knowledge is freely shared across the boundary when this is perceived to benefit and empower members (Epstein 1995, Jones et al 2004, Madara 2008). Having said this, the emphasis in self-help literature has been on how lay organisations are able to convey lifeworld values to the system, as a means of humanising its impersonal administrative logic (Kelleher 2001). However there remains little analysis of the ways that self-help groups are using system knowledge and values as a means of enhancing rather than threatening social integration and public communication in the lifeworld. This is especially so amongst authors who treat these groups as a type of social movement. This may be because it sits less comfortably with their focus on radicalism, challenge and protest, against the biomedical establishment, rather than in the type of mutually beneficial partnership with it that the vast majority of groups in the current study were hoping to achieve. This is not to suggest that the threat of co-optation is unfounded. If groups' working too closely with the system results in the uncritical adoption of its frames of reference at the expense of their own, then the linguistic and conceptual heterogeneity of civil society may be undermined, diminishing its ability to act as a space in which alternative definitions of need can be formulated. Thus any group that operates at the interface of the system and lifeworld must maintain a balance between encouraging constructive communications whilst simultaneously fending off colonisation. However it may be that Habermas' system / lifeworld dichotomy was overly stark and paid too little attention to those situations in which

system and lifeworld operate symbiotically in ways that support and enable communicative action in the lifeworld.

In the remainder of this section I will discuss how self-help groups are using their position at the interface in ways that contribute to the public sphere by means of increasing the complexity of debate, reclaiming areas of knowledge from specialist monopolisation and thus promoting mutual understanding. Following Kelleher and White I acknowledge that this can be explained in terms of the groups' defence of lifeworld autonomy, achieved through ensuring that the system remains anchored in lifeworld values. However, the current data suggest that their model does not go far enough and leaves some of the groups' activities and effects on public discourse unaccounted for. Through their engagement in open communications at the interface I will therefore illustrate how the groups also made an impact by importing knowledge and values from the system, this knowledge itself being used as a means of entrenching lifeworld independence.

9.2.1 Enhancing discourse in the public sphere

Over recent decades a number of related trends have been observed, the effect of which is widely regarded to be a deterioration in the quality of communication in the public sphere (Habermas 1989, Alexander 2006). Such 'dumbing down' of civic discourse, if it has indeed occurred, may in part be caused by the increasing separation of knowledge into specialist, technical areas of expertise which results in the majority of the population being frozen out of debates and being denied the opportunity to speak about issues that affect them. Such exclusion from fields of expert knowledge is itself likely to perpetuate this process, in turn contributing towards individuals' narrow articulation of problems in wholly emotional terms, dissociated from their wider political or scientific context and hence open to charges of being that type of "post-emotionalism" (Borkman 1999 p58, Roger 2003) that is associated with "talk-show" culture (Jacobs & Goodman 1989, Borkman 1999 p 59) and in which informed rational debate amongst citizens is ultimately

replaced by the welfare claims of passive recipients. Similarly, such isolation of fields of knowledge will affect the system; technically complex matters becoming dissociated from their broader personal, emotional and ethical context resulting in their being reduced to simplistic, criteria such as effectiveness and efficiency (Kelleher 2001, Higgs & Jones 2001).

Clearly any activity that works against such separation of knowledge fields and serves to highlight their interrelatedness will thus be adding to the sophistication of discourse in both system and lifeworld. The question in the current study is therefore whether the groups were acting in ways that increased the breadth of knowledge in either, or ideally both, social spheres, and that made the reduction of members' problems to any one isolated epistemological framework less likely.

The evidence indicates that the groups were indeed contributing to the complexity of knowledge both through importing system knowledge into the group and exporting group values in return. None of the groups disbarred any particular form of knowledge and in general did not elevate the value of any above others, seeing each as valid according to its own parameters and depending on the particular use to which it was being put. For virtually all the groups, information from any source that furthered their goals, of enhancing the efficacy of lifeworld relationships and communications, would be welcomed as adding to the collective wisdom from which any member could draw according to their own perception of need. Information from policy makers, welfare providers, third sector agencies, research bodies, private companies and especially health professionals was amalgamated with that arising from members' experience to produce a resource that was of fundamental importance to the groups' primary aims; and the knowledge thus created was freely fed back into any organisation that could play a part in the promotion of those aims.

