TWO WORLDS

SELF HELP GROUPS AND PROFESSIONALS

Judy Wilson

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British Association of Social Workers

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The subject of relationships between self help groups and professionals has long been an interest of mine. But this study has two main direct influences, first, my time in 1990 at the Institute for Policy Studies at the Johns Hopkins University in Baltimore. To my colleagues in America, Canada, Germany and many other parts of the world, I express my thanks for the inspiration of their work and the time they made available to talk about it, then and more recently. My local work provided the other major influence. To my colleagues at the Nottingham Self Help Team, particularly Angela Dobie who provided administrative support, I am most grateful.

Eight researchers and 20 people from national organisations gave generously of their time, taking part in interviews and discussions, commenting on working papers and sending me material. Colleagues in self help projects in the area covered by the former Trent Regional Health Authority ably arranged meetings and discussed ideas. All this support meant that though a sole researcher, I was not working alone.

Finally, and most importantly, over 100 self help group members and professionals in the health and social services willingly gave time and took part in interviews. It is their experiences, their thoughtful practice that is the nub of this study - thank you.

Judy Wilson

Nottingham

January 1995

ABOUT THE AUTHOR

JUDY WILSON has worked with and written about self help groups since 1982. She combines voluntary sector management, training and consultancy and research. Since 1992, she has been both Leader of the Nottingham Self Help Team, the leading local self help project in the UK, and Research Director. She holds a M.Phil. degree from Loughborough University and in 1990 was a Senior Research Fellow at the Johns Hopkins University in Baltimore, USA.

Judy has travelled widely and worked in Africa, America, Canada, Australia and in both Western and recently, in East and Central Europe. She is the author of two practical handbooks on running self help groups and carers groups and of many articles and reports. She has lived in Nottingham since 1970.

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CHAPTER 1: INTRODUCTION

"We are working as a team, and that's how it should be seen by everybody - the self help groups as well. I think sometimes they do try and set themselves apart."

Judith, group for parents of children with arthritis.

"We shy very much away from professionals. I think people would be frightened away from the group if they thought we had professional involvement."

Kate, eating disorders group.

"I don't think you can wave a magic wand. Both sides have got to earn one another's respect really."

Tim, carers group

Members of self help groups talking about the relationship of their groups with the professional world had a wide range of views on what it could be. This research project set out to explore what good practice between self help groups and professionals might be.

The purpose of the study

The study began on the basis that most self help groups and professionals wanted to work together. Experience and the literature seemed to indicate that a wish to work together was the most reasonable premise on which to start. This project sought to illuminate and clarify issues which would help this to happen.

Identifying and describing the good practice which did exist, was the first purpose of the study. As the study developed, it became clear that this could not be separated from the general relationships between people who were clients and patients and the professionals who were providing care. Identifying and discussing issues relevant to the professional/self help group relationship - professional power for example - became a second objective.

Obstacles and barriers to good practice, often underestimated by both sides, developed as a third strand of the study. It became clear that the whole relationship was a more complex one than had been appreciated when the research began. Seeing what held developing good practice back became important.

Finally, the aim was to raise issues for policy and practice and to identify changes that might need to take place.

Origins and background

The origins of this study lay in the work of the Nottingham Self Help Team, a voluntary organisation, part of Nottingham Council for Voluntary Service and funded by Nottingham Health Authority. The Team, as part of its support and information work, had for many years acted as a link between self help groups and professionals in the health and social services. The chance to look at their relationship in another country came with a research fellowship in 1990, when I explored the subject in the United States (Wilson 1990).

I brought to this study research and writing experience, including an M.Phil degree and the Fellowship held at the Johns Hopkins University in Baltimore. My work in the field, initially in community development in Africa, was relevant too. I came with long work experience in the voluntary sector, locally, nationally and internationally.

I also brought certain values. It seems only honest to spell these out for readers of this report so they are aware of my bias as well as my background. I came to this project with a strong belief of the value of people coming together in self help groups. I trusted the potential and actual ability of people in the groups to run them themselves. Alongside this, I had a sense of realism about the limits to groups and the constraints under which they operated. Last, I came with a commitment to research which illuminated practice, helped people to see more clearly what they were doing, and pointed the way for change.

Audience

This report, "Two Worlds", aims to clarify issues and inform a range of people involved in policy, planning and practice. Professionals and their managers working in statutory and voluntary organisations in the fields of health and community care will find lessons in it for them. National self help organisations and local groups will, I hope, find it useful. Other parts of the voluntary sector, particularly those with a brief for development and liaison such as Councils for Voluntary Service, are also seen as potential readers. Last, academics, Members of Parliament and others who inform and develop policy should find it useful.

Not all the issues are explored here. Two other publications, both with a more practical emphasis, are being written for self help groups and professionals separately. Details of these and other relevant publications are listed at the end in the section entitled Further Reading.

How it was undertaken

This was a qualitative study, undertaken over two years. A qualitative approach was chosen as being most suitable for the topic and the people who took part in the research. It began with a literature review (Wilson 1993), but its main emphasis was on group and

individual interviews with members of self help groups, and with a range of professionals. Interviews took place between July 1992 and September 1993. They were rounded off with four short interviews with experienced researchers and with a consultative meeting with some national self help organisations. Appendix A gives more details.

The research was planned to get a reasonable degree of coverage, within the constraints of a qualitative approach. A total of 49 different groups took part in the study, carried out through nine group interviews, in a spread of places within the area covered by the Trent Regional Health Authority. A total of 50 professionals, from many different backgrounds and jobs, were also interviewed. While the research was planned to get variety, it cannot be known how representative their views were and how typical their experience was. The emphasis of this project on good practice meant that people and groups who by and large wanted to work together were primarily sought and invited to take part. This meant that few people, from both sides, who did not want to co-operate participated. This study should be read with both limits in mind.

I undertook all the work in this project, advised by Dr. Jill Vincent of Loughborough University, and supported by an advisory group of people with wide experience in the research and self help worlds. The Joseph Rowntree Foundation funded and supported the project.

Whose voices

The emphasis of this study is on what self help group members found and thought. Most chapters highlight their views and the study aims to enable their voices to be heard. Pseudonyms are used, not people's own names.

But interwoven with this are the views and experiences of professionals working with self help groups. For this report attempts to distil the two approaches, resulting in what appears to be the essence of good practice and the tensions and unresolved difficulties that go with it. It is recognised, however, that the detail of the good practice, as the comments at the beginning of this chapter show straightaway, will depend on the group, the issue on which it is based and both the professional setting and individuals concerned.

While extensive reading was carried out about this and related fields, a conscious decision to limit the number of references given in the text was made. The rich nature of the material gathered from people involved provides most of the source. It seemed important not to dilute it.

Key questions

The overall question for this study was what lessons could be learnt about good practice in this field. Some more specific questions emerged as the study progressed. The key questions are these:

- To what extent can there be partnership between the two very different worlds of self help groups and professionals?

- How far can professionals become involved in initiating and supporting groups without distorting the nature of a group?

- Are there risks of co-option and diversion?

- Do barriers of professional power and traditional attitudes mean there cannot be co-operation? What other possible obstacles to co-operation exist?

References to these key issues will be found throughout the report. I shall return to them again in the final chapter.

Outline of the report

Chapter Two introduces self help groups, giving a concise overview and briefly setting out some definitions. The idea of the 'two worlds' of the title of this report is explored.

The heart of the report is in Chapters 3 - 7, each taking a form of the relationship and discussing what seems to be good practice within it. Four aspects of good practice are set out:

- Putting people in touch with groups
- Support and development
- Promoting self help groups
- Influencing how services are provided

A realistic appraisal on what holds good practice back follows. Chapter 8 summarises obstacles to co-operation.

The final chapter on lessons for policy and practice, summarises and answers the questions set out here, draws together what seems to be the essence of good practice and makes some recommendations for action.

CHAPTER 2: SELF HELP GROUPS: A BRIEF OVERVIEW

This chapter gives first a brief overview of self help groups, what they are and what they do - and how the word 'professional' has been interpreted within the research. The idea of their two worlds is explored. A summary of the benefits of groups as seen by their members, and how their perspective differed or not from outsiders' views concludes this chapter.

A self help group, while an opportunity for people to help themselves, is in some way a misnomer. Self help can best be seen as an idea, put into practice in different ways. Samuel Smiles (1859) emphasised the individual aspect of self help, stressing the value of effort by individuals with the aim of benefiting themselves. Mutual aid or mutual help is a better description of what happens within a self help group. Neither, however, are phrases in general use. It seems better to stay with 'self help group' as the generally accepted name, while acknowledging the importance of mutuality within it.

Some definitions

Some attempt at definition helps to achieve clarity and avoid confusion.

Self help group

The Nottingham Self Help Team has adopted a definition of a self help group, not as a prescriptive statement to be used universally, but as a tool to guide its work. This research study used the same definition:

A self help or mutual aid group is made up of people who have personal experience of the same problem or life situation, either directly or through their family or friends. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are run by and for their members. Some self help groups expand their activities. They may provide, for example, services for people who have the same problem or life situation; or they may campaign for change. Professionals may sometimes take part in the group in various ways, when asked to by the group.

Professionally led support group

A 'professionally led support group' can sometimes be confused with a self help group. A group of parents of children with kidney disease, initiated and led by social workers at a hospital, provides an example of a professionally led support group (Argles 1992). Groups led by professionals often also contain a strong element of mutual support between members, but the fact that they are headed by a professional makes an important difference. The ownership of support groups like these is more in the hands

of the professional leader - members have less control and probably less commitment. Ownership is the crucial factor in distinguishing between the two types of group.

Professionally run groups can provide very helpful support and may be much appreciated by their members. In leaving them out it was not intended to deny their usefulness, but their concept is different and they were outside the scope of this study.

Professional

The term 'professional' is of course more generally known. A dictionary describes a profession as "a calling requiring specialised knowledge and often long and intensive preparation". A professional is someone who is "engaged in one of the learned professions or in an occupation requiring a high level of training and proficiency". (Webster's Third New International Dictionary 1986.)

Developing the discussion, Charlotte Williamson, in her informative book on consumer and professional standards in health care, outlines some of the aspects of a profession: "In each profession there is a basis of common knowledge and perception and an understanding of the interests that all members share. Professionals are largely self-regulating." (Williamson 1992, pp 4-5.)

Definitions do not tell the whole picture, nor reveal the complexities of the field. Other sources may contribute a view and help to reveal some of the inbuilt tensions that arise from the nature of professionalism. To turn to a playwright, Shaw in "The Doctor's Dilemma", sees the medical profession as a conspiracy. "All professions", in fact, "are conspiracies against the laity" (Shaw 1908).

