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An investigation of the information culture of self-help groups.

by

Caroline A. Bradley B.A. (Hons)

A Master's Dissertation, submitted in partial fulfilment of the requirements for the award of the Master of Arts degree of the Loughborough University of Technology

September 1992

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Abstract

Self-help groups are prevalent in modern society. They are formed by people who share a common problem and join together to alleviate or solve this. They are effective in empowering people in a variety of ways. This study investigates the role of information in this process.

Both the history and current status of self-help are discussed. The research which forms the core of this study was carried out amongst groups in Nottingham. The Nottingham Self Help Team is a prominent self-help 'clearinghouse'. Its resources and initiatives have helped to create a healthy community of self-help groups in the locality.

The area under investigation was the information needs of groups, their methods of fulfilling them and the level of resultant success. The researcher visited several diverse groups. She gathered data by observation, interview and a questionnaire that was distributed to individual group members. The data is presented in the form of case studies.

A high degree of competence was displayed by the groups. There was general satisfaction with the quality of information collected, however the exploitation of information sources was largely unadventurous. National organisations played a positive role.
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APPENDICES
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The lack of an academic supervisor through the later stages of this project led to friends and family stepping into the breach. Sincere thanks go to: my housemates, my parents, Lil, Charlotte, Spencer, Janet and Martin.
Introduction

"You see, I have come to believe in self-help, individual initiative, the love of what you do, and the full development of all individuals. I am constantly disappointed by how little we expect of ourselves and of the world... We have to empower ourselves."

HANIF KURESHI
"The Buddha of Suburbia"

The character who states this is a sort of post-Thatcher hippy. She embraces Taoism and other ancient creeds whilst aggressively social climbing her way through London's media and artistic elite. The essence of her argument is that ultimate responsibility for an individual's emotional, intellectual and physical wellbeing lies within themselves.

The concept of mutual aid is not new. As Aristotle noted people are social animals who pool resources to overcome obstacles. Mutual aid or self-help (the more commonly used term) is intriguing as it is founded in concern for one's own condition, but has to encompass concern for others if an effective group is to be formed.

The city of Nottingham is home to numerous self-help groups. This study aims to investigate the role of information in the empowerment experienced by members of some of these groups. This will be done at a group level, addressing the individual members experience of, and attitude to, information in relation to the other activities of their group. Also under investigation will be where groups get their information from and how they organise it and expect it to be used. The extent to which professionals are relied upon for information will be
contrasted with the amount of autonomy displayed or thought necessary by the group.

It is acknowledged that, in terms of information, a group's strength lies in the bringing together of experiential knowledge. However to offer services and exist as a group they must require other, more conventionally accessible information. Investigation of group's needs, method and success at acquiring this kind of information will aid those who act as external support and facilitators to the groups.
CHAPTER ONE

Self Help in British Society

This is a consideration of some relatively recent manifestations of self-help in Britain. It is based upon a survey of relevant, published historical and sociological opinion. Its aim is to provide a chronological and societal context for the following study and discussions.

The concept of self-help and mutual aid recurs, as most good ideas do, throughout history. The medieval guilds and universities which proved to be enduring organisations were founded on a basis of mutual interest. They were formal and exclusive structures which reinforced social hierarchies. Pre-industrialist society also produced the communistic "Diggers". Their advent was at a time of social upheaval which is significant in the light of the following consideration of the origins of modern self-help.

A relevant starting point for a survey of the historical roots of modern self-help groups is the nineteenth century. From the late eighteenth to the mid nineteenth century Britain moved from being a predominantly agricultural society into becoming the first industrial nation. The process of change brought with it vast social upheaval. "The cruelties and social costs of the Industrial Revolution prompted writers and reformers like St. Simon, Fourier, Proudhon, Engels and Robert Owen to examine the conditions of European working class life. They differed greatly on leadership concepts and on the nature and the direction of required social reforms, but these writers had in common the assumption of cooperation among the disadvantaged as necessary to social progress." (1)

In the case of Robert Owen this conclusion was reached through observing the new socio-economic structure in the microcosm provided by the cotton mills of Manchester. He believed that a society reliant on
the profit motive was transmuting people into a new type of worker: dependent, unsettled and "infinitely more degraded and miserable". (2) Social relationships were disturbed and human misery was the consequence. Owens' initial reaction was to establish a model industrial community in Scotland, centred around a mill, with social and industrial welfare programs. He moved on from such practical action to become a prominent agitator for general factory reform. His experiences led to the formation of ideas, "that were to make him the forerunner of Socialism and the cooperative movement". (3) Owen recommended that government funded villages of 'unity and cooperation' be established for the unemployed. He foresaw that these would be mainly agricultural communities, possessing the most modern machinery. There would be an element of supervision, but all work including childcare would be shared out amongst the members of the community and all rewards from the work would be shared in common. The structure of communal living would thus enable the disadvantaged to improve their own position. This would have been the earliest example of government funded self-help.

After the failure of his model community in Indiana Owen returned to Britain where he became involved in the embryonic trades union movement. His efforts to this point earned him the accolade of being the first person to be called a Socialist in print. (4) He is labelled by historians (as he was by contemporaries such as Marx and Engels) as a 'Utopian Socialist'. This is a reasonable shorthand term, but should not leave the impression that his movement was a middle class industrialist's woolly optimism, imposed on unquestioning hordes. As E.P. Thompson states Owen had the support of:

"Artisans with their dreams of short-circuiting the market economy: the skilled workers with their thrust towards general unionism: the philanthropic gentry, with their desire for a rational planned society: the poor with their dream of land or of Zion: the weavers, with their hopes of self-employment: and all of these with their image of an equitable brotherly community, in which mutual aid would replace aggression and competition." (5)
Mutual aid is a term that was to reappear and be given great significance by Kropotkin at the turn of the century. The latter half of the nineteenth century was a period of consolidation for the new social order. It became unlikely that a scheme such as Owen's could ever be realistically contemplated:

"Before 1850 it was possible at least to visualise the Owenite alternative; after 1850 the vindication of Owenite questions and remedies could only be through their percolation into other minds and measures... After 1850 society came more predominantly under the influence and control of specialists and professionals. Social inquisitiveness remained, but it uncovered such extensive problems that no one could fully contemplate, let alone devise, such sweeping remedies as would be needed." (6)

This entrenchment meant the death of "communionism" as a popular, nationwide political movement. However it was not the end of it in practise. One of the unique institutions developed by common people in England to cope with the stresses of industrialism was the Friendly Society. The first friendly societies were an outgrowth of the guild system, but most lost the pretensions of these artisan bodies and were essentially an attempt by workers to meet their social and convivial needs, as well as to insure against the hazards of sickness and death. They were voluntary associations concerned with the promotion of thrift and self-help and are an example of mutual aid practised by a large promotion of the population. According to Gladstone:

"It is self-help that makes the man, and man-making is the aim which the Almighty has everywhere impressed upon creation. It is thrift by which self-help for the masses dependent upon labour is principally made effective." (7)

This quotation summarises and epitomises the reality of the new social order: it was up to the individual to improve his/her lot under the approving eye of a non-intervening government. Gladstone said those words in 1890, a time when many of his contemporaries were questioning the validity of this ideology. His words embody the values that were at their height in the 1850s and 1860s and that we think of today as
typically "Victorian". This belief system was highly pragmatic in origin and application. It was a direct response to the consequences of industrialisation:

"Victorians felt obliged to advocate certain values which offered solutions or escapes, strength where they saw weakness, virtue where they saw vice and progress where they saw despair. As a rule the values they promoted reflected not the world as they saw it, the harsh social reality around them, but the world as they would have liked it to be." (8)

The moral climate that resulted from the promotion of these values, seemed to explain Victorian economic and social success, it was thus assimilated and promulgated with fervour and assurance. The most famous self-improvement manual of this period was Samuel Smiles' *Self Help* published in 1859. Smiles was sympathetic to the collectivist and cooperative ideas, however "the doctrine of self-help underwent a transformation, and what had been originally a working class device to try to grasp some of those cultural and material benefits which were denied them in the new industrial society, became the middle class reply to workers demands for better social conditions." (9)

Through initiatives such as the Post Office Savings Bank, which Gladstone started in 1861, the late-Victorian working class were offered both the opportunity and facilities to become full members of capitalist society. Ventures of this kind were sincere, but as Fred Harrison notes they were the product of a complex psyche:

"In the culture of the deeply strange Victorians, the underclass had an important function. However successful and solidly respectable a middle class Victorian might be, there was always a sense of walking on thin ice - their journals are full of this sense of insecurity. If they tended to be driven over-achievers, part of that drive was provided by constant reminders out on the street of what lay in wait if one failed." (10)

Thus self-help was expediently incorporated into the accepted societal model and dominant *laissez-faire* ideology.
Kropotkin perceived self-help as a natural phenomenon and envisaged a political system in which it was fundamental. His libertarian theory of 'anarchic communism' regarded mutual aid as the catalyst for human survival and development. Kropotkin was an influential political activist and philosopher and his theories are often cited in academic considerations of self-help and provide an interesting contrast when juxtaposed with the philosophy of Samuel Smiles. The difference in the two men's philosophies is epitomised by the titles given to their works. Smiles published *Self Help* in 1859, Kropotkin's *Mutual Aid* appeared in 1902. It set forth a counterargument to that promoted by contemporary 'Social Darwinists' who maintained that society advanced because of the inevitable conflict that resulted from the overriding ethos of the 'survival of the fittest'. Kropotkin traced the evolution of spontaneous cooperation from the primitive tribe, peasant village and medieval commune to the variety of modern associations such as trades unions and the Red Cross that had continued to practice mutual support despite the rise of the coercive bureaucratic state. Ivan Illich echoes the thoughts of Kropotkin in his assertion that self-help groups, "are as old as man in one sense or a contemporary solution to complex problems in another." (11)

A common opinion is that modern self-help groups help to fill the space left by the demise of the extended family and mass church attendance; that they provide a sense of community which is lacking in modern society. In *A Guide for the Perplexed* (12) Schumacher opines that it is because Western civilisation has abandoned religion, and lost its accompanying teachings about self-knowledge, that our society has become incapable of dealing with the real problems of life at the human 'Level of Being'. Interestingly the label of 'secular religion' has often been applied to groups such as Alcoholics Anonymous which have deeply spiritual components within their meetings.

Echoes of this theory can be found in environmentalist philosophy such as that expounded by Tim O'Riordan (13) who places alienated societies at the heart of the capitalist mode. A more specific consideration of medicine in this context similarly claims that: "The authoritarian healing relationships endemic to the West are small-scale versions of the capitalist social relationships in general, in which
knowledge is the private property of the provider and gives her or him the power to dominate the less privileged, propertyless patient" (14)

The twentieth century has witnessed a boom in self-help groups, particularly since the war. Prior to this there had been organized societies for mainstream disabilities such as the deaf and blind, but in the post-war years parents of children with disabilities joined together to form supportive groups. Fundraising led to the development of complex organizations which in turn led to the establishment of national bodies such as MENCAP and the Spastics Society. The 1960s and 1970s witnessed a boom in groups set up by the individuals actually affected by conditions for collective support, Katz and Bender (15) link this burgeoning with the growth of individual oriented radicalism that occurred in this period and is typified by the civil rights, peace and women's movements.