9.2.2 Communication channels between system and lifeworld

Long-term professional contacts

As discussed above, the regular members of the groups were conversing primarily in terms of personal narratives and experience and using these conversations as a means of developing social goals and values as well as personal opinions about services, treatments and policies. At the same time the groups provided opportunities to feed this collective wisdom into the system and thus inform the latter's conversations through a variety of means such as consultation and education activities. One of the most important doorways into the system was through the long-term links many of the groups had developed with health professionals. These practitioners were regular visitors to meetings and were thus a party not only to formal discussion about technical matters but also to the informal conversations through which the groups developed their collective identity and social goals. Importantly these conversations would usually involve whole groups rather than just the leadership and would thus be conducted in members' everyday language. As such these professionals would be well placed to properly understand the members' real concerns and priorities. In this way the groups provided a site of exposure for their values that would be unlikely to arise in more formal, institutional settings such as Patient & Public Involvement forums which are generally time limited and constrained by official agendas, etiquette and terminology. The group setting thus comprised a space in which communicative equality was far more likely to arise. The mere fact of the professional's being heavily outnumbered, coupled with members' familiarity with the venue, the participants and the procedures would be conducive to their speaking freely and on their own terms.

Leaders' role

As might be expected in light of their different priorities and roles within the groups, leaders added another dimension to the conveyance of lifeworld values to the system and hence to the complexity of knowledge within it. As discussed above, leaders' tendency to take the impetus in building outside links with professionals and to be the most enthusiastic participants in consultation activities meant that they occupied a place one step closer to the system than regular members. There were a number of ways in which such a role could add to both the collective goals of the group itself and to public discourse more

broadly. Firstly, leaders' input into the system through participation in consultations or research meant that their voice was more directly interfaced at the institutional level that of the members. Secondly the leaders of many groups either came from a health and social care background or had the levels of ability and motivation to undertake their own extensive research. This included gathering knowledge, not only about the clinical aspects of their condition and the technical elements of its treatments but also an in-depth understanding of national and local policies, practices and structures through which services were designed and implemented. Consequently they felt able to speak the language of the system without perceiving the kind of intimidation and subtle abuse of power that has been observed in some types of user forums (Hodge 2005, Garrett 2009). In speaking for groups in this way, leaders could thus be seen to be playing a crucial role in the public sphere in terms of equalising the "systemic constraints" (Habermas 1996 p325) that result inevitably in the unequal distribution of knowledge. These constraints, which might include anything from practical considerations, such as the availability of time, to intellectual capacity or educational opportunities, can result in the entrenchment of specialist knowledge, separated off from the reach of the wider society. In turn this allows for the "monopolisation" of political questions by specialists (Habermas 1996 p317) that, due to the scope of their implications, should be open to discussion by as broad a population as possible, but at the very least by those affected by them. The group leaders clearly saw themselves as ideally placed and equipped to breach these constraints and in doing so bridge the gap between lay and expert wisdom. They were speaking to the system in ways and with an authority that, to the majority of members, would not have been possible. Leaders' technical knowledge, that originated from the system, thus provided a channel through which to express group values and goals in a manner that seems more likely to find acceptance than doing so through the groups' everyday language and frameworks. Similarly their knowledge of policy agendas and processes allowed them to present these goals in ways that emphasised their compatibility with those of the system.

Leaders were thus breaking down barriers between different forms of knowledge. Their ability to understand and speak fluently in both the language of their members and that of the system enabled them to act as 'translators' - allowing the priorities of each sphere to be put into terms in which they made sense to the other.

The question arises though as to whether leaders' speaking in these terms amounted to their capitulation to the system. If this were so then clearly they would no longer occupy space at the interface from which to engage in communicatively rational dialogue with both sides but would subsume themselves under the system's strategic action. As such they could no longer claim to be acting either in defence of lifeworld autonomy or to augment the complexity of debate in civil society through sharing values and ideas across social spheres. However, the evidence strongly points to the fact that this had not happened. Firstly, the importance of conveying lifeworld values as well as technical data to the system was indicated by the large number of leaders that encouraged regular members, who by no means shared their levels of expertise or interest in specialist or political matters, to themselves participate in consultations and education activities, in some cases even attending in the leader's place. In addition, leaders often framed their technical knowledge in the wider needs of their members and frequently adopted issues in response to concerns and stories arising from members' personal experiences. Furthermore, as discussed above, the overriding purpose that members ascribed to the groups was their enhancement of lifeworld relationships, expressed through the group's mutual support role – thus if leaders had become disengaged from the lifeworld values and conceptual frameworks that sustained these relationships it seems unlikely that the vast majority of the groups would have maintained such high levels of member ownership and collective identity.