The people who took part in this study were professionals working in the health and social services, largely in statutory organisations. They came from a variety of professions, listed in the summary on research methods. There is another category of professional concerned with self help groups. Paid workers in local or national organisations who develop and support self help groups would also call themselves professional. They have skills, are paid and aim to provide a reliable, high quality service. They are not, however, part of a self regulating group with a defined common body of knowledge. The brief of such development workers, working as community workers in social services departments, national self help organisations or in self help support organisations like the Nottingham Team, sets them apart from most people working in health and social services.

This study was about this latter group, people with a responsibility for services to individual patients and clients, and their relationship with a wide variety of groups.

Two Worlds

Professionals and self help groups inhabit very different worlds. The issue is not so much that they are different and often separate, but that the degree of difference is rarely recognised. Fig 2.1 summarises some major features.

This summary of the two worlds inevitably oversimplifies a complicated issue. It represents an ideal type which will not appear in a pure form in the real world. A self help group may for example be dominated by a powerful individual, while a professional team may work in a democratic, participative way. Once one has appreciated, however, the very real differences between the two worlds one can begin to see that good practice in working relationships is not as simple as might have been thought.

The comparison also begins to reveal the difference in resources to which the two worlds have access. Not only do self help groups depend largely on volunteer help and members' good will, they also have to raise their own funds. Professionals, even in a time of constraints on public services, start from a strong position of being paid to do a job and having an office base from which to work.

The variety of groups

Self help groups exist to meet many different needs and operate in different ways. This project focused on issues relating to health and community care. It was not intended to bring in every sort of group. It was a conscious decision to invite groups which were most likely to want to liaise with professionals in the health and social services, and whose activities were likely to be directly relevant to health and community care.

The summary on research methods gives more details of the wide variety of groups involved. A summary of those who took part, and the many different issues on which they are based, is set out in Box 2.1 herewith.

Box 2.1: Issues on which groups were based

- Chronic illness
- Disability
- Specific medical conditions
- Rare illnesses
- Carers
- Addiction/compulsive behaviour
- Isolation/social problems
- Mental health
- Bereavement
- Family problems.

Fig 2.1 Two Worlds: Self help groups and Professionals

	Self help groups	Professionals
Structure	Informal	Formal
Decision making	Participative	Hierarchical
Main concern	Mutual support and information	Provision of services
Source of knowledge	Through experience	Through training
Degree of permanence	Uncertain	Long term
Reward for time	Better coping Satisfaction from being helpful	Pay and status Satisfaction from being helpful
Resources	Volunteer help Members' homes	Paid staff Offices
Degree of integration into structures	Low	High
Language	Everyday	Jargon/shorthand

A local picture

Rather than describing some of the groups in the research study, which could breach confidentiality, the picture in one city provides some idea of the variety of groups that exist. The brief accounts that follow are included as illustrations of the spectrum of groups that operate in Nottingham. These summaries are taken from the 1993/4 Nottingham directory of self help groups. Group members themselves wrote these entries, none of them groups which took part in the research study.

Self help groups operate in very different ways, on large and small scales. Some are long established, others very new. Groups may come to a natural end or exist for many years. Most groups listed in the Nottingham Directory are city-wide. Some, however, are based on a neighbourhood rather than the whole city. Many of these, making up 14% of the entries, are for carers. One neighbourhood group describe themselves:

"The Thursday Club is a support group organised by parents of children with all kinds of handicap. In addition, we have visiting speakers and also arrange outings throughout the school holidays for the family. Meetings are held in parents' homes."

Women form a bigger proportion of membership of most groups than men. Groups based on specific issues affecting women's health form 8% of the entries in the Directory. A hysterectomy group meeting in a health centre is an example.

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

A very small proportion of groups in the directory are for people from an ethnic minority community. Mukti is a group for divorced Asian women. Their aims are as follows:

"To provide support, including counselling, welfare rights, health information and translation, for divorced Asian women. We make home visits if required, befriending and supporting as necessary."

Mental health, addiction and loneliness together form a broad grouping, again making up 14% of groups listed. Alcoholics Anonymous, the longest established of them, lists 15 weekly meetings in the Nottingham area, using church halls, community centres and a counselling centre.

"AA is a voluntary, world-wide fellowship for men and women from all walks of life who meet together to attain and maintain sobriety. The only requirement for membership is a desire to stop drinking."

Another long-established group in the mental health field has a range of activities, including campaigning. Like a fair number of groups listed, the National Schizophrenia Fellowship is affiliated to a national organisation.

"The Schizophrenia Fellowship is a support group for sufferers of schizophrenia and their relatives, giving information and advice, and campaigning for better services. General meetings are held monthly at the Day Centre and social events are arranged. There is a monthly games evening for sufferers and a small monthly informal group for new contacts."

The number of bereavement groups trebled between 1982 and 1993. They may be very specific to a particular form of bereavement. The Tamba Bereavement Support Group, for example, aims

". . . .to offer support and friendship to those who have lost a twin baby, before or after birth. We will talk on the phone or visit at home and invite to our small informal meetings. At present we are mothers who have lost a twin baby but hope in time to widen our scope. We have access to the resources of the national group. Meetings are held monthly in each other's homes. Times are flexible, but about 8.30p.m."

This provides a snapshot of the range of groups in Nottingham - Wann and Coote's book (1995) describes a wider range of groups operating under the self help umbrella.

The growth of groups

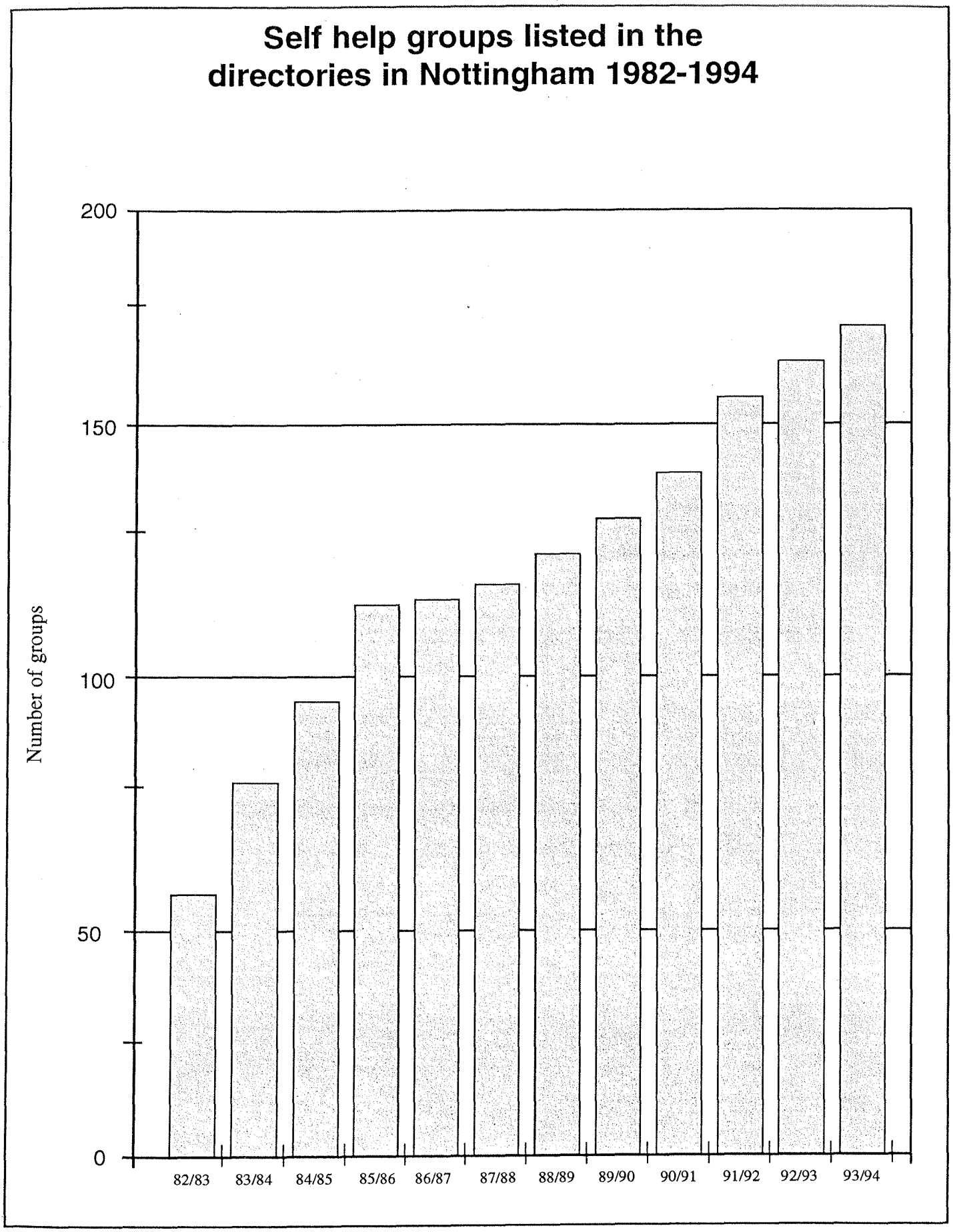
The increase in the number of groups is also demonstrated by looking at the Nottingham directories. As Fig 2.2 shows, in 1982 there were 60 entries, in 1993 there were 176. These were all groups which had become reasonably well established - brand new groups were not included.

Most accounts of self help groups comment on the growth in the number of groups, although no research has been undertaken nationally. Even allowing for a greater rate of increase in a town with an established self help project, the Nottingham figures would seem to confirm that there are now generally more self help groups than a decade ago.

The benefits of belonging

There are more groups and a great variety in the issues they address and ways they work. Why people go to them is the next question. Self help group members in this study were asked what they saw as important benefits of their groups. They identified five different important aspects (Box 2.2).

Fig 2.2


Self help groups listed in the directories in Nottingham 1982-1994
Number of groups
200
150
100
50
0
82/83
83/84
84/85
85/86
86/87
87/88
88/89
89/90
90/91
91/92
92/93
93/94

Box 2.2: The benefits of membership

Mutual support
Information
Confidence raising
Opportunity to be helpful
Influencing services

Mutual support, information, and confidence-raising were stressed as the three most significant benefits. These three came up consistently in all nine group interviews and were mentioned by a very wide variety of groups. Two other benefits, both mentioned by about a quarter of people taking part, were also valued. These were the opportunity to be helpful and the chance to influence how services were provided.

Mutual support

It is helpful to approach this question of why people go to groups and the benefits they gain from a broader perspective of people's needs. An American author reminds us of Maslow's hierarchy of needs. Katz highlights the third needs category as being most directly pertinent to the self help field - the need for belongingness, affection and social acceptance (Katz 1993).

Mutual support through sharing experiences emerged as the most important benefit of self help group membership. The value of being with people who had experienced the same situation was constantly stressed. Eileen, a woman in an endometriosis group, voiced the relief she had felt when joining:

"They understand - and they are the only people who do understand."