This analysis follows Kropotkin's reasoning that mutual aid would arise and become widespread as an antidote to the rise of statutory beaurocracy. That manifest power would be challenged by individuals joining together upon realising a mutual coincidence of needs, wants and rights. A study into self-help published in 1983 expresses it thus: "People want to feel self reliant, able to stand on their own two feet and independent from what they often see as stigmatising help from the many arms of the welfare state." (16) Self-help is now an established component of modern life. It is a spontaneous social phenomenon that many people have tried to explain. The fact that the majority of modern self-help groups are related to health care or personal well-being is revealing. Within modern western society it does seem likely that "the growth of self-help groups is a response to the isolation, depersonalization and breakdown of human values in industrial societies in general, and in technological medicine in particular". (17)

Prior to the advances of the twentieth century a great deal of the actions of physician's were pointless. Their approach and remedies had little pathological impact, yet people recovered and medical practitioners remained in business. The question of whether the physicians behaviour or the interaction between patient and professional were inherently therapeutic therefore arises. According to Hippocrates, "the patient, though conscious that his condition is
perilous, may recover his health simply through his contentment with the goodness of the physician." (18) In this century the science of medicine and the art of its practice have diverged leaving the arena of patient care as a blurred middle ground. Relations between health care professionals and self-help groups are revealing about this, they have varied from close cooperation to outright antagonism. A recent review of professional interface with mutual-aid self-help groups (19) concluded that health professionals need to learn a partnership orientation to healthcare consumers which challenges the division between professionals and laity.

According to Ivan Illich, "The medical establishment has become a major threat to health." (20) This is an extreme view, but the existence of a welfare state does beg the question of who is responsible for the health of the individual citizen. Vincent and Webb state that, "The villains of the peace are bureaucracy, the professions and the replacement of radical fervour by individual apathy. All three amount to the same thing in their different ways a large, bureaucratic welfare state - staffed by self protective professionals - has not feather-bedded ordinary people so much as taken power away from them." (21) The welfare state tends to treat material and practical problems rather than to promote personal growth and a sense of personal worth. In the current political climate, dominated by the ethos of Major's Citizens' Charter, individual responsibility is positively encouraged and state services are being increasingly assessed according to the cost of the service delivered. Both of these criteria have implications for self-help groups.

The contemporary scene

Debates and studies about self-help abroad are obviously interesting and pertinent to anyone studying self-help in this country, however, direct contrasts are generally inconclusive due to unique factors such as the National Health Service (NHS). Prior to the foundation of the service many hospitals were voluntary organizations and a great deal of social work was done by volunteers. The dominant social ideology and policy of the 50s that underlay the creation of the NHS envisaged that the provision of a statutory service would reduce the role of volunteers in the health of the nation. According to Duncan, " a
corollary of this was that there would be a movement towards the complete professionalization of the service, and that the attitude could be summed up thus: "Now that we have a National Health Service we will be able progressively to dispense with our dependence on the voluntary sector as we build up a truly professional health service." (22) According to the literature, disillusionment with professional services because of perceived elitism and ineffectiveness, has been a major contribution to the development of self-help groups. Volunteers per se made a comeback throughout the 60s and 70s and were encouraged by contemporary governments and health service policymakers. The voluntary sector became accepted and established within the statutory service (23).

The 1978 Wolfenden Committee on the Future of Voluntary Organizations distinguished four sectors which provide health and social care in Britain. These are the statutory sector; the private sector; the informal sector (self-care and care from family, neighbours and friends); and the voluntary sector, "consisting of organized forms of caring that are neither statutory or commercial". (24) Self-help groups are a component of the latter sector. Due to problems of definition, and their often transitory and informal nature, it is only possible to estimate at the number of self-help groups currently operating in the country. Gann (25) extrapolates a figure of 50,000 groups, of differing types, from his knowledge of the Wessex region and the national scene.

Part of the impetus for recent government interest in self-help stems from alarm over rising costs in the statutory sector, particularly the NHS (26). This is combined with the concern that, "the negative side of professionalization is the situation where the patient passively receives from the omniscient professional, without any effort to enlist the active participation of the patient in caring for him/her/self or to mobilise the help of others in the community." (27) The keynote of John Major's political philosophy to date has been the transformation of the passive individual into the empowered citizen through devices such as the "Patients' Charter". Although the underlying reasons for this initiative are more cynical than its
altruistic hype would lead one to believe, self-help would appear to fit snugly into this scenario.

The political Right applauds self-help as an exhibition of personal initiative and the overcoming of problems and adversity by one's own efforts rather than by relying on the state (28). A now infamous quote by Margaret Thatcher illustrates the potential link between Conservative Party thinking and the encouragement of self-help: "there is no such thing as society, there are families and there are individuals". It seems fair to assume that the ideology that produced such a statement and is proud of its Victorian heritage would support the development of 'self-care' or 'self-help'. There have been a number of national initiatives to aid and support self-help in Britain:

"Two are independent of government: the National Self Help Support Centre (first funded 1985-86), financed modestly by private trusts to provide support, information and training at a national and local level; and the Self Help Workers' Support Network (1984) organized by locally employed development workers for the purposes of meeting and discussing on a regular basis." (29) There is also a programme funded by central government as part of the Helping the Community to Care initiative. The recent government white paper, "The Health of the Nation", anticipates that future healthcare will involve a high proportion of self-care, firstly because this has always been prevalent, but also because of raised consciousness about the role of the individual in the causation of prevalent diseases such as cancer and heart disease. Implicit within its recommendations is an increase in statutory support for self-help groups as it advises District Health Authorities to increase their work with local voluntary organizations. The effects of this policy remain to be seen, but there are areas for concern as it could result in the voluntarisation of services and the general abdication of societal duty by the state.
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CHAPTER TWO

SELF-HELP, EMPOWERMENT AND INFORMATION.

INTRODUCTION: As it is essential to define terms and map out territory, before becoming embroiled in analysis, this chapter will be a general exploration of this project's main themes and pertinent observations.

WHAT IS SELF-HELP?:
Upon perusing the literature about self-help it became clear that this simple question does not have a simple answer. The most extensive debate about the definition of, and terminology involved in, self-help has been held amongst American academics. Their interest grew as it became apparent that spontaneous help systems had inherent values and qualities, but also reflected professional developments. (1) A great deal of complex sociological debate ensued and attempts were made to establish definitive typologies. The following definition which was published by Katz and Bender in 1976, has become a common starting point for subsequent discussions:

"Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not, or cannot be met by or through existing social institutions. Self help groups emphasise face to face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently 'cause'-oriented, and promulgate an
ideology or values through which members may attain an enhanced sense of personal identity." (2)

This is a wide ranging definition, but it is also a definition with attitude. It states what the structure of a self-help group is and goes on to include motivational criteria, likely actions of a group and the possible end result of the coincidence of one or more of these factors. From my personal experience of a small number of groups I consider this definition to be useful, but it should not be regarded as definitive. For any definition to have wide currency it must be simple, such as "groups of people who feel they have a common problem meeting together to support and encourage each other". (3)

General, or all-encompassing, definitions are difficult to construct as the activities of groups are so varied. The Nottingham Self-Help Team are currently deciding upon a definition of a self-help group to be used in their work. The Team produces a 'starting off' pack which contains information and ideas for new self-help groups in Nottingham. This guide is written in a very open and non-specific idiom. There is no prescriptive definition or template of what a self-help group is, or should be. It is a practical document that embodies the open-minded ethos of the Team and the belief that self determination is a crucial characteristic for a successful and healthy group.

GROUP TYPLOGIES:
Numerous typologies of self-help groups have been created. The points made above, about the problems involved in establishing a rigid definition of self-help, also apply to these classification systems. Richardson and Goodman display a healthy disregard for these essentially academic tools:

"These typologies, while useful devices for highlighting some major sources of variation amongst self-help groups, are fundamentally misleading and must be viewed as inappropriate tools for analysis. If they solely served to focus attention on some of the different ways in which mutual aid organisations
help their members, they would perform a useful function. But to
the extent that they suggest that individual groups tend to
direct themselves to a single purpose only, or even primarily,
they obscure a proper understanding of the essential nature of
self-help groups as a whole. For one of the most significant
characteristics of these organisations is that they can perform
a number of functions at the same time." (4)

A typology of group origins:
The following broad assessment and overview of the varying
circumstances in which different group types develop and expand is
presented in the light of this qualification. It is taken from epilogue
to a special self-help edition of the Journal of Applied Behavioural
Science (5). This overview is based on groups in the U.S.A., but is
broad enough to be useful to this discussion, the following is a
summary:

1. General explanations of the advent of self-help rely on a
functionalist framework. Within this, new institutions are depicted
as arising in society when there are recognised needs not being met
by existing institutions. That is when an individuals' needs "fall
between the cracks" of the services on offer and inadequate
professional response is experienced.

2. Self help groups develop to provide alternative pathways to
services already acknowledged or in existence in established
institutions in society. Groups arise not because of an unmet need,
but because of an inadequately met need. This type of group may not
offer a unique service, the emphasis is on the structure of the
group, its autonomy and solidarity and who is in charge of what
rather than what they actually do.

3. Groups may occur as a result of individuals need for association
and community with others in similar conditions. The alienating
nature of modern society acts as a stimulant. Groups of this broad
type may provide a service, but the underlying reward for group
members is the affiliation and identity needs that are met.
4. Groups occur as a modern manifestation of an inherent and traditional social pattern. According to this explanation self-help groups should be contrasted with structures such as the family, tribe and village although the puzzle of why they are mainly centred around problems of health and personal welfare remains.

WHAT IS EMPOWERMENT?:

The dictionary definition of empower is:

"1. to invest legally or formally with power or authority; to authorize, license.
2. to impart or bestow power to an end or for a purpose, to enable, permit." (6)

Roget's Thesaurus places it with the verbs enable, endow and authorize. (7)

Thus it is something that requires the actions or involvement of an external influence; a second or third party. Whether it is viewed as a positive transition depends upon the nature of the power invested in the individual or group. The sociologist Anthony Giddens defines power as:

"The ability of individuals, or the members of a group, to achieve aims or further the interests they hold. Power is a pervasive aspect of all human relationships. Many conflicts in society are struggles over power, because how much power an individual or group is able to achieve governs how far they are able to put their wishes into practice at the expense of those of others" (8)
He stresses the role of ideas, often in the form of coherent ideologies, to justify the actions of the powerful.(9) This consideration of the nature of empowerment is being conducted in relation to self-help. According to the definitions above, if a self-help group experiences empowerment, then it will be given the permission or abilities and facilities to achieve its aims. Self-help groups are made up of people who are in a similar situation, and who come together to assist one another in pursuing shared interests or coping with common problems. As has been noted, the concepts of autonomy and ownership are considered vital to successful self-help. Taken in a literal sense "empowerment" is something achieved through the benevolence of an external protagonist. This is obviously unacceptable if the autonomy experienced by groups is to be genuine.

The concept of a hierarchy is inherent within Giddens' definition of power. The majority of self-help groups are concerned with issues of personal health, behaviour or trauma. Issues which directly affect individuals, their friends and families. In a free society it seems reasonable to presume that the resources required by individuals to deal with these situations should not be controlled or dispensed by any kind of hierarchically superior authority. The kind of empowerment required by members of self-help group's is power to increase self-awareness and self-knowledge. An apt term is thus self-empowerment. According to Hopson and Scally(10) there are five dimensions of self-empowerment:

• **Awareness:** without an awareness of ourselves and others we are subject to the slings and arrows of our upbringing, daily events, social changes and crises. Without awareness we can only react.

• **Goals:** given awareness we have the potential for taking charge of ourselves and our lives. We take charge by exploring our values, developing commitments, and by specifying goals with outcomes. We learn to live by the question: 'what do I want now?' We reflect and then act.