It appears as though both members and leaders were happy to talk in the language of the system and even to present themselves as "fit[ting] into" or "complementing" government agendas; however, filtering expert ideas through the groups' communicative processes meant that these ideas were reinterpreted in a way that gave them a subtly different meaning to

professional knowledge. This explains why the groups simply did not see the technical information that was shared amongst members as akin to that of experts within the system. Rather, in response to their collectively determined goals, it was interpreted as "tips and advice;" and instead of being perceived as part of a treatment model it was conceptualised as an intrinsic aspect of the group's support role. In effect any technical knowledge or mainstream concepts that came into the group - be they from leaders, professionals or members - were reframed in the context of the group's core aims and negotiated values. Thus mainstream labels might be willingly worn and diagnosis sought in a way that suggests a simplistic form of co-optation to the system's ends. However, whist such action did follow the individualist biomedical model of locating health and illness in the individual body rather than as a function of broader socio-economic factors, the respondents, unlike the mainstream establishment, crucially saw the individual body as gaining its meaning, identity and wellbeing primarily in the context of social relationships made possible and maintained through the collective enterprise of the group. Thus any treatment, technology or medical ideology had to be interpreted and applied in ways that fulfilled this end.

Using system knowledge to enhance lifeworld communication

There was no evidence to indicate that group members saw the system and lifeworld in the kind of stark dichotomous relationship suggested at times by Habermas. Any knowledge that was seen to contribute to the reformation of personal identity or the development of collective identity was welcomed and utilised without reservation or concern as to its source. Thus biomedical frameworks of disability and mental illness as well as the opportunity for diagnosis and the clinical labels that accompanied them were happily adopted whenever members saw these as contributing to a more recognisable view of themselves and thus to more authentic and communicatively rational private relationships.

Where the adoption of such medical definitions could be problematic in Habermasian terms is if they were to result in the type of passivity and claims-making that undermines communicative action by encouraging the

juridification of private life. In effect such a process amounts to addressing problems through the imposition of control rather than through the promotion of individual autonomy and efficacy – in turn thereby increasing the very passivity which allowed it to occur in the first place. Again though there was no intimation whatsoever that any group was, either intentionally or otherwise, acting in ways to encourage such a process. System knowledge, technologies and concepts were rather being used as enabling resources insofar as they supported or promoted the social goals, identities and values determined by the group. Indeed it could be argued that the expert sources of this knowledge were acting as one of the voices within the process of negotiation of these goals and so could themselves be seen as a constitutive part of the group's collective identity creation; and, as with the other voices that contributed to this, it would inevitably itself be changed by the process of negotiation. It may be therefore that well-functioning collective identity development is an important factor in encouraging integration between social spheres, but at the same time defending against the lifeworld's colonisation – the system's voice simply being treated as one amongst many in the hotchpot of group bargaining.

A fundamentally important part of the social goals of many of the groups was to promote self-efficacy, and one of the most important ways in which groups used medical knowledge in order to achieve this was as a means of enabling them to make autonomous choices. Zygmut Bauman regards this ability as fundamental to individual empowerment and self-determination in a modern society (Jones 2001) and as such it would be something which any civic theory must take into account; and the respondents appeared to share his view of its importance. Many members described the difficulties in understanding the options being presented by clinical experts, and clearly having to make such choices without thorough knowledge and understanding of the possibilities could lead to feelings of powerlessness and manipulation as a means of serving the system's instrumental aims. Consequently the discussion of drugs, operations and treatment pathways formed a "big part" and was an extremely valuable aspect of groups' conversations.