Times of transition were seen by group members as particularly difficult, including the time when you learn a diagnosis. Judith, a sufferer of Myalgic Encephalomyelitis (ME) thought support from others in the same situation was particularly helpful at this time.

"When someone has been newly diagnosed with anything chronic, they need a lot of help, because they have got to come to terms with it - and coming to terms with anything is extremely difficult. Particularly if you do not know if you are going to get over it or not."

Pauline from a disability support group identified discharge from hospital as the time she had especially valued the special support from a group.

"Although there's plenty of practical help in hospital, when you come out there are not many groups that can give emotional support to get through the depression that can follow."

The degree of distress experienced was often high, and consequently the need for some sort of support could be acute. Having to meet the needs of people with suicidal feelings were mentioned in half the interviews with self-helpers. None were mental health groups. Marriage breakdown, caring responsibilities, disability, chronic illness, and even being the mother of twins, were examples of situations where people became isolated and at times got to the end of their tether.

Support from people in the same situation was valued particularly highly by self-helpers coping with such a high degree of distress. Professionals, some felt, did not always realise how bad people were feeling and that it was a type of distress that could be shared in a self help group. Jill, from a group of parents of children with arthritis, gave an example.

"There was a young boy who had only got it in his knee and the physios felt it was 'only a knee'. Well! When I actually did get hold of this mother, she thought it was the end of the world. Her son couldn't play football and she was devastated, absolutely devastated. But the professionals really didn't realise that it was such a big problem to that family."

Information

Information sharing was seen as a second important benefit of membership. This was a widely held conclusion, also strongly felt. People valued information about their situation, about where to go for help and how to cope. Group members could become very expert in the management of their condition and often knew a great deal about it.

Jill had talked to many other parents.

"I think people ask questions that they would not like to ask the doctor."

Judith, from the ME group, had found people shared information easily.

"With the pooling of resources you get, usually there is someone who will say - well, yes, you go to so and so for that."

Cheryl from an amputees group had been to see someone who had recently had his leg off.

"His first words to me were - what do you do when it itches where that part has gone? So I said, I don't know if it will work for you but it works for me and I scratched the cradle thing over his leg. Yes, he said, I'll try that."

And Michael, from a carers group, summed it up.

"Somebody's been there before you. It's just a joint learning group."

Confidence raising

The concept of empowerment is one which is now widely discussed. In the mental health and learning disabilities field, for example, it is a particularly important issue. Self-helpers in this study did not use the term 'empowerment'. They did however, value the way a group could help raise their confidence. Lynne from a dyspraxia group, a rare condition affecting children, described her experience.

"Apart from dealing with the condition itself, your own confidence increases and grows just by being involved."

Keith, from a cardiac support group, had had trouble with drugs, the effects of the treatment taking his confidence away even more than the heart attack.

"I was terrified to do anything. The group gave me a lot of confidence."

There were many accounts from people showing that greater confidence could lead to greater participation in the group. This then led to the group itself developing. More control over one's own life was also often mentioned as a result of membership. Kathryn, from a parents' group, had grown to feel more equal. She felt it could also lead to challenging professionals, much needed in her view.

"You've not got to feel intimidated by professionals."

An opportunity to be helpful

The opportunity to be helpful was much valued by some self-helpers. About a quarter of the people in the study mentioned it as important to them. The strong motivation people had to be of use to others in the same situation is shown by comments like these:

"You get a lot of pleasure."

"I didn't want another person to go through what I went through."

"You give something back."

For even where people might be expected to pass through groups as part of their recovery, many stayed to be helpful. Kaneez, from an Asian women and children group, found it very satisfying.

"I've been through it and I know how it feels. I help whenever I can. The main thing I get is satisfaction. If I make somebody smile for about half an hour, I think it's worth it."

Tim, a member of a carers' group, also found it very fulfilling, looking on it, he said, as a job.

"I retired about two years ago to look after my mother who suffered with dementia. It got to a stage where I could not cope any more, so after that (when she was admitted to hospital) *I had a reasonable amount of free time."*

Ann Richardson's influential report in 1983 drew attention to the way people moved to being more a helper than helped. Serial reciprocity, as she described it, could be seen as an important aspect of the benefits of membership. (Richardson 1983.) Riessman (1965), another American author, used the phrase 'helper therapy to highlight the importance of being helpful .

Influencing service provision

A current issue for planners and managers in health and social services is how to seek out and use the views of patients, clients and carers on the services they use. Self-helpers rarely mentioned formal ways of commenting on services as being of value to them. They were more concerned with the benefits to them as individuals that came through taking part in the group.

Less formal ways of influencing services were, however, welcomed, particularly by groups which had found it satisfying to look outwards to the needs of others in the same situation, not necessarily group members. These informal, less structured opportunities are looked at in more detail in Chapter 6. To give one example here, a parents group valued the chance to make things better for patients, feeling they should not be passive. A letter to a hospital department had had a remarkable effect.

"She completely changed her organisation to what we had been asking for. It was amazing. When we went to visit her again, she actually thanked us for going along. You don't have to be nasty, just assertive."

Degree of consensus

Self-helpers from very different groups found it easy to agree on most of these benefits and to understand the very strong feelings that people in other groups expressed. A comparison between their views and the opinions of professionals, while showing some consensus, revealed some differences. The self help world may be well understood by people within it, but not always by those outside it.

Most professionals in the study agreed on the three main benefits identified by self-helpers. They particularly valued mutual support and, to a slightly lesser extent, information. This agreement on the value of mutual support was also emphasised by researchers interviewed and is confirmed by the literature.

There was, however, a difference of degree. Some professionals interviewed in this study did not appear always to appreciate the extent and strength of isolation and distress

some people felt, and hence the very strong need for support and information. A second difference was that few professionals appeared to perceive how beneficial it was to be helpful to individuals. Nor did they mention that being able to influence services so that other people got a better deal could be satisfying. A few did mention the 'boost' that helping someone else could bring, but the importance of the boost could be being underestimated by professionals. Third, two researchers and a few professionals made assumptions that people joined groups in order to influence how services were provided and planned. There appeared to be some risk of confusion between voluntary groups set up to campaign for change and self help groups whose main aim is to provide mutual support and information.

Such differences in perception are not perhaps entirely surprising. While a simple idea, the way self help is put into practice is very varied. Groups are not co-ordinated. Nor do people in individual groups always put over to outsiders quite why membership can be so helpful, nor promote their groups clearly.

Some differences can, however, be looked at in the context of the two worlds, and their two different perspectives. Professionals and researchers may interpret the benefits of self help group membership as they would like them to be from their own perspective. This issue, leading to the question of possible diversion and distortion of self help groups, is one to be looked at again later.

Professionals' viewpoints could also extend knowledge on the benefits of self help groups. Sometimes their perspective added a wider view, seeing benefits of membership that individual self-helpers could not always perceive. They had the opportunity to see a series of patients or clients benefit from self help groups and how this fitted in to recovery or prevention. Three examples of people I later describe as 'specially skilled professionals' (Chapter 5) demonstrate this approach. There were other comments too. A social worker felt that contact with the group had led to some people accepting operations which otherwise would have been refused. A nurse saw self help group membership as preventing unneeded readmission to a cardiac unit. And a GP stressed the value of information and coping strategies from groups on conditions which were relatively rare and not yet fully understood by professionals.

If working with self help groups is to become part of accepted practice, it may be necessary to delve further into how their role can directly fit into policies and treatment. The self-helper's largely individual view is featured in this study. A more strategic view, as a number of these specially skilled professionals took, is also part of the picture.

Conclusion

In conclusion, there was no chasm of dramatically different understanding of the benefits of self help groups. Self-helpers and professionals largely agreed on the most important results from membership. But there were some differences and some evidence of lack of awareness of each other's perception of the benefits of belonging.

CHAPTER 3: PUTTING PEOPLE IN TOUCH

The focus of this study was on what good practice already exists between self help groups and professionals. This chapter is the first of four which look at ways in which self help groups and professionals can work effectively together. A major theme in the research was information. Giving patients and clients a variety of information, not just about self help groups, is generally becoming a normal part of professional practice. A number of policies, such as the 1989 Children Act and the Patients' Charter require this action.

With such apparent endorsement, it would seem a straightforward and acceptable part of professional practice to put people in touch with self help groups. This chapter reviews the extent to which this took place, with examples of good practice. A number of constraints and dilemmas which made putting people in touch with groups more complex and difficult than might be thought are discussed.

Self-helpers' views

All the groups in this study wanted professionals to put people in touch with them. The wish was unanimous. They did not want this done selectively, but rather on a regular basis, systematically. Potential members should have choice about whether to join or not.

Group members' concern to see this happen stemmed from their strong belief in the value of belonging to a group. Members wanted other people to have the option of benefiting in the same way as they had done. Some people, taking a more strategic viewpoint, urged this to be done on a regular basis to make sure there was a steady stream of new members. Groups helping people through a time of transition, where it was less likely that members would stay for long, saw this indeed as essential for the group's survival. Generally it was felt this was not happening in the way they wanted.

Not 'referral'

Professionals often slipped into the word "referral". Referral is the normal professional practice of identifying and prescribing other services, and then giving the agency to whom the person is being referred personal information about that individual. This was often confused with a different process, that of providing information and enabling people to make an informed decision on whether to join a self help group or not. Groups found the term unsuitable, a word they rarely used.

Nor did they wish to be told much about a new member. They found it embarrassing to be offered details about someone who was likely to join their group, feeling that new members should choose when and how much to say about themselves. "Referral" to

a self help group could be incompatible with a principle of confidentiality. Using the term, even as shorthand, is confusing and inappropriate. "Putting people in touch" is suggested as the action that is needed and the term that will be used here.

Systems for putting people in touch

Groups wanted systems, not selection. There were a number of illustrations of systems for putting people in touch which appeared to work well in some areas. Beryl, the secretary of a branch of the British Diabetic Association, outlined the system that had been developed for putting people in touch with her group.

"When a patient goes to the clinic they always give them our programme, which has my name and address, and they are told to contact me if they wish to join."

A Drugs Centre had a system which the parents support group felt worked well.

"If someone rings up, they are automatically given our number and it doesn't matter if the person on the phone thinks they need that help or not. They will say, there is a support group."

Sometimes a professional took a more active role, which Jo from a Down's syndrome group found useful.

"The health visitor goes to visit new parents and she will tell them about the group and then introduce them to us, you know - maybe bring them along."

Systems like these for putting people in touch with groups, mentioned quite often in some areas, were much welcomed. Such systems were identified as the most important way in which professionals could help both the group and the individual person concerned.

Common but not universal practice

As well as there being systems in place, it appeared to be reasonably common practice for individual nurses, health visitors and social workers to link some of their clients with groups. Groups spoke warmly of the way in which many of them did this. Ellie, from the Alzheimer's Disease Society, appreciated getting calls from the hospital.