• **Values:** a value is a belief which has been chosen freely from
alternatives after weighing the consequences of each alternative; it is prized and cherished, shared publicly and acted upon repeatedly and consistently. The self-empowered person, by our definition, has values which include recognizing the worth of self and others, of being proactive, working for healthy systems, at home, in employment, in the community and at leisure; helping other people to become more self-empowered.

* **Life skills:** values are good as far as they go, but it is only by developing skills that we can translate them into action. We may believe that we are responsible for our own destiny, but we require the skills to achieve what we wish for ourselves. In a school setting, for example, we require the skills of goal setting and action-planning, time management, reading, writing and numeracy, study skills, problem-solving skills and team work skills.

* **Information:** information is the raw material for awareness of self and the surrounding world. It is the fuel for shaping our goals. Information equals power. Without it we are helpless, which is of course why so many people and systems attempt to keep information to themselves. We must realize that information is essential (a concept), that we need to know how to get appropriate information, and where from (a skill).

It is almost a truism to state that involvement by an individual in a self-help group leads to empowerment. The essential characteristics of a group lead the individual to experience self-empowerment. By contrasting the five dimensions expressed above with the activities of the majority of groups this will be seen to be true.

Firstly there is 'awareness'; a person must be aware of a condition or issue to join a group oriented around it. Secondly the setting and realisation of 'goals'; most groups have clearly expressed aims or goals, Killilea includes constructive action towards shared goals as a primary characteristic of self-help groups in her survey of
the literature(11). Membership of a group usually requires the adoption of these criteria and subsequent positive action towards achieving them. Thirdly the possession of 'values' that "include recognizing the worth of self and others ... helping other people to become more self-empowered."; most groups are of an egalitarian nature and place value on sharing, although it is feasible for self-help to be used in a selfish way. The "helper therapy principle", first enunciated by Frank Riessman in 1965(12), posits that the more group members help others, the more they are helped themselves. Penultimately, the acquisition of 'life skills' which occurs because of the practicalities involved in group work, both in participating in the groups activities and in organising the group itself. The structure of the group will determine the range of opportunities available for individual members to develop 'life skills'. For example members of groups organised by a specific individual or impenetrable committee would only be able to acquire and practise 'life skills' within the groups' meetings and activities. Finally there is 'information'. Many self-help groups have an important information role providing formal and informal information to members, potential members, professionals and the public at large. This study's primary concern is the role of the last of these characteristics.

Judy Wilson, who is the Team Leader of the Nottingham Self-Help Team and a respected authority on self-help states that her beliefs and values "include valuing the contribution of groups run by their members, believing there is a need to empower people who wish to run their own lives and that people who appear to be only recipients of help have potential to be givers of help as well."(13) There is an inextricable link between 'self-empowerment' and the empowerment of the individual within the health and social services system. The Welfare State is a collectivist structure whose effect and influence is highly pervasive throughout our society. An individual's needs are addressed by resources provided by the tax-paying public. Thus, in a theoretical sense, self-help groups actually circumvent the current system although, paradoxically, they are often perceived or intended to be complementary to the state's services. (14) Empowerment of the individual through the acquisition of life-skills and knowledge of
resources and opportunities, has been called the "essential political thrust of self-help". (15) There are inherent implications within this process for the nature of the client-professional relationship at all levels of interaction within the Welfare State:

"At root, self help challenges and considerably modifies the traditional professional role... by empowering the client (it) promises to redesign the professional role and move towards another rebalancing in our human service systems." (16)

This study is concerned with the role of information in the empowerment provided by self-help groups.

INFORMATION AND EMPOWERMENT

Self-help groups are a grassroots movement. They are organised by ordinary people for their own and other people's benefit. Information is an integral part of most self-help groups:

"Information, including both technical and anticipatory guidance expectable problems and phases and transitions, is an important element in almost all mutual help organizations. What constitutes "help" is often a new definition of the problem and specific information about practicalities learned through experience and shared with others because it "works"." (17)

Self-help groups have a rich information culture spanning experiential knowledge - which is not easily available from books, professionals, or formal caregiving institutions - as well as more formal and conventional information. The 'starting off' pack provided by the Nottingham Self Help Team includes the following advice:

"People are often desperate for information. Support meetings and informal conversation may give the chance to pass on information, but there are other ways too: Inviting speakers and showing videos. Buying books. Collecting articles and storing them... Keeping a scrapbook. Affiliating to a national organisation, thus getting their literature."
Access to, or the acquisition of, information may be difficult for groups that do not have a strongly established status. Many self-help groups are linked with national associations, but this does not prevent them from displaying autonomy. In a recent consideration of developments that could promote self-help groups for persons impacted by life-compromising conditions in the U.S.A. and the subsequent empowerment that the groups provide (18), the role of 'clearinghouses' such as the Self Help Team was stressed to be vital.

It has been said that we are living in the 'Information Age', and that the accompanying technology is, "a social phenomenon that shapes, and is shaped by its host society." (19) Information is a potent force; 1984 has come and gone and we know that George Orwell's fictional prediction was not accurately realised, but many people are concerned about the state's use and storage of personal information. If people are ignorant about, or adopt a "Luddite" attitude to, information technology their unease will remain. Wariness and fear will lead to helplessness.

Access to information is becoming easier in terms of purely technical capabilities. It has been argued "that the new information technologies distribute and disperse information capabilities, tending to decentralize control of information and its concomitant power" (20). Most small information centres, such as the library at the Nottingham Self-Help Team or the Victoria Health Centre, now either own, or have access to, tools such as databases. The possession and dissemination of a wide range of information by accessible, unthreatening outlets is thus becoming widespread. A recent evaluation of the Self-Help Team's Information Section established that 62% of requests received over a given period were made by members of the public. If this general trend continues within health information and elsewhere it would, in effect, be a reversal of the centralization of information within society that began during the Industrial Revolution.

In recent years, the public's demand for information about their health and the ways in which they can contribute towards it has risen enormously, "not least because of the indisputable links between the
causes of morbidity and people's life-styles." (21) The fact that many of these conditions are preventable has precipitated a development in the attitude of healthcare professionals who are now more inclined to encourage and help people to become more responsible for maintaining good health over a longer life-span.

Francis Bacon said that "knowledge is power", (22) this is the crux of any consideration of self-help groups' use of information. The consensus of academic and experiential opinion is that autonomy and self-determination are vital components of successful self-help. Empowerment is the result of successful self-help. Information equals power. The three elements: self-help, information and empowerment are thus linked; the first two being ingredients in the production of the third.
REFERENCES


9. Ibid., p. 52.


12. Ibid., p. 69.


16. Ibid.,


20. Ibid.,


CHAPTER THREE

Methodology

INTRODUCTION
The following is an account of the methodology of this study. It includes practical details, but also traces the notional development of the project.

A period of three weeks was spent informally observing and thus familiarising myself with the work of the Self Help Team. I attended an evening meeting for members of new groups, helped at a display of information about the team at the Queens Medical Centre and also at an "information market" for voluntary and community groups in the city. I attended the meetings of several self-help groups, namely Depressives Anonymous, the Macular Disease Society, Make Children Happy and the Alzheimers Disease Society. I met and interviewed personnel from the Nottingham Council for Voluntary Service and the Community Radio Team. I accompanied the Teams Groups Liason Officer to a presentation and discussion given to student doctors in which I participated. I also attended a one day conference on tranquiliser dependency in the local area which debated the role of self help groups and heard contributions from their members. During this period I also spent two days at a NHS resource centre and two days at the information office in the Victoria Health Centre.

These activities enabled me to acquire a contextual overview of the self-help community in Nottingham. When I had completed this period of familiarisation I began to plan the project in earnest. In discussions with the Information Officer at the Self-Help Team general questions
about the role of information in the operation of self-help groups were considered. It was decided that the main focus of the study should be an investigation of the role of information in empowerment.

It is generally agreed that an important element of self-help is that the individual is empowered, and that "independently operating groups emphasizing personal mutual aid and equality enhance the empowerment experienced by members." (1) Self-help involves both control and participation by individuals who are changed by their actions and attendance of the group. What is unclear is, what is the role of information in this process? If successful self-help relies upon group autonomy and interdependence then it would seem reasonable to assume that the successful group must perceive that it has a right to and is in control of any information that it uses or requires; that it can obtain information easily, in a suitable medium for its needs, accumulating the authority and confidence to disseminate information or share it within the group. So where do the groups get their information from? How do they organise/keep/disseminate it? Do they campaign or publicise preventative measures or is most of the flow of information directed within the group itself? Do groups want information about self-help itself as a concept/to know that they are part of a wider movement? What is communication and exchange of information like between self-help groups and the traditional health care sector? For example how often do groups have contact with professionals and how do they think they are perceived by professionals?

Specific investigation of all of these areas was impractical and so they were distilled and concentrated. There are over one hundred and fifty groups in the current Directory of self-help groups in Nottingham. It was decided that new groups (less than two years old) would be a valid and interesting sub-group to survey. It was hoped that their recent formation would mean that their demand for information would be high. It was also presumed that this demand would be quite far ranging in terms of types of information; it could include practical, medical or authoritative information about the condition as well as information related to setting up a self-help group. Self-help groups are self-
selecting organisations, if people do not feel their needs are being met or are not comfortable with the groups' method of doing things they will leave. Thus it was hoped that new groups would provide a relatively wide breadth of opinion, before homogenisation occurred over time.

The method decided upon was as follows: I would attend a meeting of each group chosen and be a participant observer, but also interview one or more of the key group members to ascertain fundamental information about how the group functions. There would be a voluntary questionnaire which it was hoped the majority of group members would complete.

Attention was given to the phrasing of categories used in the interview schedule and questionnaire. For example the term "self-help type books" was used instead of "lay-health information", as it was thought the latter phrase was an example of jargon and that the former would be more easily understood.

Respondents were asked to prioritise their top two motivational criteria. It was hoped that this request would make the respondents consider their answer more carefully than if they had been asked for an unprioritised indication of several criteria depicting their motivation. Five point semantic differentials were chosen to assess respondents evaluation of information from national organisations, the frequency of their use of their groups' library and their assessment of the size of their contribution to the group.

The aims of the questionnaire were broadly designated to be as follows:
1. To discover the opinion of group members on the role of information within a functioning group.
2. To gauge group members personal experience of information.
3. To assess the role of national organisations as sources of information for individuals and its affect on the dynamics of the group.
4. To discover what priority information is given by individual members relative to their other motivational criteria.
5. To investigate whether there is any relationship between the structure of a group and its use of information.
Effort was made to keep the questionnaire simple. See appendix A for a copy of the questionnaire.

LIMITATIONS OF THE QUESTIONNAIRE:
A: Fulfillment of the questionnaire was voluntary and their contents thus arbitrary.
B: Only present attitudes to present conditions could be assessed.
C: Unsupervised completion of the questionnaire meant that some respondents could misunderstand instructions and therefore misanswer questions.
D: Some groups did not actually hold meetings, fulfillment of the questionnaire was therefore not possible and the opinion of group organisers had to be relied upon.

The aims of the wider study were designated to be as follows:
1. To discover both the source and type of information self-help groups collect and share.
2. To discover how groups view and use leaflets and newsletters.
3. To find out groups' opinions on the quality of the information that they possess or have access to.
4. To establish whether the future plans of groups will require new information or knowledge of new information sources.
5. To assess the level of professional involvement in groups and whether this is a factor affecting their structure.
6. To establish fundamental information which questionnaire findings could be compared with.

See appendix B for a copy of the questions asked in interview.