An important indication of the way the groups were working at the interface to encourage a symbiosis between system and lifeworld was that the personal

empowerment that relied on resources originating in both of these spheres was put into effect not only in terms of lifeworld relationships but also vis a vis the system itself. As such it provided another means by which lifeworld values were able to find a route back to the system. Members used their increased knowledge of both clinical matters and of the structural and political factors underlying them, for example the reasons why different clinicians followed different treatment pathways, in order to better "stand up to" professionals and have their voice heard in interactions with them. However this was not in a way that fundamentally challenged the ideology or frameworks of clinicians but rather promoted the incorporation of lifeworld perspectives into them. Thus when a respondent talked about using the group to become a "better" patient it may not, as had appeared at first sight, be indicative of the group's having been co-opted to fulfil the strategic aims of the system. Rather it is possible that through the groups acting as a space in which to reflect on and recast different forms of knowledge they were able to contribute to the reformulation of notions such as what constitutes a "better" patient. Their communicative links into both system and lifeworld thus provided a potential means through which to encourage both clinicians and group members to interpret the "better" patient in a more complex way. Patients' increased technical knowledge allowed them to be more demanding and assertive but within the context of mutual understanding and collaborative, complementary goals.

9.2.3 Informing public debate

At a slightly more abstract level, knowledge emanating from the groups' engagement at the interface with the system provided the means by which to enhance the quality of their political understanding and the complexity of their articulation of social need. Again this is an area that throws up doubts about the appropriateness of taking too negative a view of the system's role in public discourse and invites a more nuanced approach to the constructive interplay between the spheres. A number of groups, unsurprisingly in light of their focus on personal support, tended to concentrate on the individual issues of members

rather than wider political debates. The problem with this approach is that such a focus, whilst having the potential, as Habermas described, to "dramatize" (1996 p359) broader political questions, can also result in a narrow, inward looking concern that fails to acknowledge the types of universal moral question, engagement with which Habermas felt was an essential component of legitimate civic conversation. Similarly a view of one's own problems in isolation from their broader context could encourage the type of simplistic demands for welfare benefits that Habermas perceived as anathema to the public sphere. By engaging with the system however, through participation in consultation, research and bodies such as NICE, members' perception of their own condition and how it should be addressed by public services had the opportunity to become contextualised in wider system requirements, such as efficiency, and broader political and economic constraints. Admittedly, whilst in practice the system may be guided as much by political expediency, contextual factors such as efficiency are clearly valid considerations in many political decisions in modern welfare states, and can ultimately be conceptualised as resting on universal moral ideas such as justice and fairness. Associations working at the interface can thus play an important role in bringing the moral components of such ideas to the fore thereby broadening the scope of both system and lifeworld conversations. The fact that these considerations tend to reflect a liberal view of the public sphere (Benhabib 1992, Habermas 1996), and are not directly concerned with questions of power or social justice, should not cloud the fact that incorporation of ideas of procedural justice into concepts such as efficiency or resource allocation is still a valid means of extending and elaborating political debate. And in a number of groups, including those that had the closest links with the system, there was clearly an acknowledgement of needs beyond those of the membership and of the necessity for equitable, efficient distribution of resources as a means of addressing them. Respondents used ideas such as efficiency and fairness as a means of locating claims related to their condition within the overall scope of health and welfare services. By contextualising the lifeworld experiences of their members within system imperatives they can thus make their own arguments more amenable to consideration by the system. At the same time they can transpose concepts, such as efficiency, that appear dehumanised and

impersonal in the hands of the system, but which may nonetheless be important considerations in the development of policy, into language that can inform more complex debate in the lifeworld. In doing this they encourage a type of discourse whose focus takes account of needs beyond those of the participants.

9.2.4 Maintaining autonomy

Despite the extent to which they worked together, the groups were very keen to defend their independence and to stress that they were "separate" or fundamentally "different" from mainstream services. Similarly they resented interference in what they were doing, although very few in fact saw such threats to their autonomy as a significant risk. It may be though that their failure to give consideration to the possibility of co-optation increases its chance of occurring. For example those groups that wanted closer links to the system through the receipt of more patient referrals as well as those that were moving towards a more formal service provision type role had generally given little attention to whether this could constrain their freedom by increasing the levels of public accountability to which they may become subjected. And whilst there was no evidence of this having taken place as yet, previous research warns that voluntary associations' evolution towards service delivery can indeed have such consequences (McLean 1995, Burge 1999, Lewis 2005).