"The Sister will phone up and say, I've got a couple here, one suffering from Alzheimer's - what support can you give them? I send the meeting dates and any literature they want."

Occupational therapists, physiotherapists, consultants and receptionists were mentioned frequently, too, suggesting that a wide range of professionals take on this role already. General Practitioners, described by one group as "the most difficult professional nut to crack", seemed much less likely to tell their patients about groups than other professionals. Doctors generally, even when they appeared to appreciate

the work of groups, as a recent study found, did not always take what might seem logical action, that of linking their patients with groups (Temple *et al.* forthcoming). Groups found this diminishing and puzzling. Lucy, the exasperated initiator of a tranquilliser group, tackled a doctor at a conference.

"I said to the consultant: do you think self help groups give a service? And he said of course I do. And I said, well, why don't you liaise with them"

"If only they would say," said a carer, *"There's no more we can do for you - but there is a self help group."*

This study found that putting people in touch with groups was not generally automatic practice. Groups' experience was that it was patchy, influenced by a number of factors, one being the type of group. Groups based on an issue which meant they operated well outside the professional system of care found people rarely heard about the group from a professional. The tranquilliser group quoted above provided one example, an eating disorders group another.

"Most of the people who come along hear about it from the Council for Voluntary Service's self help directory. There is a doctor at the hospital now who has started to tell people about us, but only people he thinks will benefit. He wouldn't do it as a matter of course."

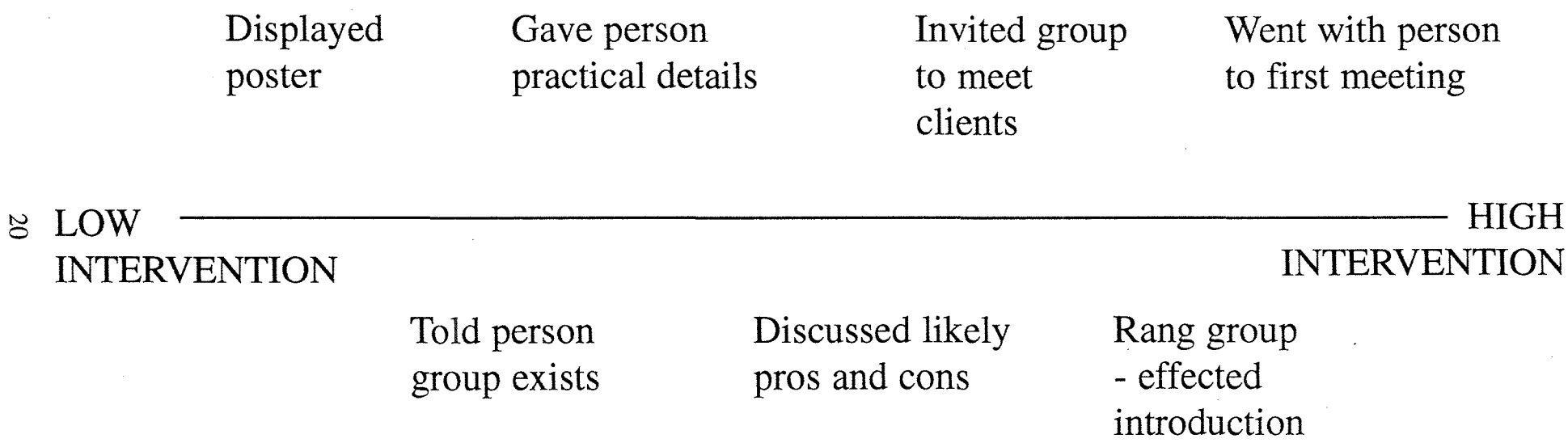
In contrast, groups close to the professional system of care, and based on a specific condition, often found it easier to evolve and maintain effective procedures.

There were indications that reluctance to mention groups outside a professional system of care could be less of a problem in the future. The experience of the national Eating Disorders Association suggests that there is increasing willingness, at national level at least, to co-operate. A number of local groups in this study, however, who were not always acceptable to professionals, found developing systems difficult.

A few groups tried to quantify what proportion of their members came through professionals. It varied greatly. One group said they got all their members this way. At the other end of the spectrum, Joan, from a single parents group, felt few came through professionals putting their clients in touch.

"I wouldn't say it was a really high proportion, probably as little as 5%."

Fig 3.1 **Ways in which professionals put people in touch with groups**



How the link was made

Groups saw putting people in touch as a straightforward procedure, not always aware of the complexities underlying the development of systems. No one procedure was recommended however. A number of ways people could be put in touch with groups had been found, summarised in Fig 3.1. This diagram summarises some of the methods used. Providing basic information, for example, was seen as an essential first step, as Chris from a visual impairment group had found.

"The biggest thing is having access to information, and that's what I find most difficult. People need information before they can have a choice."

Varying degrees of involvement could be appropriate. Making information available through displaying a poster or listing groups in a handbook, was an indirect, low key method that worked. A sounding board role, helping people explore the pros and cons of joining, could be useful in some cases. A health visitor for example had undertaken this role with people with multiple sclerosis, who were anxious about how they would cope when meeting people worse than they were.

More active roles could also be appropriate. There was ample evidence of professionals initiating the link, so making it easier for the person concerned to join the group. Physiotherapists and a group for parents of children with arthritis had a good system working. It dealt with the problem of retaining confidentiality, an important issue, got over the barrier of making a call to a stranger and gave people a choice about how they could get in touch.

"They will give them my name and say, do you want Judith to contact you, or do you want to contact her? Usually they want me to contact them - it's a lot easier for me to make the first move. They're very supportive."

Sometimes, enabling people to meet group members informally but regularly was appropriate, as Keith from a cardiac support group welcomed.

"We go along to the rehabilitation every Thursday, mash tea for them - and we do a talk every six weeks about the group."

Group members pointed out the distinction between giving information and making decisions. While publicising information might require professional initiative, the decision to join the group had to come largely from the person concerned. No one blueprint emerged. Systems appropriate to the group and to the professional setting had to evolve. Certain key principles were, however, recommended by self-helpers, summarised in Box 3.1.

Box 3.1: Principles recommended by self-helpers

Tell everyone, don't be selective
Give people the choice, don't over-push
Perform introductions where appropriate
Tell people sooner rather than later
Provide written material as well as verbal information

Universal or selective action

Groups and professionals on the whole agreed that professionals could usefully put people in touch with groups. But there was not consensus on whether this action should be universal or selective. Ann, a health visitor very committed to the idea of self help groups, still retained the right to choose whether she mentioned a group or not. She was very conscious of her responsibility for her clients and her need to be well informed about any group. If she did not have enough information, she would not mention it.

"It's no good sending somebody off if you don't really know what's going on there. It just makes you feel bad."

There was a strong sense among professionals of their need to match the person with the group. Rob, a Community Psychiatric Nurse, was working in an area with a well established policy of encouraging the formation of mental health self help groups, resulting in there being many to choose from. He saw his role as matching the person with the group that met their needs, as he perceived them.

There is a distinction between offering a range of relevant information and making a choice for someone. Phil, from a group for depressed people, did not think professionals were in a position to make choices for a patient.

"To make fine distinctions between people isn't very helpful. At that point they may not be ready for a group, but be happy just to know it's there. We have had three years' delay before people actually come. If they didn't have that information, they could never come."

Sally, from a parents support group, felt you never could tell. She was quite angry about the prospect of people being deprived of knowledge that they could find useful.

"How do they perceive one person to be in greater need than another?"

Both self help groups and professionals approached this issue, ironically, from a concept of quality of service. There was a strong feeling from many different professionals that they only felt able to pass on reliable, high quality information, going to great lengths sometimes to get it. Self-helpers, such as Kathy, a Twins Group secretary, felt equally

strongly that universal systems were needed to ensure equality of access to a quality service.

"To have this screening system is, well, what it means effectively, is that some people get a better service than others."

The theme of isolation was one which came up repeatedly when self-helpers were describing the benefits of their group. A social worker reflected on how many conditions could lead to isolation. He suggested that not telling people about a group could be seen in fact as condemning people to unnecessary isolation, hence a lower quality of life. He felt that withholding information could be poor professional practice.

To summarise, there were strongly differing views on this subject. There was not full agreement between self-helpers and professionals on whether people should be put in touch with groups as part of a system, so that everyone got to know, or whether professionals should select which people should be told about particular groups. Professionals, mistakenly in self-helpers' views, too often saw it as referral, this then leading to problems which would be less likely to arise if there was greater clarity on what the action actually was.

Constraints

Two particular constraints appeared to hold back the development of systems of putting people in touch with groups: attitudes, and lack of knowledge. Later in this report (Chapter 7) the whole question of obstacles to co-operation will be discussed in some detail. A briefer discussion here suggests how these two constraints operate and hold back the practice of putting people in touch with groups.

Attitudes

Attitudes emerged as a major influence on relationships generally between self help groups and professionals, but there was no clear picture. While self-helpers often assumed unhelpful attitudes were due to hostility, in fact they could arise from professionals being protective of clients. Even when people had positive attitudes, these could range from qualified support to enthusiasm.

Attitudes to groups were not necessarily the central issue. A feeling of responsibility and protection of the individual client led to professionals being unwilling to take action which, as they saw it, might be harmful to that person.

Fundamental were attitudes to identifying and appreciating clients' needs that lay outside the compass of that particular professional service. Professionals who did not see such needs as their concern seemed less likely to make time for networking. Networking did require effort, as a social worker had found.

"Networking is difficult enough with fellow professionals, never mind self help groups."

Attitudes to knowledge gained through experience rather than training were another influence, an important issue discussed in more detail in Chapter 7. Last, attitudes to the management of chronic illness influenced the likelihood of professionals linking clients with self help groups. Terry, a member of a Tinnitus Group, suggested doctors were unlikely to do so if there was no cure.

"They will tell you to go away and live with it. They don't tell you how to live with it."

Information

Lack of information also hindered good practice. An important constraint was the difficulty in getting and maintaining information about practical details of groups. This held even if professional agencies had tried to set up systems, as a Visual Impairment Team had attempted.

"We put it on a disc, but it was difficult because they kept changing. It became an administrative nightmare!"

The time needed to build up information was a factor. A health visitor who made telling people about groups a conscious part of her work had worked in the same area for nearly 20 years. She described herself expressively.

"I am at ease with my caseload".

Her situation contrasted with an overburdened social worker.

"If it is going to take me three days to find a group, I'm not going to do it."

A further problem arose when professionals felt they needed more than just hard information. If they had no experience of the group, some said, they felt unable to mention it, as it would be seen as a recommendation. If matching a client with a group is seen as essential, then not having the feel of the group is likely to hold back linking a client with it.

Lastly, change of staff, meaning new people were less well informed, could have an effect. Cheryl, a member of an amputees support group, came back from holiday to find a change of sister on the ward.