LIMITATIONS OF INTERVIEW/OBSERVATION:
A: Many of the newer groups had relied heavily upon the Self Help Team and thus had not initiated thought or actions concerning information from other sources.
B: Only some people were happy to be taped in interview, thus additional but pertinent opinions could not be recorded for all groups.
The "General observations/report" section of the case studies is written from interview material and first-hand observation. The questionnaire and interview data is presented in specific sections.

CHOICE OF GROUPS:
Staff at the Self Help Team presented me with a list of approximately 20 new groups. My plan was to produce case studies of five of these groups contrasted with about three case studies of older groups. I hoped to be able to investigate and represent groups from across the self-help spectrum. Several groups that were approached were unwilling to cooperate. This was, of course, quite understandable but it meant that the range of choice was narrowed further. The final choice was as follows:

PUDDLE (Parents Under Daily Duress Living with Enuresis)
MUKTI (Support group for divorced Asian women)
TAMBA (Twins and Multiple Births Association Bereavement Support Group)
PEOPLE IN HARMONY (Anti-racism support group)
LYMPHOMA SUPPORT GROUP
HYSTERECTOMY SELF HELP
POSITIVE HEALTH GROUP (Exercise and relaxation oriented healthcare group)
M.E. SUPPORT GROUP

Only the latter two have been established for more than 2 years. I was unable to distribute questionnaires to three of the groups, but more detailed interviews were held in these instances.

The 'sample' offers a broad range of groups. There are three that are 'disease specific' and two that are non-medical (three if TAMBA is included). PUDDLE is specifically for carers, but the M.E. and Lymphoma groups also include carers. There is a broad range of group structures represented. It would, of course, be foolish to suggest that concrete conclusions could be drawn from investigation of this subgroup. The
groups were chosen in a fairly haphazard fashion and should only be
viewed as representative of self-help in Nottingham in the sense that
they offer a range of illustrative characteristics which are held by
other groups in the city. The conclusions of this study will therefore be
an assessment of broad issues, tendencies and examples of attitudes
elicited and observed via the method described above.
REFERENCES

CHAPTER 4

Self Help in Nottingham

INTRODUCTION:
The data of this study will be presented in this chapter in the form of case studies. The first part of the chapter will provide an overview of the environment in which the groups exist and operate.

PART I:
The Nottingham Self-Help Team is part of the Nottingham Council for Voluntary Service, it has strong links with the Nottingham Health Authority, but is independent of public authorities. The team is made up of paid and volunteer staff, many of whom are members of self-help groups. There are two distinct elements to the Team's work:

1. Supporting people setting up new groups, providing resources and support for existing groups, liaising between and contributing to the relationship between groups and professionals.

2. Providing an information service about local self-help groups and national self-help organisations. There is a full time, professional Information Officer whose duties include the maintenance of a library containing a comprehensive and possibly unrivalled range of lay health-care information.

The Team publishes an annual "Directory of Self-help Groups in Nottingham and District", which is distributed to every doctors' surgery and health centre in the locality. Information about the Team
and a diary of group's meetings are published every week in the Nottingham Evening Post. The Team publishes a number of other booklets and guides including "Starting Off: information and ideas for new self-help groups in Nottingham" and "Promoting Partnership: guidelines for self-help groups and health professionals on how they might work and grow together."

The Team began in 1982 as a result of innovative participant-action research (1), it was a pioneering project and has achieved wide renown.

This project has been undertaken under the auspices of the Self-Help Team, particularly the Information Officer who has given guidance and advice throughout its duration. I interviewed the team's Information Officer (IO) and Groups Liaison Officer (GLO), separately and informally, about their work and their role in the information culture of groups. Their answers and opinions can be summarised as follows:

Information Officer:
Provides a scanning service, whereby relevant articles from journals subscribed to by the Team, are sent to groups. Typically these will be lay-health-care information or its equivalent.

There are established lines of communication between the IO and groups. The fundamental one being the inclusion of groups in the Directory, information about their entry is checked every year. Sometimes this is the only contact between group and the IO. The other lines of communication identified as being within the IO's domain (apart from direct enquiries/meetings) are 'mail outs' which are regular postal bulletins which can contain information on conferences, potential funding, fundraising initiatives etc.

New groups are "supported" through their initial stages by volunteers from the Team. These Supporters are aware of both the information needs of groups and the Team's information resources. Advice and aid given to Supporters by the IO is an indirect line of communication with groups. The information needs of new groups were identified as being "lay-health information nearly 100% of the time. At the regularly held "New Groups Evening" group members are invited to browse through the Team's information collection. In general the collection does not contain
anything over three years old. The IO revealed that received requests for information are becoming increasingly specific or concerned with rare or complex health problems. This trend reflects what has occurred in the U.S.A. As people become more aware of their needs for information their demands increase, and as these are met, their requests for lay-health information become increasingly sophisticated. The IO was confident that the Team would be the first point of reference for most groups requiring information. She thought it likely that national organisations would also be given precedence as a source of information. Groups are not given a formal statement of the IO's services.

Groups Liaison Officer:
Helps groups to focus their ideas when they want to produce posters and leaflets. Gives advice and information when groups make applications for funding. This often necessitates the writing of a constitution about which the GLO can also provide information and advice. The GLO finds that she tends to remain in contact with the individual or group of people who originally contact the Team about starting a group. The majority of her work with groups is with new groups. Groups tend to "report back" when they have achieved or done things on their own, such as attract sponsorship. The GLO organises a regular seminar given to student G.P.'s about self-help. Representative's from groups attend and share their experiences with the students. The GLO feels that this is a positive exercise for the groups, they can feel that they are being given an influential platform and are a successful example of self-help.

The Victoria Health Centre[VHC] was opened in April 1987. It is a city centre health centre which places great emphasis on health promotion and health information. Both these services are freely available to the public on a 'drop-in' basis. The region's new telephone health information service is based at the VHC. The centre is therefore a valuable and accessible information resource to the public and professionals in Nottingham and its surrounding area.
There is a healthy and well established working relationship between the Self Help Team and the VHC staff. Resources are shared and the organizations respective information officers often liaise.

Memorial House houses the Nottingham Health Promotion Resources Centre. This is a large library of materials for anyone interested in health promotion. It contains books, videos, teaching packs, models, journals, leaflets and posters and computer software. It is staffed by friendly people some of whom also work at the VHC, there is good knowledge about other local health information resources. The librarian is in regular contact with the information officers mentioned above.

Nottingham Community Radio Team (CRT) is part of the Nottingham Council for Voluntary Service. It produces and presents social action broadcasts on the local commercial and BBC radio stations. Self help groups are often approached to participate in broadcasts and can use the team for publicity. The CRT provides a telephone helpline (much in demand after broadcasts) which aims to put callers in touch with the services they need. This role of the CRT requires what was described to me as an "information mapping" system. The CRT is wary of building up its own information resource and, instead, works closely with social services and agencies such as the Self Help Team. As part of the media the CRT has a high profile.

The two main hospitals in Nottingham are the City Hospital and the Queen's Medical Centre.
Case study 1: Hysterectomy Self Help Group

INTRODUCTORY FACTS:
The group has been meeting for over a year, it is not associated with a national organization. Its entry in the Directory is as follows:

- The group aims to provide self help support to those about to undergo, or those who have had an hysterectomy operation to resume a full life as soon as possible. We share feelings and experiences and provide information. Our meetings are friendly and informal.

GENERAL OBSERVATIONS/REPORT:
The groups' monthly meeting is held in the Victoria Health Centre. It is organised by two women, the founder member (T.) and a woman who joined the group in its infancy. The group's membership is volatile and the turnout at meetings is unpredictable. The meeting that I attended was held on the 2nd of July 1992, and the two organizers were the only members present. This was assumed to be because of the good weather and the likelihood that people would be on holidays. Consequently I was unable to survey any ordinary members. Instead, I informally interviewed the two organizers.

T. had just been counselling a woman on her home telephone. The conversation had lasted for nearly an hour and she expressed exasperation at the demand that there was for this kind of help. She wants to help, but finds it straining in terms of time, 'phone bills and personal resilience. She and her fellow organizer are hoping to set up a 'phone line in a local school that is closing down and being offered to the community as a resource. The staffing of this line seemed likely to be problematic due to the characteristics of the group's membership. It was explained that generally women came to meetings for a few months and then ceased attendance. This pattern is understandable given the nature of hysterectomies. It is a trauma, but
it is one that people recover from and then continue with their lives. The group is basically concerned with providing a supportive sorority to allow individuals to experience an informed recuperation. The group has received excellent support from healthcare professionals, a doctor had recently referred a patient to the group saying that he "totally believed in it". The group's leaflets are distributed at hospitals and the organizers plan to produce a Help Pack for women to receive whilst in hospital. It was envisaged that this would be achieved with the help of the health authority/hospitals. The founder member of the group is a nurse and is confident in her professional knowledge in the subject combined with the resource of experiential information gleaned from the group. There is no formal central resource of information. The Self Help Team were praised for their help. It was stressed that the group hoped to become more structured, or as it was put "more controllable". The two organizers were full of ideas and plans to establish a known and respected advice and support group for the Nottingham area. Their aims were being frustrated by the lack of people willing to help. They know that the demand is there, but cannot currently provide the service they would like to from a purely voluntary basis. Publicity leaflets are produced in English and three Asian languages. T. is herself of Asian origin and is keen to extend membership of the group to this section of the community. After she appeared on the local radio (courtesy of the Community Radio Team) the group received several telephone enquiries from Asian men, but so far no Asian women have attended any meetings.

DATA FROM INTERVIEW:
The group meets monthly, it is not associated with a national organization. It does not have regular contact with professionals, although the group founder is a nurse. The group does not produce a newsletter at the moment. The group produces publicity leaflets and hopes to produce an information pack in the future. The group has used the Self Help Team, the Community Radio Team and Trent Health Line for information, it does not have a formal library although literature containing advice and information is made available at meetings. The
group has plans for major future developments and would consult the Self Help Team for advice and information.

CONCLUSIONS:
The opinion of individual members was not assessed. The group is successful at providing support, its organisers feel that they are reaching women who need the services that the group provides and are keen to do more. However, they expressed concern that the group was being treated as a service rather than a group to which people belonged. Their plans to establish a permanent base for their activities might help to inject some of the group ethos that was being mourned.
Case study 2: Lymphoma Support Group

INTRODUCTORY FACTS:
The Lymphoma Support Group has been meeting regularly since January. Its formation was initiated by a Ward Sister at the Queens Medical Centre (Q.M.C.) who contacted the Hodgkins Disease Association for advice. The group is now loosely associated with that organization. It meets monthly at a room in the Q.M.C.

GENERAL REPORT/OBSERVATIONS:
The meeting that I attended on July 1st. was a 'social' evening, which meant a very relaxed welcoming period in which people mingled and chatted followed by a general knowledge quiz and raffle. Announcements about group activities were made towards the end of the meeting. Attendance was lower than usual at 10 people, and this was attributed to the good weather and people being on holidays. The group's regular meetings normally feature a presentation or speaker. There is also an informal network in operation: "If people aren't feeling well enough to come along to meetings they do have telephone numbers to contact the members on the steering committee and then if there is a problem we can help them and identify it and give them support throughout." As the group is still new, the person I spoke to, who was on the steering committee, was taking a proactive role to establish this practice: "Since we've been going it's a steady stream of regulars, if you like, so what I tend to do is if they don't attend the meetings I try and give them a 'phone-call to try and give them contact and say 'sorry we missed you at the meeting,' nothing threatening, but just general are they O.K. and how are things?..."