Similarly the groups did not, on the whole, fear that their attendance at consultations would affect the autonomy of their voice. Whilst stressing that they were essentially on the same side as mainstream services, they defended their right to ask the "difficult questions" and in a number of cases held onto the possibility of taking up a more oppositional type stance if the circumstances so demanded – clearly still seeing themselves therefore as located in a position extraneous to the system. Of course the evidence from the findings was limited to the respondents' own perceptions and it could be argued that in fact it indicated the existence of "concealed strategic action" through which the groups were being unknowingly manipulated through the

"unconscious deception" (Habermas 1996, Scambler & Britten 2001 p54) of the medical establishment's systemically distorted communications. However the notion of concealed strategic action needs to be treated with care as it can ultimately undermine Habermas' own concern to maintain the place of individual moral agency within discourse based theory – genuine, rationally attained consensus with the system being too easily dismissed as a form of false consciousness. Indeed it is notable that those groups with the greatest involvement in consultations tended to have leaders and key members with very high levels of awareness, not just about technical and clinical matters, but also about the political issues and power structures on which health and social care services rested, thus providing a bulwark against such inadvertent co-optation.

Multiple boundaries

The unique type of role that self-help groups may be able to play in promoting public discourse is perhaps better served by thinking in terms of boundaries rather than a boundary between system and lifeworld. As well as their communicative relationship with health services a number of groups were engaged in important conversations about broader issues such as ethnicity, religion and "political correctness" regarding which there was a belief that voices have been silenced by mainstream agencies. Members clearly saw meetings as a safe space in which to raise concerns about such sensitive matters; at the same time their links with the system, through which they had come to understand the importance of framing ideas in admissible language forms, may allow them to articulate grassroots concerns in ways that are acceptable to the establishment, thus brokering communication in highly polarised debates and increasing the likelihood of attaining consensus. The nature of the groups' communications, as largely free from institutional constraints, also served to highlight the problem in Habermasian theory's tendency to refer to "the system" or the process of "colonisation" in unitary terms. The respondents used meetings to discuss how agencies such as universities or even Self Help Nottingham, not traditionally associated with the risk of colonisation, could themselves take advantage of language distortions to serve strategic ends. Groups were thus happy to adopt concepts from one

dominant framework , for example the idea of the "patient" from biomedical discourse, as a way of challenging the perceived linguistic hegemony arising from another part of the system, thereby increasing the communicative exchange between different frameworks and adding to the complexity of understanding of social phenomena within both system and lifeworld.

Structure and funding

Borkman et al (2005-6) raise the possibility that state funding of self-help organisations runs the risk of undermining their unique ethos and ways of working and in this they reflect a view common in voluntary sector literature which sees many charities as having become part of a "shadow state" (Fyfe & Milligan 2003 p2070) through their receipt of public money. However, the associations to which these observations refer were all far larger and in much more formal relationships with the system than any of the groups in the current study. The groups here were generally in receipt of small sums to which very few subsequent conditions were attached. Indeed even those whose funding levels allowed them to obtain dedicated premises or consider paying staff reported that they were left alone and subjected to little or no interference. Having said this, prior to being granted the funding, the groups were generally required to adopt certain structural forms which, as organisational structure was an intrinsic part of the groups' collective identity creation, could be seen to have the potential to affect this process. It similarly appeared possible that requirements for written constitutions and statements of group values could interfere in the autonomous and organic development of cultural norms, the open negotiation of which is also at the heart of collective identity formation. This seemed particularly so as such documents were usually drafted with extensive assistance from outside agencies such as Self Help Nottingham. In practice however these risks did not appear to materialise. The groups, whilst adopting the nominal structures, policies and constitutions that were required, negotiated their actual roles and applied and developed rules in a far more flexible and interpretive fashion, through processes of open discussion and deliberation.

9.3 Conclusions

The findings support the view of self-help groups as not being overtly politicised or engaged in the types of direct political action that are typical of some new social movements or activist groups. However the value of using a Habermasian framework is that it provides the means to conceptualise indirectly political behaviour in terms of its democratising effects in the public sphere. Indeed a rarely discussed implication of his model, in its reliance on inclusive communicative action as well as its objection to claims-making, is that in certain ways it could be said to elevate the democratising effects of discourse oriented to the enabling end of the spectrum of civil society over that directed to the protest sector. And it was this end of the continuum at which self-help groups clearly wished to operate.

The groups were acting as sites of active citizenship in a number of different ways.