"She was very loath to let me go on the ward. I explained who I was and what we did. I've heard of you, she said. I went away and came back the following week."

While the tact of the group in not forcing the issue led in time to a resolution of the problem, support from just one person in an agency was not enough. Information needed to be generally available, not held by one key gatekeeper.

Factors that helped

Some groups and some professionals had found ways of getting over such difficulties. A number of factors helped good practice to develop. Box 3.2 summarises what emerged as consensus between self help groups and professionals.

Box 3.2: Factors that helped the process of putting people in touch

Clarity on what the process was
Reliable and accessible sources of information
Systems rather than individual commitment
Interaction between groups and professionals
Policies that endorsed practice

Clarity

In joint discussions it was agreed that both groups and professionals needed to be clear that the process was one of giving people information - and enabling them to make up their own minds about whether to join a group or not. It was neither referral nor recommendation. Only information agreed by the person concerned should be given to the group, to ensure confidentiality was maintained.

Information sources

Local, central sources of information were valued. Directories of groups, produced by local self help projects, and by Councils for Voluntary Service, were the most used and appreciated ways of finding out about groups. Self help projects in particular were seen to be useful for finding more about groups than just basic information in a directory. Access to both sorts of information; basic, hard facts and getting the feel of the group were both needed. While self help projects would not see themselves as vetting or endorsing any particular group, they were seen as legitimising groups' activities. They also gave access to national organisations if no local group existed.

Other reliable information sources also helped, but only if properly resourced. These could be internal. One mental health team for example had developed a parallel resource team which maintained a broadly based information base.

Systems

Systems within an agency helped. When putting people in touch with groups was part of normal team practice, this made it more likely to happen. As often happens with pioneering styles of work, individual professionals often made it their business to know

about groups and link their clients with them. This may well be inevitable at an early stage of a new form of practice, but endorsement of this practice by an agency, making it part of normal professional methods, made it more likely that there would be consistent action.

Interaction

Interaction, which may need to be initiated by the group as much as by the professional, aided the process of new members learning about the group and making an informed decision about whether to join. Various forms of interaction emerged as working well: visits by professionals to groups, giving talks to each other, visits to hospitals, and phonecalls. Not all groups wanted such close or frequent contact, and attendance at meetings by professionals was not always appropriate. Interaction generally, though, led to easier relationships and more confidence by professionals in telling clients about a group.

Policies

Less apparent but of potentially great importance were policies which endorsed, or even required, professionals to supply information. The 1990 Children Act appeared to have increased the amount of information made available to parents about voluntary groups. Local groups alerted to such opportunities by their national organisation had found it had strengthened their case when they were able to quote legislation.

Structural and inevitable dilemmas and tensions

While these factors all helped good practice, a number of dilemmas and difficulties in this part of good practice were also identified. The differences between the two worlds may well mean there has to be acceptance of some built-in tensions and areas of untidiness. Five particular issues emerged.

Professional control

Many professionals wanted control over the process, feeling responsible for the link and selecting whom to tell. Self-helpers, on the other hand, saw responsibility as resting with the potential member, who should take and accept any risks involved.

Experiential as opposed to learned knowledge

Professionals trained over many years may not be able to appreciate other routes to knowledge. Unless they see and understand the different but complementary value of knowledge gained through self help groups, they may be unlikely to link their clients with

such groups. Even if better appreciated, the nature of the knowledge may well cause tension.

Investment in networking

Networking requires investment of time, to gain an intangible return. Natural networkers seem able to make time to locate, understand and use other forms of help in the community. Others, less instinctively aware of its value and pressured to deliver services, are unlikely to commit time to building up knowledge and contacts.

Quality

Emphasis on quality of help and information may be part of important professional standards. On the other hand, this emphasis may lead to depriving people of what could be crucial help. Over-emphasis on quality and professional selection and control may mean people do not have the option of support from a self help group, and hence a lower quality of service.

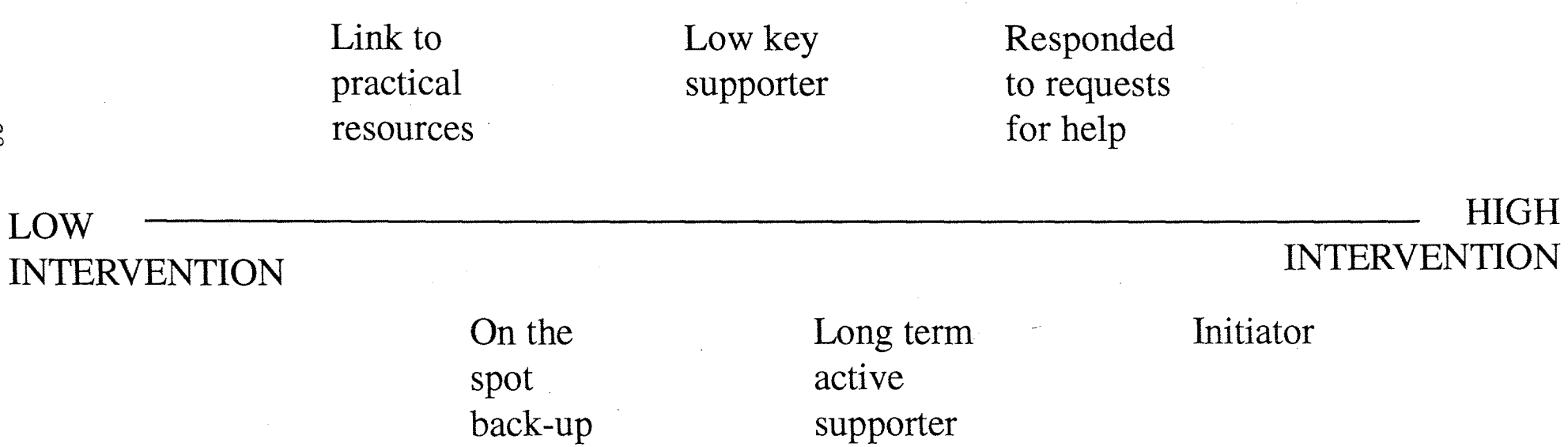
Priorities for groups

Groups with limited energy and resources may want in principle to develop co-operation with professionals so that they get more members. They have to face, however, the dilemma of whether they too invest time in a long-term, and sometimes depressing, process which may divert them from their basic activities.

Conclusion

Putting people in touch with groups is important and achievable, but quite how it is done has to be approached carefully, flexibly and realistically. Processes such as referral may be normal in one world but cannot easily be used in the other. Professionals provide unique and sometimes crucial access to the self help world but the complexities of what might appear to be a simple procedure have to be recognised and taken account of.

Fig 4.1 **Effective roles played by professionals when groups began**



CHAPTER 4: SUPPORT AND DEVELOPMENT

Support and development by professionals emerged as both common and usually appreciated by groups, if undertaken appropriately. In this chapter, the role of professionals in giving support to groups and to helping their development, a second form of good practice, will be discussed. Not only helping groups to start but also enabling groups to continue, change and develop proved to be useful roles for professionals to undertake in many situations. How this can be done and the dilemmas and tensions there are within these roles too are discussed.

Support was welcomed in five different ways, summarised in Box 4.1.

Box 4.1: Support and development from professionals

Help when groups began
Giving background support
Providing access to practical resources
Attending meetings and giving talks
Acting as a figurehead

Initiation of groups

The self-helpers' views

Few groups, less than a fifth of those in the study, referred to support as they began as an important part of their relationship with professionals. This could simply have been that they were well established and that professional involvement was now history. Even so, this was less of an important role than might have been thought and less significant than a study of the literature alone would suggest.

Most groups wanted to run it themselves. A robust comment from Keith of a heart support group demonstrated their confidence.

"You get doctors and so on interested just to get it off the ground. Let's face it, once it's off the ground, we can do it without them."

Judith from a parents' group agreed.

"That's how it should be, they should be able to stand back and let the non-professionals take over. Their role is advisory."

People differed in how much they thought the initiative should come from the professionals. A bereavement group and a parents' group for example both referred to the ability of hospital staff with an overview to see how isolated people were. They

welcomed the initiative from the professionals. Lynne from a dyspraxia group disagreed.

"I don't think the health authority should be responsible for setting up groups. They should start spontaneously."

Groups who had taken the initiative still welcomed support for their idea and help in getting to the first set of members, as Cheryl from an amputees group described.

"I'm very out-going, you've probably noticed. We went along to the OT and Physio Departments, this is what we would like to do, can you help us? They said, yes, we'll ask people if they'd be interested. They finished up giving us a list of names and we wrote to everyone."

Not everyone had her confidence. Cheryl also described another similar group, where a hospital sister had remained too involved with the group. It had ended splitting in two, with the more dependent group of people staying with the nurse. The issue of easy dependence on professionals who take too much of a leading role was raised by some group members. People felt it was easy to cling onto professional support, one person describing this as being "weak-willed".

Professionals' involvement

About half of the professionals interviewed mentioned having been involved in the early stages of a self help group. They either initiated the group or responded to a request for help. Help by professionals when groups began ranged from very high involvement to very low. Fig 4.1 outlines ways in which professionals had been effectively involved. This diagram inevitably oversimplifies what was often a complex and changing situation, but demonstrates that there were various appropriate degrees of intervention. Short accounts of three professionals illustrate different ways of being involved.

Jill, a social worker with families affected by a rare degenerative illness, was one of the few people in the study who took a leadership role, though she saw herself as the means to a new development, rather than the controller of the group.

"I started this group with an NHS colleague, a health visitor, in response to requests from families to meet others. It would not have started if we hadn't started it. . . . You can't just put an advert in the paper. It's an isolating condition and very rare, so the chances of two people being likely to meet is unlikely."

Jill was also a self-helper. Herself a committed member of other self help groups, her attitude was one of enabling members to participate and be in charge of the group. As an experienced professional, her assessment was that the situation required her both to be a catalyst and to continue her involvement as part of her job.

Dora, a hospital nurse, responded to a request for help from a cardiac support group.

"I saw a letter in the local paper written by an ex-patient. I responded and liaised with the consultant and have been involved ever since."

Dora continued her involvement, at one time chairing the group. She was still a committee member, at the request of the group, and was taking a particular role in ensuring there were effective links with the hospital.

As an example of the other end of the spectrum, Angela, a health visitor, had been involved with a number of new parents' groups. She worked in an area where the Community Health Trust had funded a self help project. Aware of the limits on her time and skills, she saw her support as giving access to practical resources but no more. She knew all about the self help project and the help it could give.

"From then on, they really need to go to a self help co-ordinator."

The complexity of the job was not always appreciated when people first got involved. Extracting themselves from the group if they had initiated it was rarely easy. Indeed, Catherine, a rehabilitation assistant in a visual impairment team, had found it "a horribly difficult process".