The group's close relationship with the hospital seems to have affected the level and kind of "support" that it judges it should provide. The following comments were made in response to a question about how much contact with professionals the group has: "with Lymphoma there are that many strains and different types that perhaps not one person will be receiving the same treatment, it's not like you all have chemotherapy, there are various combinations of
treatment so one of the things that we try to discourage is people—when they actually come to the group—not to dwell on the fact of their illness or what they are going through... if they do have any problems they're encouraged to go back to D.[the Sister on the unit] or the consultant that they are actually dealing with because hopefully it just won't be people from the Q.M.C. that actually receive the support, but on a wider scale in the Nottinghamshire area. So obviously we don't want to step on anyone's toes, so we try to discourage anyone from talking about it, from being too specific...and to go back and see their consultant."

The "support" that the group provides occurs through a sense of camaraderie. There is a positive and cheerful atmosphere, but people's personal space is respected. There is not the sharing fervour that I observed in other self-help groups such as Depressives Anonymous or the group for carers of Alzheimer and dementia sufferers, which at first seems anomalous for a disease specific group. It is a similar ethos to the Positive Health Group in that the focus of support is not on the individual but at a removed, group level. This structure allows a great deal of positivity to be expressed by people in dire circumstances. I am tempted to say that this attitude has an element of the British 'stiff upper lip' in it combined with a little of 'don't let the bastards grind you down'.

The group has received guidance from the Self Help Team, "they've been very good, given us a lot of support and direction: what we should be doing and how we should be progressing. Really helping us to identify if we were doing anything wrong". The group has a steering committee which is trying to discover which direction the members of the group wish the group to go in now that the group is established. A 'one-off' newsletter has been produced and received a positive reception. It is recognised to be an important method of communication for the housebound or reticent, "so that they don't feel isolated and that they've still got that point of contact", and a bi-monthly edition is planned. Introductory leaflets to the group and the disease are in production. They will include contact numbers and it is anticipated that these will be given to people, upon diagnosis, by the ward Sister.
A group library is being assembled:

"We are getting information together and we do have booklets ...there is back-up that you can get for additional information, but we haven't really got that under control yet. That was one of the other points that was raised at one of the meetings, to actually see what peoples' expectations were, you know because obviously when you are first diagnosed you're shellshocked. You don't really know what you are going to actually need, you perhaps come away, you don't like to ring the hospital back to say "hey!". Some people don't back track it and say I can go to X, Y and Z to find that information out. So we did say that we really did ought to get sort of a nucleus of relevant information. Guided again by what Dr. T. (the consultant) would feel happy with the patients having available, because we are very fortunate in that when you are diagnosed you are given a booklet produced by the Q.M.C. and that gives you an outline." The group had sought information from public libraries and social services and had recently found out about the Trent Health Line. When asked where they would first go for information they cited the Self Help Team, unless the information was medical in which case they would expect the ward Sister to know the right contact.

The meeting ended with me being asked questions about other groups and their meetings. This spontaneous interrogation was conducted out of genuine interest and curiosity. They were particularly interested to hear about the Positive Health Groups reflexology lecture and complementary therapies were discussed earnestly. It was hoped that aromatherapy would soon be available at the hospital.

QUESTIONNAIRE FINDINGS:

All 8 people attending the meeting completed questionnaires.
The group is loosely connected with a national organization, has produced one newsletter and is building a central collection of information.
One respondent is a member of the national group and they do not receive any information from it. The newsletter had been produced by a lone member of the group, it had been produced as bulletin on the
groups foundation. Only one respondent knew about the central collection of information, they indicated that they had used it more in the past.

The respondents indicated that their motivation was as follows:

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<tr>
<th>OPTION</th>
<th>1ST</th>
<th>2ND</th>
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<tbody>
<tr>
<td>Frustration with other services</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>To feel more positive</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Find out more about condition</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Get out of house</td>
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<tr>
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<td>5</td>
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<tr>
<td>Support</td>
<td>5</td>
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<tr>
<td>To try and change things</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
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Two respondents added further options, but did not prioritise them. These were as follows:

To show appreciation of the care received
To help others worse off

The criteria for describing the groups structure were ticked as indicated:

Flexible 5                                      Relaxed 7
Dominated by one or more individuals 0         Committee led 2
Democratic 3                                   Rigid 0
Too relaxed 0                                 Chaotic 0
Organised/led by specific people 2
DATA FROM INTERVIEW:
The group meets monthly.
It has regular contact with professionals due to its close association with the hospital.
The library/central information store contains the following:

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<thead>
<tr>
<th>ITEM</th>
<th>YES</th>
<th>NOT SURE</th>
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<tbody>
<tr>
<td>Self-help type books</td>
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<tr>
<td>Leaflets</td>
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<tr>
<td>Literature from nat. org</td>
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The group has used the following for information:

<table>
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<th>SOURCE</th>
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<tr>
<td>Social services</td>
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<tr>
<td>Self help team</td>
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The group feels that its information is up to date and sufficient for the group's current needs, but it is anticipated that these will soon change and new information and sources will be sought. The Self Help Team would be the first agency consulted.

CONCLUSIONS:
The personal experience of information indicated by the respondents in the questionnaire is not great. However, the interview with the member of the steering committee indicated that the group's organisers are concerned to provide information. The questionnaire only addresses existing behaviour and practice and thus does not reveal what the group members feel about the proposed changes.

Friendship and support are the main motivational criteria for belonging to the group. Support was given the greatest emphasis by the respondents. It seems reasonable to assume that the group's close involvement with the hospital has influenced its identity and feeling of community. Most members are seen by the same medical staff and can compare and contrast experiences. I believe that the feeling of support
derived by members from the group in its current form has its foundation in this shared situation. People are encouraged not to dwell on their illness and so the support must come from the group's activities. The majority of the group's meetings so far have been presentations or question and answer sessions. These have been both specifically about Lymphoma and to do with subjects such as hobbies and leisure time activities.

A newsletter and library are being organised and it is anticipated that they will be welcomed and fit in with the groups burgeoning ethos. It is reasonable to conclude that support is derived from the group's social element, but also from the information that people acquire and have access to through attendance. Through the steering committee's consultations it is the group itself that decides how it should develop. Which after the strong initial input from the Ward Sister indicates a healthy level of autonomy which seems to be respected and desired by both sets of protagonists.
Case study 3: M.E. Support Group

INTRODUCTORY FACTS:
The Nottingham and South Notts. M.E. Support Group has been meeting for about 4 years. The monthly meetings are held in the meeting room at the Self Help Team, but the high attendance means that alternative premises will soon have to be sought. The group is for both sufferers and carers.
The groups entry in the Directory is as follows:

"A self help group which enables M.E. sufferers and their carers to meet and help each other cope with this illness. The group is in contact with the National M.E. Association, an organisation which distributes information about the illness and funds research. Meetings are held approximately every four weeks."

The group is also associated with the M.E Action Campaign.

GENERAL OBSERVATIONS/REPORT:
I attended a meeting of the above M.E. support group on June 25th, 1992. There were 15 people attending: 9 women and 5 men, all of whom were white. This was a lower than normal turnout, the group is in a very healthy state at the moment, after apparently nearly disbanding about 12 months ago. The meeting was started with the reading of general announcements such as the availability of a new British Rail leaflet containing information on travel for people with disabilities, and also announcements from the National M.E. Association newsletter. People were cordially reminded to pay an attendance fee of fifty pence and raffle prizes were advertised. The evening's speaker, from the Department of Social Security Information Service was then introduced. She gave a very detailed and structured presentation on what pertinent benefits are available, the circumstances these benefits are aimed at, how benefits are assessed,
what information claimants should provide and what is the best procedure to adopt when dealing with various statutory departments.

There was a break for refreshments, individual members' announcements and the raffle. The presentation then continued for a second hour. The entire meeting was very businesslike, but relaxed. The group offers support but is also concerned with raising funds and increasing understanding and the profile of M.E.

The group has recently been featured in an article that appeared in the Nottingham Evening Post and is busy organising a huge fundraising concert to be held in November. Mention of contact with healthcare professionals brought a wry smile to the face of the chairperson. This is an obvious area of contention for the group as most M.E. sufferers have had bad experiences when interacting with healthcare professionals because of the conditions relatively recent discovery and recognition. Because of this negative climate there is a tremendous thirst for information felt by the group's members. There is a prominent library containing literature and videos and the national organisations are relied upon heavily.

The chairperson expressed a belief that after a period of recent growth the group now needed a period of consolidation after which the aims and direction of the group would be assessed, discussed and fixed upon.

A 'Listening Ear' service is offered via telephone numbers that are circulated in group literature.

QUESTIONNAIRE FINDINGS:

Of the 15 people attending 9 completed questionnaires. The group is associated with two national organisations. 6 of the respondents are members of one or both of these organisations. All of these 6 indicated that they received information which was evaluated as essential by 2 respondents, very important by another 2 and valuable by the remaining 2. This information would be immediately shared with the group by 5 of the 6 relevant respondents and mentioned if the topic came up by the other individual.

5 respondents had contributed to the group's newsletter, only one indicated that they thought they had needed special information; this
was cited as having come from "various members". All 9 respondents knew about the library and 8 were accurate/knowledgable about its contents.

3 respondents used it occasionally, 2 sometimes, 2 regularly, 1 very often and 1 had yet to use it due to being a new member.

The respondents indicated their motivation as follows:

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<th>OPTION</th>
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<tr>
<td>Frustration with other services</td>
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<td>2</td>
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<tr>
<td>To feel more positive</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Find out more about condition</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Get out of house</td>
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<tr>
<td>Friendship</td>
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<td>1</td>
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<tr>
<td>Support</td>
<td>4</td>
<td>2</td>
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<tr>
<td>To try and change things</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
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</table>

The criteria for describing the group structure were ticked as follows:

Flexible 2
Dominated by one or more individuals 1
Committee led 2
Too relaxed 0
Organised/led by specific people 5

Relaxed 4
Democratic 0
Rigid 0
Chaotic 0

DATA FROM INTERVIEW:
The group meets monthly. It does not have regular contact with traditional healthcare professionals, but does with alternative therapists and people such as the DSS Information Service.

The library contains the following:

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<tr>
<th>ITEM</th>
<th>YES</th>
<th>NOT SURE</th>
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</thead>
<tbody>
<tr>
<td>Self-help type books</td>
<td>*</td>
<td></td>
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<tr>
<td>Leaflets</td>
<td></td>
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<tr>
<td>Literature from nat org</td>
<td>*</td>
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<tr>
<td>Videos</td>
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</tbody>
</table>
Information on relevant services are published in the newsletter. The Self Help Team was the main source of information used. The group feels confident about the quality of its information about M.E. as it comes from the national organizations which are at the forefront of research into this disease. The future of the group is anticipated to be a continuation of the current format with the addition of greater fundraising activities.

CONCLUSIONS:
The personal experience of information indicated by the respondents to the questionnaire is varied and substantial. Those respondents who are members of national organizations tend to value the information they receive and most would immediately contribute this information to the group. The option to "find out more about the condition", came second only to "support" as a motivational criteria. The library is well used. Taking all of this into account it can be said that there is a strong information culture within the group. An important factor in this is the generally poor treatment that M.E. has received from the media and the medical profession in the past. There is almost a siege mentality prevalent in the group, or at least an element of 'I told you so', which is the result of frustration with the lack of recognition that this condition has received until recently. The group is proud of its self sufficiency and achievements. The group members trust and depend on its information and are eager to add to it.

The newsletter provides an outlet for this. It contains 'newsy' items about the group's activities, information from the national organizations and health information, but also a personal account of coping with the condition. This exchange of experiential information is obviously valued.