Perhaps the most important of these was their goal of reconstituting communicative processes and relationships in the lifeworld. Groups were being used as a means of reframing personal and collective identities. These reframed identities allowed members to renew their participation in the community through social activity, awareness events, public speaking and network formation. Such behaviour was clearly a means through which to foster individual autonomy in the lifeworld. It allowed members to develop a more confident voice through the knowledge they helped to create; when they spoke it was in a voice that they recognised as their own and one that their increased confidence meant that they could demand others recognised. This authentic, undistorted self and social recognition was clearly a prerequisite for consensus building in the lifeworld, as without it true mutual understanding would not be possible.

Habermas' concern that an ideal public sphere should act as a site in which previously excluded groups are brought into public debate was taking place within many of the groups. This is an area in which larger, more formally organised social movements such as many AIDS and anti-psychiatry

associations have sometimes been lacking. And it may be that the small size, low levels of funding and consequent flexible structural arrangements, the evolution of which itself constituted part of the groups' processes of collective identity creation, allowed all members to take a direct part in conversations. It was the existence of this type of communicative equality intrinsic to processes of identity negotiation that meant that groups with ostensibly dominant leaders were still perceived as acting democratically.

The groups afforded an opportunity for members' exposure to many sources of knowledge and topics of conversation with which they would otherwise not have been in contact. The input of health, welfare, academic and educational agencies meant that groups could go some way to breaking the monopoly of knowledge held by technical specialists; and as such they were providing another way in which excluded voices were being brought into public conversations. The input from this range of sources also enabled groups to borrow concepts from a number of frameworks and to reinterpret and rearrange this knowledge in ways that helped fulfil the social goals and lifeworld values negotiated in the group.

Again such communicative processes had the effect of increasing personal autonomy and efficacy which meant that members were able to use the knowledge created in the groups in their interactions with the system. To most respondents this resulted in more equal relationships with clinicians and the ability to make more informed choices about their own treatment and welfare. By supporting the communicative integration of system and lifeworld the groups were ensuring that both sides engaged with and better understood each other's epistemological perspective and how this could contribute to the pursuit of complimentary social goals. Again therefore we see the groups as promoters of mutual understanding and social consensus.

Closing reflections

On completing the thesis I became aware that it could be accused of presenting an idealised view of self-help groups. This is a claim that has also been

levelled against previous studies and that reflects the general methodological issue inherent in this field with respect to the difficulty in accessing people who choose not to attend or not to continue participating in these groups. Thus, I make no claim that self-help groups would be universally beneficial or that everybody would regard them as a desirable channel through which to get their voice heard, manage their health condition or bolster their self-confidence and personal identity.

In fact the positive picture of the groups that the thesis portrays only gradually emerged through the course of the study and in many ways took me by surprise as it did so. During the early stages of my work I had been somewhat cynical about the effects that I thought I would find; in response to certain aspects of the literature, especially those which linked self-help groups to 'victim' mentalities, 'talk-show' culture and medicalization I had expected to conclude that a significant proportion, perhaps even the majority, of these groups would be having deleterious effects on civic discourse. However over the duration of the fieldwork and even more so whilst writing up the findings I became firmly convinced that the opposite was the case.

The civic impact made by self-help groups may be small-scale; they neither talk loudly nor carry big sticks. But they do talk - and they talk in ways that, for those who subscribe to them, increase personal autonomy, enhance social relationships, foster social networks and increase knowledge and understanding - both of the self and the society in which the self must find meaning, survive and thrive.

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Appendices

Appendix 1: ethics approval correspondence

The University of Nottingham

Please quote ref no: **D/2/2008**

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Faculty of Medicine and Health Sciences

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Sarah Chaudhary
Room B49 (research Office)
School of Nursing-B Floor Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
NG7 2UH

25 February 2008

Dear Ms Chaudhary

Ethics Reference No: D/2/2008 - ***Please quote this number on all correspondence***
Study Title: Developing evidence based guidance to enable health professionals to support self help groups for people with long term conditions.
Lead Investigator: Professor Mark Avis, Head of School
Co Investigators: Sarah Chaudhary, Research Associate, School of Nursing, Dr Carol Munn-Giddings, Reader, Dept of Advanced practice, Anglia Ruskin University, Dr Stephen Meluish, Consultant Clinical Psychologist, Clinical Psychology, Nottingham PCT.