"It was very difficult for me not to dominate. .. My personal feeling was to protect and take over. I've stepped back now but I am still not back as far as I would like to be. But you cannot just get people together and say, well, there you are, you wanted to meet each other, get on with it."

There were no clear rules, though working towards group control from the beginning would seem to be an essential rule of thumb. This had not happened in a parents' group started enthusiastically by a health visitor, and heavily supported by her for 12 years. It seemed likely to end shortly when she retired. Where a professional had initiated a group, there had consistently been problems in it becoming self-running unless the whole question of who owned the group and the role of the professional had been clarified at the beginning.

Issues in supporting new groups

A number of factors appeared to affect professionals' roles with groups as they began. Among professionals was the ability of being able to perceive, acknowledge and play their potential role as catalyst and development worker, rather than leader. Among self help groups was the issue of the degree of dependence on professionals by group members as individuals. Appropriate attitudes, an ever-recurring theme, affected professionals' roles. Attitudes needed included trust and seeing potential ability in members. Monitoring, reviewing and changing roles were other issues, and being able to decrease their degree of involvement at the right pace.

The presence of these to a greater or lesser extent all influenced how effectively professionals helped groups to start. Fundamental was clarity on role - and ability to review and change it.

Background support

Giving background support once groups had started was a little easier though still often difficult for professionals trained to be caseworkers or group workers. Background support could take a number of forms. A social worker's long term commitment for example was much appreciated by an Asian single parents' group. Kaneez, a leading member of the group, spoke warmly of Ruth's support.

"I don't know loads of things - she tells me how to cope with certain kinds of situations. She's very good - you can get advice on everything."

Ruth, who also took part in the study was very clear about her role. She saw her link with the group as having potential for mutual benefit while recognising their autonomy.

"The group is part of the centre, but with a degree of independence. I don't attend the group. I've talked to them for mutual help and advice - I ask the leader for advice on problems I'm coming across, she might ask me to recommend speakers."

David, a community psychiatric nurse, had been involved with a group of people dependent on tranquillisers when it began. He defined two further stages of support: first, being used regularly by the group to check out if what they were doing was okay; and later, when invited to come to a meeting occasionally "as a guest" as he saw it, responding and helping with whatever was the current problem.

One form of support could stem from a professional helping the group clarify what it was doing. An experienced social worker regularly asked a group what they were there for, who could come and so on. While this helped him with the process of telling clients about the group, he felt it could also alert a group to the need for clarity and for self-evaluation. While it was not known if his gentle and acceptable questioning had influenced the group, this particular group of carers were the only ones who had analysed their membership list by postcode. This had resulted in awareness of the lack of members from the inner city, questioning why this was, and discussing ways of reaching out to people not at present coming to the group.

Formal roles could sometimes work. Cancerlink (1993) suggests that some groups may wish to have a formal medical adviser. The Alzheimer's Disease Society asks groups becoming a branch of their organisation to invite professionals onto the committee. A tranquilliser support group member found this practice inhibiting. Pamela recalled:

"When I first got on that committee, I wouldn't open my mouth. He scared me to death. I was terrified of him and I still feel a bit intimidated by him now. You don't like to speak up in case you make a fool of yourself."

Formal roles were rare in the groups in this study, and comments such as Pamela's suggest they may not be appropriate. Many did, however, value and use the less formal support given by a wide range of professionals. Box 4.2 summarises relevant issues, some similar to the approaches needed for helping groups begin.

Fig 4.2 **Practical resources acquired via professionals**

Meeting rooms

Storage for group's library of books

Access to grants

Help with filling in application forms

Place to hold fund-raising events

Speakers at meetings

Use of notice boards

Photocopying

Box 4.2: Issues relating to ongoing support

Mutually agreed arrangements, not defined solely by professionals.
Reviewing and changing roles, with the option of involvement ending.
The length of time a professional was committed to a group.
Being clear about the difference between providing information and intervening in the dynamics of a group.

While few professionals had community work skills, many had personal qualities - warmth and trust in clients being examples - which meant their support was welcomed and helpful. Some could be described as specially skilled professionals, with a high but often unconscious level of knowledge and ability. They were a group to which I shall return in Chapter 5. Whatever the level of ability, there was without doubt a role here for some professionals and in some groups.

Access to practical resources

Giving access to practical resources was another form of support. It was sometimes more manageable than support which required such a delicate degree of involvement with the group. Fig 4.2 lists the ways in which groups said they had benefited from practical resources.

Few professionals in the study mentioned giving such help. Perhaps many arrangements were discreet and could have been challenged if over-formalised, or help had become so much part of the system that people may just never have thought to mention it. Self help groups, however, spoke warmly about all such forms of practical help and many had benefited from it. The theme of appropriateness returns, however. Access to meeting rooms is an example of different practices being appropriate for different groups. While a Twins Group secretary urged the regular use of free rooms at a hospital, Kathryn in a parents' group had found this inappropriate.

"Although the support group began at the hospital, we don't meet there any more. Professionals were also coming to the meetings. People thought, well, if they are there I'm not going to be there. It put a lot of people off."

Apparently simple matters, like access to notice boards, were also more complicated than had been thought. A Down's syndrome group had experienced problems, as Jo recounted.

"It's a known fact that GPs don't like our posters, because it upsets the ante-natal mums. Which you can understand in a way, but there again, these things have to be faced."

Kathy, from an Eating Disorders group, felt antagonism to the group could also be a cause.

"There was a particular doctor at the hospital who refused to put a poster on the notice board, because he did not believe in self help groups. He said people would pick up bad habits from each other."

Good practice by professionals towards self help groups should certainly include giving access to practical resources. As the posters stories indicate, the differences between the two worlds and tensions between them means that provision is rarely straightforward. There is also the principle of choice, for groups wanted to be able to choose whether and when they used practical resources. What was needed was access and information, so that their choice was an informed one.

Attending meetings and giving talks

Three different patterns of attendance by professionals at group meetings were identified: regular attendance; intermittent visits; and open meetings, publicised to outsiders. All could be a means of support and development.

A variety of people came to group meetings. Some were professionals with a strong link with the group or interest in the issue it was based on. Their role was sometimes as invited speakers, singly or on a panel. A few groups mentioned researchers and students attending. Some groups felt these sorts of arrangements worked well and saw a number of advantages. Professionals got the chance to understand the problem on which the group was based better for example, and to see the group in action.

A health visitor mentioned another sort of benefit. She had been able to advise a group on how best to approach the authorities when they were discussing making a complaint about poor services, by giving a quick, informal piece of information.

Groups which had a pattern of speakers found people largely happy to give talks. A Back Pain group, for example, found the willingness of consultant surgeons and complementary therapists alike to give talks very supportive and useful. While having professionals as speakers normally worked well, an ME (Myalgic Encephomyelitis) group had not liked one speaker's patronising attitudes. He had left them feeling belittled.

"It seemed to me he was giving a talk he had given to some students or doctors. A lot of it was in jargon. It was almost as if we were disparaged, because at times he was talking about 'they'. He did pull himself up once and said, that was 'you', but it was almost as if he had forgotten where he was."

The experience of the Nottingham Self Help Team suggests that professionals can make assumptions that their presence is always welcome. The Team was asked for advice by a small bereavement group. It emerged that the group had not realised they could ask an over-supportive professional to stop coming to their very intimate meetings, where her presence was affecting the process of sharing grief. An eating disorders group found so many students doing projects turning up as observers at meetings that these too were distorted. They were reluctant to turn them away as they wanted them to learn.

Two concepts often seemed crucial when professionals were attending meetings: "invitation" and "guest". If the arrangements for attendance, occasional or long-term, were controlled by the group and the professional appreciated their role as guest, then it worked very well. This could mean professionals having to ask permission beforehand and accepting a refusal graciously. Professionals who "think they are God", as one group termed it, may find this difficult.

Figurehead

A figurehead, being a medical president or professional adviser, was a role played by professionals in a small number of groups. This role was seen by some self help groups as appropriate and helpful. Some groups maintained interesting balancing acts, having a strong sense of control over the group themselves, combined with formal office holding by professionals. A chronic pain group had found this useful when fund-raising.

"If you can get them involved, their name on the letterhead, this does add credibility when you're writing letters."

This would be anathema to some self help groups. Twelve-step groups, based on the principles of Alcoholics Anonymous, for example, have traditions which mean such roles would never be taken. Some formally structured groups, however, often affiliated to a national self help organisation appeared to find this a useful option.

We return again to the need for choice and flexibility. Taking a figurehead role could be useful, but probably not very often. If professionals undertook such roles, it worked best to carry them out as a way of lending credibility to the group rather than a form of control.

Dilemmas and tensions

Supportive roles, when undertaken sensitively, could help the initiation, maintenance and development of groups. If professionals had appropriate attitudes, many groups welcomed such forms of support. But a number of dilemmas and tensions again surround the relationship and make practice less straightforward than might have been presumed. Four particular difficulties have been identified.

Community work skills

Professionals are trained and skilled in one to one support to individual clients and patients and their families. Community work skills are rarely part of a repertoire, yet if professionals are expected to support self help groups, these skills are what are needed. It is not an easy job to support, as distinct from lead, a group. Instinct and experience outside professional roles can mean the limits of training can be overcome, but for most people this is a challenging and often stressful role. Some, indeed, recognising its difficulties, decline to take it on. Others do not perceive it as relevant to their jobs.

Enthusiasm

On one hand, professionals enthusiastic about self help groups can take too great a role in initiating a group. Unless its potential members feel the need for a group and that they "own" the group, it can be seen as belonging to that worker. On the other hand, if an attitude of "this is nothing to do with us" is consistently maintained, opportunities to foster useful developments could be missed. Both the degree and timing of involvement are difficult issues, not always appreciated as being important and not always approached correctly.

Over-involvement

Boundary lines between giving too low a level of help, or none, and giving too much are blurred. Professionals wanting to be helpful face a problem of understanding and working within such boundaries, even when they appreciate their existence. Groups do not always appreciate that they can set limits. Systems of re-evaluating involvement rarely exist.

Time

Professionals faced with heavy case-loads have to make decisions on how best to use limited time. The dilemma of investing time in activity which may have only long-term and unmeasurable results is one which faces all networkers, acting as a brake on joint working generally. Evening meetings bring additional tensions for people with family and personal commitments, an issue recognised by group members. Time off-in-lieu arrangements could lead to cuts in services for individuals. Unless work with the group was planned by managers as part of a worker's responsibility, there was no easy answer to the problem of limited time.

Underlying principles

Like putting people in touch with groups, support and development proved to be a complex issue, subject to a variety of tensions and constraints. Martin, a psychologist with substantial experience of working with mental health groups, summed it up:

"It's always been a difficult thing, managing the relationship. It's very easy to control that group, if you want to or not. That's one side of the coin, the other side is not being involved at all. Actually managing the relationship, where there is liaison, communication, access, general awareness of what is going on in the group and contributing to that, in a healthy kind of way - but not getting too involved so that you are encouraging dependence, or get in a position where you're in control - is very difficult."