The level of professional involvement in the group is high on a superficial level as they have a great number of visiting speakers and experts, but none are involved in the group's organization apart from the Self Help Team, whose advise is clearly valued. The group's
future plan to increase their fundraising activities is likely to increase their links with the national organization, on whom they appear to rely for direction. In comparison with other groups, the national organization is expected and trusted to provide comprehensive information. This appears to be due to the campaigning nature of both the national and local group. The national organization is referred to as 'Head Office', and there is a definite sense of communal purpose.
Case study 4: Mukti

INTRODUCTORY FACTS:
Mukti was started 2 years ago, its entry in the Directory is as follows:
To provide support for divorced Asian women.
We visit them at home or any other places they require.

GENERAL OBSERVATIONS/REPORT:
In the Spring 1990 edition of the Self Help Teams newsletter Mukti was described by its founder (S.) as a listening group. It does not meet because of the stigma attached to divorce within the Asian community, "we did meet once or twice, but nobody turned up...the main problem is that if somebody sees them it would be 'oh god what's she doing in a group like that?'...so we go to the houses, we interview them and see what she wants. I do individual counselling, my friend does financial help."
Because of this I was unable to survey any of the group members, but conducted an extensive interview with the group's founder. Mukti is very much the founder's baby, she works in close conjunction with a friend and cannot foresee the group existing without her. This, however, has a logical basis when cultural factors are taken into consideration. For example S. would like the group to have a permanent base with a phoneline or drop-in centre and is lobbying the council to try and achieve this. The council has responded positively, but wish to use their own paid workers. S. is concerned about loss of the groups' security in terms of its information and operation, "it's not my group it's my ladies' group and if I can do it and they trust me...they come to me when they're desperate...if I go that way they won't come to me". When I interviewed S. I was impressed by her drive and deep commitment. She repeatedly referred to her own experience of divorce within the Asian community:"two years before I wanted to start a group, when I was first divorced...I needed someone to talk to, that's all I wanted, somebody to talk to and somebody to tell me that -because I'm
an Asian woman— I haven't done nothing wrong and it's not my fault. When anything goes wrong it's the woman's fault... I went to all the Indian centres, all the community centres: not one of them would help me, someone sent me down here to see Judy and I haven't looked back since then."

I asked S. if she had a self-help group in mind at this time she responded: "No I just wanted someone to talk to. I went to the English groups (single parent) and they were really nice to me, but what I needed wasn't there. I needed someone to tell me as an Asian woman that there's nothing wrong in what I've done, because I lost all of my Asian friends and everybody cut me straight dead...to be an Asian divorced woman in the Asian community is like committing suicide".

Empowerment is at the very crux of Mukti's purpose. Information is personified by S. and her friend who works in an advice centre. They do not have a formal central information resource, but have built up an informal network of contacts in places such as the D.S.S. I think it is fair to say that S. is aware of her role as an empowering facilitator:

"That's the reason I started the group. Maybe I'm good, I know the laws, I've been in this country over 35 years; I know where to go, I know which department to go for anything I want, but what about the ladies who come here who can't speak English? Where are they going to go? Where are they going to get help from? Alright we got this Indian Welfare Officer and this and that, how do I know they're treating them right?". 'Mukti' means 'leave it'. S. takes her role very seriously and very personally she revels in the trust that exists between herself and her "ladies", proudly informing me that there are no named files in existence, everything is coded. The impression one is left with is that of a successful guerilla campaigner. S. is keen to see similar groups set up in other areas of the country and has attended social work conferences to promote her achievements in Nottingham.
DATA FROM INTERVIEW:

The group does not meet, it is a supportive counselling service that responds to individual requests. The counsellors have regular contact with a number of professionals with whom they have built up good, informal relationships. The group has used public libraries, social services and the Self Help Team for information. It is felt that the information held by the group is sufficient for its needs. A great deal of the groups activity is to advise and provide information on practical matters.

CONCLUSIONS:

It was impossible to gauge individual members experience of information as there are no 'members' of Mukti as such. Leaflets are used as a publicity tool. The future plans of the group (to establish a permanent base and 'phoneline) is likely to require the formalisation of information in some way. S. is unhappy to do this if it means the advent of outsiders into the essential core of the group. The same attitude is extended to sources of information. S. is convinced that she has contacts in all the places that she needs and that this informal network is the best way for the group to operate. Without observing the group in operation it is unfair to make any judgements.
Case study 5: People in Harmony

INTRODUCTORY FACTS:
People in Harmony as a national organisation started about 20 years ago. It is an anti-racism organisation that campaigns for a peaceful multi-cultural society. The group meets at a suburban Afro-Carribean community centre. A creche is provided.

GENERAL OBSERVATIONS/REPORT:
I attended a meeting of People in Harmony on June 14th. 1992. It was attended by 10 people, 7 white females, 1 white male and two black females. The person from the group with whom I had made initial contact was very keen to ensure that I recognised that People in Harmony was not a problem oriented group and thus not what they perceived as a "typical" self-help group. The group that is now Nottingham People in Harmony was originally started as a support group for white mothers with interracial children. However the emphasis of the group has changed so that it is now more of a social, consciousness raising discussion group. They do not wish to be perceived as problem oriented as the problem that they face is racism and that is a problem for society to address. I think that it is fair to describe the group as self-help as it is a forum for people with shared circumstances joining together to share experiences, ideas and attempting to ease their own circumstances:

The meeting that I attended started off in a relaxed and informal manner with an open discussion about events the group is involved in, such as local summer fairs, and whether or not the next months meeting should be replaced by a picnic. During this discussion deeper issues did arise such as whether the group could provide positively led activities for the older children. The issue that concerns the group's members with reference to their children is the provision of culturally apposite, positive role models.

The group is very relaxed. Most of the organisation seems to have been taken on by one individual who has been involved in a similar group in the past and started this one. She, however is obviously keen
that the group be democratic and egalitarian and constantly leaves space and opportunity for people to suggest or volunteer or lead the group. On the whole people were slow or reluctant to do this. I surmised that peoples' unwillingness to do so was either due to them being happy for someone else to do the work or because they didn't actually have that clear an idea on what they should be doing as a group. I think the latter explanation is more likely and not a criticism of the group, just a reflection on its broad remit and I am sure that peoples confidence will increase with time. The group has recently increased its emphasis on outreach work and feel that this has reduced some of the cliqueyness that it feels it initially experienced. The leading individual is well informed about local community groups, resources and activities. Suggestions of "events to share" were made by her and similar suggestions were encouraged from the other group members.

Exchange of information was informal between group members and was based on practical considerations such as the care of afro hair or how to deal with difficult questions from a child. Refreshments were available and this added to the relaxed atmosphere. The latter half of the meeting was taken up by a discussion about adoption. The head of Nottingham's Black and Asian adoption unit gave a riveting talk on her team's work and their philosophy. The discussion that followed started off as hypothetical, but personal opinions, experiences or situations were introduced. This was a potentially confrontational situation as the team's policy (and accepted good practice amongst adoption agencies) is that ideally an interacial child should be placed with an interacial family, but if this is not possible then it should be placed in a black family. The reasoning behind this is that society will treat the child as black and so it is crucial that the child should have positive black role models and a strong tie to the black community. The majority of the women at the group were single white women with interacial children who felt that the perpetuation of this philosophy reflected badly on their own situations. They were made to feel inadequate, guilty or just plain wrong by this judgement. The social worker stuck to her position and repeated the arguments behind it. The atmosphere remained friendly,
but a lot of worries had been unearthed. I think this is an inevitable consequence of the way the group operates and that greater group focus could be achieved if occasionally time was set aside for the discussion of problems.

QUESTIONNAIRE FINDINGS:
Of the 10 people attending, 5 completed questionnaires. The group does not publish a newsletter or have a library. The group is associated with a national group and 3 of the 5 were individual members of this. They all described the information they received from this organisation as valuable. Two respondents stated that they would mention this information with the group if the topic came up. The other respondents split their answer between immediately sharing the information and mentioning it if it was topical.
The respondents indicated that their motivation was as following:

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<td>Frustration with other services</td>
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<tr>
<td>To feel more positive</td>
<td></td>
<td></td>
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<tr>
<td>Find out more about condition</td>
<td></td>
<td>1</td>
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<tr>
<td>Get out of house</td>
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<tr>
<td>Friendship</td>
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<tr>
<td>Support</td>
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<td>To try and change things</td>
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<tr>
<td>Other</td>
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The 'other' option was: "To learn more/discuss how to give positive images to my mixed race child."

The group was described by the respondents as primarily relaxed (5) and flexible (3) with the descriptors, "democratic", "chaotic" and led by "specific people" receiving a single tick each.

DATA FROM INTERVIEW:

The group meets monthly. It does not have regular contact with professionals. The group possesses a few books and leaflets, but these are not considered to be a central store of information. The leaflets are from the national organization. The public library, particularly the Education Worker, was cited as an information source as was the Self Help Team, local community groups and social services.
CONCLUSIONS:

Defined or specific information is not a priority for this group. There is no newsletter or library and outside information would only be introduced if it was thought to be topical.

The respondents indicated overwhelmingly that their main reason for belonging to the group was to find support. It must therefore be concluded that information is not perceived as an important element in this sought support at the moment. However attendance by people at a meeting featuring a speaker on a topic of interest, rather than direct relevance, to the groups' focus is indicative of openness and a certain thirst for information.

The group is independent and autonomous. It is democratic, but the main organiser is a very competent individual with previous experience of a successful People in Harmony group and knowledge of local resources. She is an empowered individual and her attitude and expectations pervade the group in a positive manner. The group's future plans includes a lot of "project work". the information and motivation for this naturally arises from the group's membership.
Case study 6: The Positive Health Group

INTRODUCTORY FACTS:
The Positive Health Group has been going for 10 years. Its entry in the Directory of self-help groups in Nottingham is as follows:

to promote positive health through exercise, education and relaxation in a caring social environment. Open to both sexes of any age. New members welcome at any time.

GENERAL REPORT/OBSERVATIONS:
I attended a meeting of the Positive Health Group on the 17th of June. Nineteen people attended, they were all female, white and mainly elderly. The 3 hour meeting was structured into three segments: an hour of aerobic exercise followed by half an hour of group relaxation/self-hypnotherapy, there was then a social break with refreshments followed by a presentation from a guest speaker who was a Reflexologist.

Although most members of the group experience serious health problems the ethos of the meetings is to concentrate on the positive actions an individual can take for her own health and mental wellbeing. The atmosphere was cheerful, confident, brusque and affirmative. A local consultant who came as a speaker on arthritis waived his fee because he was so impressed by the group's positive response. The supportive action of the group is on a higher level than simple problem sharing. The support was achieved through indulging in group activity removed from the members own problems. This ethos appeared to be understood by all members who were almost gung-ho about their open-mindedness and enthusiasm.

This homogeneity can probably be attributed to the group's library which contained various lay texts on health and wellbeing. It was felt that everyone had read the contents of the library and so they were being sold off to group members. When asked what they would replace these books with the group's organisers were not sure if they just needed more up to date information or something different. They were
aware that the group was not purely health based and that a strong social element existed, thus events such as quizzes were regularly held in the speaker's slot. The group does not do any promotion, apart from their entry in the Self-help Directory, new members are gained by word of mouth and are generally friends or acquaintances of existing members. The groups uniformity must be reinforced by this. When a few members were asked whether any men or members of the ethnic communities had ever attended their meetings the answers were enlightening:

"Well a few men came, but I think they were embarrassed or a bit overwhelmed"

"Yes we did have some coloured ladies come, but they didn't attend regularly, and were always late", (this seemed to be taken as a snub or was felt to reflect a lack of commitment)

"One time she [the Afro-carribean woman] came into the middle of the A.G.K., bang-crash! it was amazing."