Thank you for submitting the above application which was considered at the Medical School Research Ethics Committee at its meeting on 21st February 2008. The following documents were reviewed:

- Application form dated 1/28/2008
- Project proposal dated 1/28/2008
- Information sheet v4 dated 30/1/08
- Consent form dated 30/01/08
- Interview topic guide dated 30/1/08

This study was approved subject to the following concerns:

1. The Committee would like more details about the contact to the self help groups. We would like to see a specimen introductory letter that the self help groups will send out.

2. The Committee was concerned about contacting participants directly particularly by telephone. We felt this was unduly coercive. We would approve the sending of a letter informing people of the nature of the study and including a reply slip for them to return to indicate that they would like to be contacted and participate. This is the usual approach to subjects that we use in such studies and we would be grateful if you would comply with this.

3. The Committee would like clarification about the chaperoning arrangement. We would draw your attention to the fact that this is to protect both interviewee and the researcher. Our recommendations would be that most of the interviews should take place on University premises in the presence of a third party either in the same room or close by. In the event of visiting the participant's home we would insist that the researcher be accompanied.

Please reply to the specific comments that we make listing our comments first and then give your response underlined, this will make it much easier for us to confirm that you have indeed done what was asked and will speed the processing of your revision. You should also highlight all the changes that have been made in any documents you resubmit.

On receipt of a sample letter and clarification of the above issues I am empowered to give Chair's approval.

Yours sincerely

Reply

Professor R C Spiller
Chairman, Nottingham University Medical School Ethics Committee

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14 August 2008

Sarah Chaudhary
Room B49 (research Office)
School of Nursing-B Floor Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
NG7 2UH

Dear Ms Chaudhary

Ethics Reference No: D/2/2008 - ***Please quote this number on all correspondence***
Study Title: Developing evidence based guidance to enable health professionals to support self help groups for people with long term conditions.
Lead Investigator: Professor Mark Avis, Head of School
Co Investigators: Sarah Chaudhary, Research Associate, School of Nursing, Dr Carol Munn-Giddings, Reader, Dept of Advanced practice, Anglia Ruskin University, Dr Stephen Meluish, Consultant Clinical Psychologist, Clinical Psychology, Nottingham PCT.

Thank you for your letter dated 11th August 2008 clarifying the issues raised by the Committee and enclosing:

- Sample letter to potential volunteers.
- Confirmation that initial contact with potential group members will be done through Caroline Bell at Self Help Nottingham which is an intermediary organisation that works with self help groups and is in regular contact by phone and letter.

These have been reviewed and are satisfactory and the study is approved.

These have been reviewed and are satisfactory and the study amendments are approved. The REC does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require ethical review by the Committee and may be implemented immediately, provided that it does not affect the management approval for the research given by the host organisation(s).

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Ethic's Committee of

(i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.

(iii) All adverse drug reactions that are both serious and unexpected.

(iv) New information that may affect adversely the safety of the subjects or the conduct of the study.

(v) The attached End of Project Progress Report is completed and returned when the study has finished.

Statement of Compliance (from May 2004 only)

The University of Nottingham Medical Research Ethics Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

Professor R C Spiller
Chairman, Nottingham University Medical School Research Ethics Committee

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The University of Nottingham
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11 February 2009

Sarah Chaudhary
Room B49 (research Office)
School of Nursing-B Floor Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
NG7 2UH

Dear Ms Chaudhary

Ethics Reference No: D/2/2008 - ***Please quote this number on all correspondence***
Study Title: Developing evidence based guidance to enable health professionals to support self help groups for people with long term conditions.
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Co Investigators: Sarah Chaudhary, Research Associate, School of Nursing, Dr Carol Munn-Giddings, Reader, Dept of Advanced practice, Anglia Ruskin University, Dr Stephen Meluish, Consultant Clinical Psychologist, Clinical Psychology, Nottingham PCT.

Thank you for your letter dated 20th January 2008 requesting an amendment to the above study as follows:

- At the suggestion by several study participants approval for investigator to conduct non participant observations of the self help group meeting subject to approval according to the procedures of the relevant self help group.

This has been reviewed and is satisfactory and the study amendment is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Ethic's Committee of

(i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.

(ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.

(iii) All adverse drug reactions that are both serious and unexpected.

(iv) New information that may affect adversely the safety of the subjects or the conduct of the study.

(v) The attached End of Project Progress Report is completed and returned when the study has finished.

Statement of Compliance (from May 2004 only)

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Yours sincerely

Professor R C Spiller
Chairman, Nottingham University Medical School Research Ethics Committee