A further publication giving more-detailed guidance to professionals will describe these difficulties more fully (Wilson, forthcoming). Certain underlying principles can, however, be drawn out, summarised in Box 4.3. They give a foundation on which practice can be based, and raise issues which have implications for how professionals are trained and their jobs structured.

Box 4.3: Principles underlying effective support

Attitudes which value and acknowledge the ability of people to run their own groups.
Acceptance that self help groups can choose what forms of support they use, and from whom.
Seeing the likelihood of mutuality in the relationship.
The need for reappraisal and renegotiation of roles.
Practice tailored to suit the situation of both group and professional and the issue on which it is based.

Conclusion

The issues raised here are not exclusive to the two worlds of self help groups and professionals. Recognising the limits to which people from one world can help those in another is a basic challenge to anyone involved in community development. The evidence from this study would seem to suggest that, in the self help field, professionals can play a role in support and development and that many self help groups welcome this. Support is valued as a form of validation as much as for its practical benefits.

However, it is both complex and difficult, needs constant review and IS not always appropriate. It is asking a lot for professionals trained to work with individuals to undertake such roles without further training or support. Getting the balance right, as the psychologist felt, is not easy. If too little help is given a group may falter or fail; if too much, it may become dependent or alienated. Much more could be done to alert professionals and self-helpers to possibilities and problems and in sharing good practice in different areas of need.

CHAPTER 5: PROMOTING SELF HELP GROUPS

It could be argued that it is the responsibility of members of a group to promote its value and benefits. Self-helpers in this study did accept the job of advertising their group. However, they welcomed people and agencies outside the group who also took on a promotional role. An alternative argument might be that if public authorities feel self help groups provide important help, then general publicity and endorsement should follow.

Some professionals in this study agreed and there were many examples of good practice in this aspect of the relationship. This chapter outlines ways in which professionals promoted self help groups and discusses what holds back their promotion by professionals. The contribution of specially skilful professionals to this and other ways of working with self help groups is also raised.

A three-pronged approach

Promotion of groups is not simply lauding them. It involves telling people they exist and what they do, outlining the benefits of belonging and their limits, and clarifying misunderstandings. A three-pronged approach appeared to work well, for groups, self help projects, and professionals could all contribute to the promotion of groups. Their individual efforts complemented each other.

First, self-helpers were keen to promote their group.

"It's a case of the group selling themselves.",

Judith from a Twins group was one of several people who used such phrases. There were reports of a number of imaginative methods that had been adopted. Discussion about the difficulties of putting these into practice demonstrated, however, the limits within which they worked. A member of a small, new, eating disorders group pointed out their particular problems.

"There have to be a lot of members willing to do publicity."

It could work well for a time, and then end. Lynne from a parents group had had this experience.

"We had a brilliant local co-ordinator who became burnt out. Another took her place who hasn't got the same enthusiasm and time to give to the group."

The general limits of groups will be discussed in Chapter 7. Confidence, essential before one's product can be sold, was one particular hurdle in promoting groups. Lack of access to, and understanding of, professional structures was seen as another problem.

Self help projects provided a second means of promotion. Half the interviews in the study were in districts where the health or social services authorities had funded self help workers or teams. Both group members and professionals mentioned such projects, many speaking appreciatively for example of the value of their directories of groups. Groups had benefited too from jointly organised publicity events. Murray, a social worker, saw centrally provided information and promotion as essential.

"Information promoting can't be a function of a self help group - publicising themselves is often just too much for them. Organisations of voluntary organisations are needed to do that."

This study showed there was, third, both a role and suitable methods available for professionals to help too. Promotion could mean promoting individual groups, or groups generally which related to the agency. It could be carried out by individuals or a whole agency. In this chapter this third approach is outlined and discussed, recognising however that this may well only be part of the picture.

Promoting groups: the professional role

A number of different methods had been used, summarised in Box 5.1

Box 5.1: How professionals promoted groups

Getting groups to give talks
Noticeboards
Inclusion in handbooks
Giving opportunities for fund-raising on their premises
Individuals challenging doubtful colleagues

Talks by groups

A member of an Ileostomy Group had tried to get herself invited, and had felt rebuffed.

"I've written time and again to the administrator and I can't get a reply. Nobody will even acknowledge the letter. It's very hard to get a foot in the door."

Several groups mentioned a similar lack of success in getting invitations, but 13 groups, a quarter of those taking part, had given talks to groups of professionals. Sometimes this had been to inform the audience about the conditions on which the group was based - more of this in the next chapter - but even if this was the focus of the event, it still enabled people to learn more about the group and its activities.

A group of health visitors had found this method very useful.

"Staff didn't know very much about epilepsy, so we requested that they came and talked to us as a group, so that everybody got some information - so it made it very worthwhile."

This health visitor suggested there should be regular invitations to groups to attend staff meetings to talk about what they did.

It had not always been easy. The health visitors identified a number of difficulties groups had to get over: whom to contact to arrange talks, what was possible, overcoming lack of confidence and risking rebuffs. Another felt:

"Don't you think people in self help groups stand in awe of professionals, are a bit concerned how to approach them, concerned about the reaction they will get? I would think they have not had a terribly good deal before."

A twins group reported a less-direct and very successful approach. Their regional organisation had undertaken a survey of professionals asking what they needed to know.

"They're obliged to tick boxes - would you like more information? Would you like a talk? The net result was that we're going to do 50 talks in that area."

On the whole, however, the likelihood of groups being able to find the right people, and always being confident enough to claim the time, seemed doubtful. Two methods seemed to work: the indirect, sounding-out approach of the survey, or professionals taking the initiative. Professionals taking the lead helped, but not only for practical reasons. Groups perceived invitations as a form of validation of their contribution. Even the more confident members valued any form of endorsement of what they did, and the more encouragement they got, the more they felt able to carry on with and extend the work of their group. In contrast, rejection could leave them dispirited.

Noticeboards

The usefulness of noticeboards in helping people to find out about groups was touched on in Chapter 3. Noticeboards were also useful in promoting groups generally. Access to them seemed to be easier when there was a clear focus to its subject, a board in an antenatal clinic about parents' groups, for example. Some displays might be broader but relevant, such as noticeboards specifically dedicated to community information.

Refusal of permission to display a poster showed the significance of noticeboards. The Eating Disorders' group's story in Chapter 3, of the doctor who felt it would lead to *"people picking up bad habits"* was one example. A Down's syndrome group and a parents' drugs group had also been refused permission, because of the issue on which their groups were based.

Access to noticeboards could be seen as endorsement or disapproval of an activity. Sandra, a twins group secretary, returned later to see if their poster was still up in a health centre. It was no longer there.

"[The notice board] was full of different things, there was one about a private nursing home which I found very strange. It made me quite grumpy actually, to think they'd taken down our poster and they'd got a private nursing care poster up - in an NHS surgery!"

Providing noticeboards dedicated or readily available to groups, was seen by groups as a small but significant action. Noticeboards were an easy way for professionals to promote the idea and existence of self help groups. Perhaps they were also a weapon? In denying access, were people hostile to self help groups refusing endorsement? More likely, publicity outlets like this were not clearly understood by staff for what they are and can be. Lack of clarity, time, money and effort was a more probable reason why access was sometimes difficult.

Handbooks

Inclusion in handbooks was mentioned less often, but was also a form of endorsement. Handbooks for mothers expecting babies, and in large print for people who were losing their sight, were two examples. In both publications, given out as part of a system to everyone in touch with the agency, information about self help groups was included and people's attention was drawn to it.

Some national organisations had seen opportunities provided in legislation and felt this had led to information being made available more widely, if not always very effectively. The Children Act 1990, for example, mentioned earlier, specifies that information on services should be provided to parents of children with special needs. If self help groups are considered to be services, then this information ought to be included.

Handbooks that contained self help group information were a way to endorse and promote their value. Including them alongside information about professional services demonstrated to groups the importance an agency set on their contribution.

Opportunities to fundraise

Welcoming other people onto your patch and to use your facilities indicates willingness to blur boundaries, share resources and endorse activities. A small number of groups had welcomed the opportunity to raise funds through holding events on professional premises. An amputees group contrasted an unsuccessful event at a shopping centre with efforts at a hospital.

"Fund-raising we have done at the hospital has been brilliant, we've always done great. Everyone knows you and they are used to seeing me walk about. The nurses will come and the doctors will come and everyone will come and have a chat."

Fund-raising events gave a chance for people from the two worlds to intermingle. Groups felt it was an endorsement of their work and they gave an opportunity for a wider section of people to meet members than might normally happen. It was not only the ease with which the money was raised, it was an opportunity to be visible.

It was also an opportunity for individual professionals to demonstrate their special support for a group. A social worker could never get to meetings, but wanted to help.

"I was happy to bake a cake."

There was not a lot of evidence of this in this study, but the Nottingham experience both confirms the general value and demonstrates the subtleties that may lie behind the practice of fund-raising on professional ground. One group had used it deliberately, for example, as part of a quiet campaign to get services radically changed. On the other hand, fund-raising on professional premises could also lead to manipulation. A consultant, much appreciated for his skilful care of people as patients, put pressure on a group to direct their fundraising to benefit his own research. While fund-raising on professional premises was an opportunity, it could at times also be a threat. While groups might want to contribute money to hospital activities, it had to be their own choice.

Challenging doubtful colleagues

A final method used by professionals to promote self help groups was rather different: challenging doubtful colleagues. A handful of people in the study clearly saw themselves as "product champions". They supported groups systematically, regularly fed information into their team, initiated talks - and they challenged statements with which they did not agree. David, a community psychiatric nurse was one.

"Some people say: 'They don't know what they are doing; they don't have the training; I can do it better'. I always make comments back to the contrary."

People who felt able to disagree with their colleagues were showing confidence in the product - the self help group. But also, perhaps they could appreciate that a period of turbulence in the relationship before real co-operation could emerge had to be weathered. Smoothing tensions over, or, for example, using bland words such as partnership when it does not really exist are not helpful in the long run. Parallels can be drawn with combating racism and sexism. A stormy period may be needed before real change can take place.

The product champion could well be important. Self-helpers are constrained by being both users or carers, and also members of a self help group, often a difficult dual role. Many also lack confidence. Nor indeed are professionals likely to criticise them face to face.

Not enough is known about how many professionals saw themselves in this role of product champion, but those who undertook it seemed to be playing a significant part. This period of the relationship between self help groups and professionals may well be one of transition. A period of debate and greater openness about tensions may be needed before real co-operation can take place. Professionals who challenged colleagues' views appeared to make debate possible in a way self help groups could rarely do.