This white, elderly, middle class English woman obviously was truly amazed at this breach of protocol. The group has a definite ethos and culture and despite its own sincere belief that it is open to everybody, it is quite a closed community. They are happy with their current formula, their plans for the future are to, "carry on as we are" and they do not anticipate a need to discover new information sources feeling that they are, "self-sufficient within the group". An initial consideration of the empowerment that is resultant of the group is epitomised by the following quote:

"I'm so pleased my dear, I have a problem with incontinence and I'm solving it myself! I'm leaking like a tap!"

QUESTIONNAIRE FINDINGS:

Of the 23 people attending the meeting 12 completed questionnaires. The group does not feel that a newsletter is necessary due to its regular (weekly) meetings. It is not associated with a national group. It does have a library, but this is being run down. Eight of the respondents knew about the library and were accurate in describing its contents. Three respondents described their use of the library as
occasional, two as sometimes and two as regular. Four respondents used the library more in the past, two stated that they did not.

The respondents indicated that their motivation was as following:

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<th>OPTION</th>
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<tbody>
<tr>
<td>Frustration with other services</td>
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</tr>
<tr>
<td>To feel more positive</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Find out more about condition</td>
<td></td>
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<tr>
<td>Get out of house</td>
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<td>Other</td>
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one respondent indicated that the "get out of the house" option was of third priority to her.

The group structure categories were ticked as follows:

Flexible 5                        Relaxed 9
Dominated by one or more individuals 0  Committee led 2
Democratic 7                         Rigid 0
Too relaxed 0                        Chaotic 0
Organised/led by specific people 1

DATA FROM INTERVIEW:
The group meets weekly. It has regular speakers, but that is its main contact with professionals. The group's library contains the following:

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<th>ITEM</th>
<th>YES</th>
<th>NOT SURE</th>
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<tbody>
<tr>
<td>Self-help type books</td>
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<td></td>
</tr>
<tr>
<td>Leaflets</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Information on services</td>
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</table>

The group has used the following for information:

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<tr>
<th>SOURCE</th>
<th>YES</th>
<th>NOT SURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public library</td>
<td>*</td>
<td></td>
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<tr>
<td>Self Help Team</td>
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</table>
The group feels that its library's contents have been read by the majority of members and they are thus being sold off. It is unsure what to replace these with.

CONCLUSIONS:
The group is settled and comfortable in its membership and structure and also in its approach to information. A successful formula has been found and maintained. The selling off of the library is interesting. The group has, in effect, conducted an information audit: assessing demand against the available supply of information and acting accordingly. There are no immediate plans to restock the library, but the group is very relaxed and democratic and will respond to any requests for information from group members.

None of the respondents indicated that information seeking was part of their motivation for belonging to the group. "Friendship" and "support" were the main categories of motivation indicated along with particularly apt "to feel more positive" option. In casual conversation most group members praised the speakers and group discussions very highly, they are on varied and wide ranging topics, although an effort is made to ensure a theme of self-healthcare exists. Information is
INTRODUCTORY FACTS:
The group entitled Parents Under Daily Duress Living with Eneuresis is being organised by a single individual who is convinced, due to her own experiences, that there is the need for a support group for families living with this condition. The group was launched in July 1992.

GENERAL OBSERVATIONS/REPORT:
I met and interviewed the founder of PUDDLE (D.) on the 2nd of July 1992. The group was due to be launched the following week. Leaflets and posters had been printed and distributed, she was in touch with the community radio team and expected to be involved in a broadcast in the near future.

I was interested to find out what D.'s motivation and expectations were. She is the mother of a child who is incontinent and thus a "bed-wetter". She appears to have struggled to get consistent medical attention and treatment for her son and is angry that the enduring resultant advice from medical consultation is, "learn to live with it".

In practical terms this means up to five changes of bedclothes per night, constant worry about odour and cleanliness plus the trauma to the child.

D. has not found the national eneuresis organization particularly helpful in her attempt to set up a local group, she is a member and on their mailing list, but her request for information suitable for the group was met with subscription and recruitment advice. She saw a feature about the Self Help Team in the Nottingham Evening Post -their tenth anniversary- and got in touch. D. said that she read the 'starter pack' three times from cover to cover as she was determined to,"do this properly". Her main ambition for the group is, "to get people talking, to let them admit that they have a problem, that this is serious... I want to change peoples attitudes to this and make them see that you can do something". D. stated that she wanted to change
doctors opinions, that she wanted the group to campaign in one way, but to be there as support when people needed it. She expected that her ideas would be clarified when people attended the first meeting and shared their ideas with her. She definitely foresaw that she would be the leader of the group, although she would readily welcome assistance. I asked where she had got the information that she would expect the group to need from, "experience mainly, I think I've gone through every twist and turn with this, oh and magazines and for the group then definitely the Self Help Team,". D.'s experiential knowledge certainly appeared to be comprehensive. She was informed about benefits, holiday grants from trusts, the fact that you could get nappies and plastic sheets from the Health Authority, what prescription drugs were available and what they did. This knowledge had been built up by D. as an individual, but she is an individual who is prepared to challenge authority. She has also established good relations with a number of professionals such as a health visitor who is the regional continence advisor, the practice manager at the Victoria Health Centre (where the group is to meet) and via this relationship the information office at the centre (which houses the new regional health line). D. is a motivated individual anxious to help others in similar situations, but also to find reassurance and make progress as a result of finding these people.

DATA FROM INTERVIEW:
The group will meet monthly.
It has regular contact with the professionals at the Victoria Health Centre who offer practical support and advice and a platform within the health service.
There is no current plan to collect a central store of information.
The groups founder has used the following for information:
   Self Help Team
   Local advice centre
   Trent health line
   Social services
   Doctors' surgery
The group founder is not yet fully aware of the group's information requirements, but anticipates that she will be able to meet them without difficulty.

CONCLUSIONS:
This case study is not really able to address the objectives of the project. It does however provide insight into the considerations that are experienced by those launching a group. The foundation of PUDDLE appears to be exemplary. The founder is a capable and motivated person who is definitely seeking empowerment from the nascent group. Her personal experience of information is that acquisition of it has not really changed her situation in practical terms. She is counting on the foundation of the group to provide support for herself and its members, but also to give her opinions and needs weight. The founder has, on the whole had an unsatisfactory relationship with healthcare professionals.
Case study 8: TANBA

INTRODUCTORY FACTS:
The group has been meeting for 18 months, it is associated with the national Twins & Multiple Births Association, Bereavement Support Group and has access to their resources including a network of specialised groups. The group describes itself as a small local group that meets in each others homes for friendship and support. In their leaflet that is distributed to all the city's libraries, a large proportion of health centres and the Family Care Sister at the City Hospital, assurance is given that confidences will be respected. The leaflet states that, "we are always happy to visit, talk on the telephone or write to parents who have suffered bereavement recently or sometime in the past."

GENERAL OBSERVATIONS/REPORT:
I attended a meeting of Tamba Bereavement Support on the June 15th 1992. The meeting was held in a group members house. Three people attended, all women. They all knew each other and the atmosphere was very informal and friendly. The initial impression given was that the three women were friends anyway and the group was an incidental extra. This impression faded after the social pleasantries were discussed and the meeting began. The friendships were genuine, but had obviously been formed as a consequence of the emotive nature of the group. Intimate sharing, empathy and sympathy formed the basis of the groups activities, plus practical considerations about the health and running of the group. Information was sought by individuals from other group members on an informal basis and was shared within the group. The flow of information was anecdotal, members of the group seemed to have thought, "I must tell so and so that at the meeting", and were reminded or stimulated to do so when the conversation was relevant. The members have had similar experiences, but they know what happened, there is no need for information in a pure sense: "we're not really supplying information, it's not like a disease". The empowerment of the
individual comes from being reassured and healed through supportive sharing and discussion.

One member of the group was very up, open and motivated. She acted as a gatekeeper between the group and the national organisation. When she heard of a local family who had lost a twin due to a cot death she wrote to them expressing sympathy and support. This member had been the driving force behind the foundation of the group, which had been set up with guidance from the Self Help Team and a lot of support from the Family Care Sister at the hospital. At one time, permanent attendance of the group by the Sister was discussed. The group members said that they thought long and hard about this and decided against it as it would take away the groups foundation on, and essence of, mutual experience. They foresaw benefits in keeping distance between the group and professionals stating that:"she's someone we could go and see if we wanted to at the hospital...we can invite her to particular meetings and it's nice to know that she is there."

When discussing professional involvement in the group one member recounted the following experience. After giving birth to twins she, "had one baby die, the other was O.K. and we were discharged, I was given no counselling, nothing. The doctor offered me sleeping pills and that was it. My Health Visitor came round, but that was out of friendship, I relied on friends and family really until I saw the leaflet and rang D....[the group founder]"

When asked about the group's information needs the members indicated that they were happy with their current situation, stating that if people who came to the group requested information they would direct them to the national organisation. They stated that at one point they had considered trying to find out the statistical likelihood of a twin dying but, "that was more out of curiosity than anything else"

Plans for the future of the group were as follows: "I can't see it getting to the stage where we have to hire a room...we've got together and we all get on so well, it's not like a group." "We know there are people out there who want to talk, you know we've just got to be here, do our best".
QUESTIONNAIRE FINDINGS:
All three attending members of Tamba completed questionnaires. The
group does not have a newsletter, but does have a central collection of
information. All three respondents are members of the national
organisation with which the group is associated. They all receive
information from this body and all consider this to be valuable. Two
respondents indicated that they would immediately share this
information with the group, the third respondent would mention the
information if the topic arose.
All three respondents knew about the central collection of information
and were accurate about its contents. Its use was described as
occasional by two people and as sometimes by the third. Two respondents
considered that their use of this information had been greater in the
past, the third did not.

The respondents indicated that their motivation was as follows

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<tr>
<th>OPTION</th>
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<th>2ND</th>
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<tr>
<td>Frustration with other services</td>
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<tr>
<td>To feel more positive</td>
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<td>To find out more about the condition</td>
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<td>To get out of the house</td>
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<td>Friendship</td>
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<td>Support</td>
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<tr>
<td>To try and change things</td>
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<tr>
<td>Other</td>
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The ratings given above reflects a unanimous answer pattern.

The group structure was uniformly described by all respondents as being
flexible and relaxed. All three respondents assessed their contribution
to the group as average.
INTERVIEW DATA:
The group meets monthly. It has an established and informal contact with a single professional who publicises the group and acts as an adviser when requested to.
The central store of information is made up of information from the national organisation such as a contact list and accounts of similar experiences.
The group has used the Self Help Team for information and would turn to them for any further advice or information regarding the group.

CONCLUSIONS:
TAMBA Bereavement Support is an intimate group. In terms of information the national organisation plays an important role providing a list of contacts and personal accounts of bereavement. This information is valued and shared by the group members, although it is not a primary concern of the group. The group seems to have a dual focus: inward and intersupportive, but also outward in wanting to contact or at least know about people who have had similar experiences.
A quote from the national newsletter illustrates this point:
"The experience was too much of a nightmare to really ever come to terms with. But I have shared here what I can with you and would do my utmost to help anyone who might feel the need to write or talk to anyone further".
Leaflets are used to publicise the group. The group does not appear likely to greatly change its information needs in the future. The group's information needs are fulfilled by their national organisation, their good relationship with the Family Care Sister and the Self Help Team.
REFERENCES:

CHAPTER FIVE

Conclusions

A concluding overview will be achieved by assessing the conclusions from the case studies, according to the aims of the study expressed in the methodology chapter.

Role of the national organisation:
Four of the five groups whose members completed questionnaires are associated with national organisations. Within three of these groups the majority of respondents are individual members of the organisations. They gave positive value to the information received from the organisation. They consistently indicated that their subsequent use of the information would be to share it with the group, either immediately or when the topic arose. Both of these options were towards the positive end of the differentiated five point scale presented to the respondents. Thus it is reasonable to state that national organisations are a valued source of information for members of self-help groups associated with them. The group members do not perceive there to be any territorial or political barriers to the introduction of this information to the group.

Reasons for belonging to the group:
More than half of the respondents from the M.E. Support Group included to "find out more about your condition" amongst their motivational criteria. This was the only group in which such a positive response was given for this category. No significant indication was given by the other four groups that the need for information was considered to be an important motivational criteria. "Friendship" and "support" were
consistently cited as key factors amongst group members' reasons for belonging to their group. "Support" was always given greater emphasis than "friendship". Interestingly there was no comparative reference to "friendship" by respondents from the M.E. Support Group although the trend to cite "support" as the most important motivational criteria was maintained.

Respondents were asked to limit their indication of motivational criteria to two choices. It appears to be likely that information was given precedence by members of the M.E. group because lack of information - about their condition - is an issue of great importance to people affected by this disease. In retrospect, limiting the number of 'votes' available to the respondents for this question was a mistake. A wider range of choices would have been more revealing. As the results stand, one can only speculate what the third choice or fourth choice would have been for most people, had that option been available.

The more or less direct substitution of to "find out more about your condition", for "friendship", by the respondents from the M.E. group indicates that this could have been a prominent third choice. The M.E. group was not obviously any less friendly than the other groups surveyed. It is organised by specific individuals. As well as noting this its members described it as "relaxed", "flexible" and "committee led". It was the most campaign oriented of the groups visited and gave information a high profile. Its members described the level of value attached to information received from the associated national organisations in more positive terms than any other group's. The high incidence of information as a motivational criteria fits in with the group's other characteristics. However, the group's overall character was not overtly different to that of the other groups surveyed, thus the other groups may share the same general attitude towards information, although this was not picked up by the study.

It should be noted that the criteria of "support" and "friendship" are both labels for types of behaviour which have the sharing of information implicit within them. In general, one is supported when one receives information, whether it is anecdotal, practical, experiential or formal. Furthermore an individual will usually share information
with people considered to be friends. Friendships are based on mutual trust and tend to be of an egalitarian nature. Thus the consistent indication that "support" and "friendship" were the main reasons that people belonged to their group does not obviate the need for information within an individual’s motivational criteria.

In an analysis of what attracted members to join four specific self-help groups, Richardson and Goodman noted that in the case of groups of lone parents and widows, the emphasis on securing emotional support diminished over time. The majority of groups included in the current study were founded recently. Only two groups have been established for over two years, one is the M.E. group, the other is the Positive Health Group. The motivation of the M.E. group’s members has been discussed: "support", was given priority with "to find out more about your condition", second. The Positive Health Group’s members were the only group to give top priority to a motivational criteria other than "support". The opposite criteria of "to feel more positive" was given precedence; "support" was next, followed by "friendship". It would be wrong to draw any great conclusion from this single example of the demotion of "support". It may be due to the characteristic described by Richardson and Goodman, but it may be due to other reasons such as the similarity between the criteria and the group’s name. Further investigation of similar groups will be necessary to establish whether this a true reflection of a general tendency.

Relationship between group structure and use of information:
The wide variety of organisational structures and range of differing attitudes to information displayed by the groups surveyed means that an attempt to extrapolate firm conclusions about the relationship between these two factors would be unwise.

Use and experience of information within a group:
The uniform eagerness of relevant respondents to share information from national organisations indicates that group members view the exchange of information as an accepted and normal activity within the group. Three of the surveyed groups had established libraries. Of the members who used these the majority in two groups indicated that their use had
been greater in the past. The group in which did not display this trend was the M.E. Support Group. As has been discussed the importance given to information in this group is relatively high. The groups concern with campaigning for and publicising their condition may explain this stress on the contemporary use of information. A further question should have been included to assess the motivation behind this change in behaviour. As it is, it must be assumed that greater use of information in the past is either due to the individual progressing in some way and no longer needing information or because the information held by the group is of limited applicability.

There is a tendency for specific individuals within groups to acquire a greater knowledge or confidence about information than other members. Typically they will be members of the committee if there is one, or one of those involved with the nuts and bolts of organising the group. This specialisation may cause an imbalance in the group as members may no longer perceive these individuals to be peers. The basis of mutual assistance through common need could be altered. Although most groups had specific organisers, all seemed to occupy this position through the common consent of their co-members. It appeared to be a reflection of natural group dynamics rather than a bid for power. These individuals are usually not in possession of specialist information.

The interviews that were held with members of Mukti, PUDDLE and Hysterectomy Self Help revealed that relatively more importance was given to information by the first two groups. The founder of PUDDLE assumed that the provision of information would be a priority of her group. The organiser of Mukti revealed that a high proportion of the practical support that her group provides requires specific information.

Sources and type of information:
The role of the Self-Help Team as a source of information for groups has dominated the study's findings. The public library and the social services were the next most frequently cited sources of information. Trent Health Line's resources were used by the two groups based at the Victoria Health Centre. The main category of information collected and shared by groups was, perhaps unsurprisingly, "self-help type books". 

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Leaflets and information from national organisations were the next most popular categories.

Overall both the type and medium of information sought and the sources used by the groups are fairly mundane. In one sense this may be a positive indication that the information required by groups is readily available. They do not have to turn to "obscure" sources. In another sense it may be that groups miss out on sources of information that would be useful to them, such as the store of NHS health education resources held at Memorial House. This resource has advertised its service in Self-Help News but received no known response. Groups must maintain their autonomy and so their lack of reaction to this promotion must be respected, even if it appears to an outsider to result in the loss of useful information. The three groups that had the widest spread of sources of information were Mukti, PUDDLE and People in Harmony. These three groups all had very capable and individually motivated people at their helm. There may be significance between these two factors.

**Leaflets and newsletters:**

Seven out of the eight groups produce leaflets. They all use leaflets purely as promotional tools. Only one of the groups currently produces a newsletter: the M.E. Support Group. The Lymphoma Support Group intends to start a regular newsletter after success with a pilot edition. Both of these groups indicated that they used the newsletter to provide and maintain a sense of community within the group. Both groups indicated that it was a vital means of communicating with members who did not attend meetings often or regularly. The groups do not produce literature to inform people about their condition or issue. They produce literature to attract people to the group and to encourage them to stay once they are members. Both of the groups that produce newsletters include information within them, but this does not appear to be their primary purpose.

**Quality of information:**

All of the groups appear to be happy with the quality of the information that they receive from the various sources, which supports their previously noted contentedness. The founder of PUDDLE declared
that she was unhappy with the quality of information provided by medical professionals to her personally. This was one of her main motivations.

**Future plans:**

When asked about their future plans and whether they foresaw any major changes in their information needs five of the groups indicated they would rely almost exclusively upon the Self-Help Team. Most of the groups expected to develop and require new information. This reflects the newness of the groups sampled, but this attitude was apparent amongst the two older groups. The oldest group (Positive Health Group) expected to need new information, but was confidently waiting to see what the new needs would be and expected to be able to fulfill them without a great deal of external help.

**Professional involvement:**

Professional involvement is apparent in an organisational sense in only two groups, and even in these cases it is not in the ascendancy. Many of the groups regularly have presentations by professionals, but there is strict demarcation and no suggestion that the group is reliant. The groups have their own identity and are confident in inviting professionals into their midst.

**CONCLUDING REMARK**

An interesting point to note is that when members of self-help groups asked me what I was studying, and I replied "the role of information within self-help groups", the majority responded with an "aah" and a nod of the head. There were few sparks of recognition and even fewer spontaneous opinions offered. This reflects the problem of singling information out from the mass of ingredients that make up self-help. Information is an intrinsic part of self-help and its influence is not easily traced by the outsider looking in.
BIBLIOGRAPHY


INTRODUCTION
This short questionnaire is completely anonymous. The results will be used in a discussion paper which has been endorsed by the Self Help Team. The topic being investigated is how self-help group members obtain and use information.

What is the name of your self-help group? ____________________________

How long have you been a member of the group? ____________________________

Approximately how many meetings do you attend in a year? __________

Are you a member of a national organisation that is concerned with the condition/issue that your group deals with? YES / NO (please circle)
If your answer is NO please go onto question 5
If your answer is YES what is the organisations' name? ____________________________

4a. Do you receive information from this organisation about your condition or the issue you are concerned with? YES / NO
If your answer is NO please go onto question 5

4b. On the following scale how important is this information to you? (please circle)

ESSENTIAL**VERY IMPORTANT**VALUABLE**OF LITTLE VALUE**NOT IMPORTANT

4c. Within the group do you a) keep this information to yourself? b) assume that others will know? c) mention it if the topic comes up? d) immediately share the information? (please tick)

Are you male □ or female □ (please tick)

Please tick the age range that applies to you:

under 20 □ 20-29 □ 30-39 □ 40-49 □ 50-59 □ 60-69 □ 70-79 □ over 80 □
2.

7. If your group produces a newsletter have you ever contributed to it?  YES / NO (please circle, if NO go to question 8)
7a. If your answer is yes, how did you contribute? ____________

7b. Did you have to find out any special information for this? YES / NO

If YES where did you get this from? ______________

8. Does your group have a library/central collection of information? YES / NO

If your answer is NO go onto question 9.
8a. If YES, what does it contain? _________________

8b. Please circle a category that describes how often you use it?
NEVER**OCCASIONALLY**SOMETIMES**REGULARLY**VERY OFTEN

8c. Did you use it more in the past? YES / NO

9. From the following list please choose two options that best describe your reasons for belonging to your group:

(please number them 1 & 2 in order of importance)

- Frustration with other services
- Support
- Find out more about your condition
- To get out of the house
- Friendship
- To feel more positive
- To try and change things
- Other (please specify)

10. Please circle a category that describes how much you generally contribute to the group:

A LOT**ABOVE AVERAGE** AVERAGE**LITTLE** NOTHING

11. Would you describe your group structure as any of the following?

(you can tick more than one)

- Flexible
- Dominated by one or more individuals
- Democratic
- Too relaxed
- Organised/led by specific people
- Relaxed
- Committee led
- Rigid
- Chaotic

THANK-YOU FOR YOUR TIME.
INTERVIEW QUESTIONS

1. How often does the group meet?

2. Is your group associated with a national organisation?
   If so which one?

3. Does your group have regular contact with professionals?

4. Does your group produce a newsletter?
   If yes: how? Who does it go to? What does it contain?

5. Does your group produce leaflets?
   If yes: Who are they aimed at? How are they distributed?
   What has been their effect?

6. Does your group have a library/central store of information?
   If yes, does it contain any of the following:
   * self-help type books
   * leaflets
   * literature from national organization
   * videos
   * information on services
   * teaching packs
   * detailed medical information
   * list of local sufferers
7. Has your group used any of the following to obtain this, or any other, information?

- public library
- social services
- Self Help Team
- Trent Health Line
- Memorial House resource centre (NHS)
- doctors surgery
- CVS
- Community Radio Team

8. Do you think that the information that your group has is up to date?

9. Is it sufficient for your groups needs?

10. Is there any other information you would like your group to have?
    
    If yes, how and where would you get this?

11. What are your ideas/plans for the future of the group?

12. Will any of these changes require new information?
    
    If yes where will you get it from?