Specially skilful professionals

Being a product champion was a task taken on by some of the small category of people described in Chapter 4 as specially skilful professionals. They belonged to no one particular profession. They all, however, took action which had substantially benefited self help groups and saw it as part of their professional practice. Specially skilful professionals merit a special look. They promoted groups, supported them, systematically put people in touch with them and were clear about the relationship.

David, the psychiatric nurse quoted above and elsewhere, provided one example. Ruth, an African-Caribbean social worker who supported an Asian single parents group (Chapter 4), was another. The practice of three other professionals illustrates this theme further.

Hospital nurse

A cardiac support group spoke consistently of the good relationship they had developed with a Sister on the coronary care unit. Dora, who had responded to a request for support in the local paper, spoke of her enjoyment of her contacts with the group. But it was not just a form of voluntary work, though extra hours were needed. Dora could also see the value for the hospital.

"Psychological care is very lacking. Patients can be petrified when discharged - they can be readmitted because they felt they had had another heart attack, when all it was was twinges. If they could see other people who had had the same thing, they would feel more able to cope and some readmissions could be avoided."

She was very clear about why she supported the group, had been able to change her role within it when needed and had made a long-term commitment to working with the group.

Specialist health visitor

A parents' group warmly praised the sensitivity of a health visitor and valued the consistency of her support. Beth worked in the community as a specialist health visitor. She had identified all the groups in the locality which related to her particular field of work and had developed and then maintained links with them all. Beth found it useful to listen to group members, and to know what they did.

"It is a learning process for me to go along. We get a lot of value out of going to the groups - it is not just being there to give support if it is required."

Beth had an awareness of the special knowledge held in the group. She saw opportunities through their speakers to extend her own knowledge. By putting her clients in touch with groups, she saw herself as giving them, too, a chance to learn.

Social worker

A carers' group had had a lot of support from a social worker when they had started. They spoke appreciatively of Murray's help. When he was interviewed, his realism was marked. He valued the group but this was matched with a down-to-earth approach about the limits to groups, and the need to take a 'warts and all' approach. Murray was very clear about the need for the principle of giving information to clients and helping them make their own choice about going. He pointed out the risk of appearing to impose a professional standard of competency on a small, informal group.

"If the group was just a bit vague or naff, then it would be up to the client to decide. The perception of professional or self-helper on what is useful or not can be different. There might be a need for social contact, for, say, tinnitus sufferers, even if the group was not very competent about the actual tinnitus."

His skill stemmed from his clarity on the difference in roles and standards between the contributions of self help groups and professionals. Murray, like the other specially skilful professionals, had a strong awareness of the difference between the two worlds.

Training and past relevant experience sometimes appeared to have an influence. Murray, for example, came from a community work background, and had incorporated these skills into his casework job. No other people in this category mentioned having had this type of work experience or training. Instead they seemed to know instinctively what best to do and to understand the nature of self help groups naturally. They appeared to have what Andy Farquharson, a Canadian researcher, called "an unconscious level of knowledge" (conversation August 1992).

Characteristics

To summarise, these and other specially skilful professionals shared these characteristics:

- they valued the knowledge and ability of clients and patients, individually and in self help groups, and were aware of the limits to professional care
- they were clear about their role as professionals, about ownership of the group by its members and the need to set limits to professional involvement with groups
- they were aware of the limits of groups and the difficulties involved in running them
- they committed time, in and out of working hours, to develop and maintain relationships and knowledge

A number of questions arise. How far were they influenced by personal experience rather than training? To what extent did their skills stem from instinct and attitudes? Could such skills be identified and used as the basis for training other professionals? Further research to answer these and other questions could be useful.

Committed agencies

A step further from skilful and committed individuals were committed agencies. Two agencies provided illustrations of organisations who appeared to appreciate the contribution of self help groups. They understood how groups were part of a spectrum of care and what action was needed to make working relationships effective.

Two examples were a mental health team and a drugs counselling centre. The mental health team worked in a rural area with long traditions of services based in the community rather than in hospital. The team was set up on principles of enabling users of services both to have a watchdog role and to contribute to care. Substantial sums of money were put into a resource team to develop groups and to ensure the casework team had easy access to information. The organisation felt stable and had operated in this way over a number of years. Its leader, a psychologist, had particular insight into how self help groups worked, but there was clear commitment by the whole team, not just individuals within it, to valuing and working effectively with them.

Deborah, a member of a group of parents of children who took drugs, described the team of workers at a drugs counselling centre in an urban area.

"It's freedom of choice. The people that come in there are not told they have got to come off drugs, they are told - if you are going to use it, then use it this way, it's safe. I think that's what makes it easier for us to work there, because it's all freedom of choice. If a third party rings there they are automatically given our number, it doesn't matter if the person on the phone thinks they need that help or not. They (the staff) will say, there is a support group, here is the number. But you can still come in here if you want."

While the group was thinking of moving its base to become more independent, this consistent endorsement of their work was very important to them.

Agency commitment may be contrasted with the work of the specially skilful individuals. They might often be the only persons in their team who gave time to working with self help groups. Committed individuals and committed agencies were likely to share the same values and attitudes. The difference was that promotion of groups - and supporting and providing information about them - became institutionalised and reliable when an agency as a whole was committed. If the agency was committed, when a member of the team moved on, knowledge was not removed with them. Groups could approach an organisation rather than an individual. Information and support, integrated into the services of the organisation, became a form of endorsement and promotion.

Factors that affected practice

A number of factors affected the practice of promoting groups, positively or negatively. This could be seen in both individual and agency practices.

Factors that helped

Six factors that helped professionals take a role in promoting groups can be identified, some of these being similar to those drawn out in discussing other aspects of the relationship.

- individuals' values and attitudes to both patients and clients, and to self help groups
- awareness of the complementary nature of self help groups' contribution
- professionals identifying specific benefits to statutory services from clients' involvement with groups
- statutory requirements to make information available
- access to up to date information about groups
- the culture of attitudes and practice within a team

Constraints on promoting groups

Several problems seemed to hold professionals back from promoting groups:

- the dilemma of appearing to recommend groups when not a lot of information was known about them
- the uncertainty of whose responsibility it was to promote groups
- lack of appreciation of the limits on groups' abilities to promote themselves
- unwillingness to let tensions be identified, to surface and to be faced

Conclusion

I return again to the need for a three-pronged approach to the issue of greater promotion of self help groups. There are changes and approaches groups could adopt, to be included in another publication arising from this study (Wilson 1994). Their limits, however, need to be recognised.

Professionals do have a role to play in promoting groups and a policy which aimed to increase the contribution of self help groups to care would need to endorse this role. Specially skilful professionals provide examples of good practice already. If real change is to take place, however, an agency or organisation has to become committed to promoting groups, not just individual workers.

There is a limit also on the extent to which most professionals can be expected to undertake this work, even if they have the skills. Their jobs are largely to provide services to individuals. The need for a certain distance between the two worlds suggests also that too great an endorsement of groups could lead to co-option. A self help project, or a worker with a brief to support self help groups, would ideally seem to be needed as well. Their resources and neutral but respected position can complement the efforts of both self help groups and professionals in promoting groups.

CHAPTER 6: INFLUENCING HOW SERVICES ARE PROVIDED

Providing mutual support and information was seen by groups as their prime functions. None of the groups who were interviewed saw campaigning and influencing how services were provided and planned as their main job. Many voluntary groups exist, of course, often also run by people who have experienced the problem themselves, which are primarily campaigning and advocacy groups. Many authors have written about their role for example Croft and Beresford 1993, Rigge and Cole 1993, Morris and Lindow 1993.

While none of the groups in this study saw it as their prime function, about a third of them welcomed the chance to influence services, especially if it was integrated into what they wanted to do. The rest, perhaps seeing it as a diversion away from their main aims, wanted neither to take opportunities nor initiate action. A survey by Cancerlink of the activities of cancer support groups confirms this as very low on the list of how members of cancer groups wanted to spend their time.

Four experienced university researchers, all knowledgeable about the voluntary sector were asked their views on the role of self help groups. Three out of the four identified commenting on plans and operation of statutory services as a very important function. One saw it as their prime task. His views were expressed so forcefully that the question of whether self help groups were at risk of being commandeered in the current enthusiasm for getting users' views became an issue for reflection.

Professionals varied in the extent to which they mentioned this role. A few voiced regret that self help groups did not do more, seeing them as ideally placed to influence services for the better. Others had found ways to draw on the knowledge and experience of group members without diverting them from the group's main emphasis.

In this chapter, ways in which group members had influenced ways in which services were provided are outlined. The common threads there seemed to be when this had worked well are identified. While the current climate may offer opportunities, there are also threats. These too are explored.

How groups contributed

Interviews with groups were held in the summer and autumn of 1992, by which time consultative procedures on community care plans were in place. The whole move towards involving users and carers had a public momentum. The emphasis of the research, however, was not on consultation procedures on community and health care. It was on the relationship between local self help groups and local field level professionals. People in groups had a lot to say about professional practice, as it affected them individually. Very few, however, made a connection between day-to-day services and how they were provided, with the opportunities there were for involvement in more-strategic planning.

This did not mean that self-helpers in this study were not influencing how services were provided, but it was usually quietly and informally done, and outside any formal pattern of consultation. Secondly, it was more likely to be geared to improving the quality of service at a field level, rather than influencing strategy. It came about in four different ways.

Box 6.1: How self help groups influenced services

Educational campaigns
Being invited to give regular talks
Involvement in specially organised events
Informal feedback

Educational campaigns

While groups often talked about the lack of awareness of the problems they experienced, it was rare that they mentioned undertaking educational campaigns. A woman whose daughter and granddaughter were both affected by epilepsy was an exception. Rachel was angry, vociferous and confident. She was also an energetic member of a national association and had become an official speaker for them, taking an educational video round to teachers and to doctors.

"It's imperative that we have groups and get together because the stigma attached to epilepsy is tremendous still. Our main aim is education."

Other groups acknowledged the climate of lack of understanding they worked in, in both their communities and the professional world. No others apart from Rachel mentioned battling to educate and change attitudes as a main aim. One member of a group for people with restricted growth had, however, appreciated a chance she had been offered.

"It's wonderful. I went to do a video for television and a teacher used it in her class - so I'm educating a professional and I've also educated a class of children without knowing it."

Giving regular talks

Self-helpers liked to give talks. Talks validated their experience and expertise and gave the opportunity to influence professionals. The willingness of group members to give talks when invited, mentioned in the previous chapter, showed how comfortable they felt about this role. One group, based on mental health, undertook talks very regularly. They received a £50 fee for their group each time. Another group, concerned with bereavement, had turned such interest into an opportunity. Their main income-generating activity each year was an oversubscribed course on counselling. They charged a proper fee, made a substantial profit - and also influenced professional practice.

Groups did not always get paid and sometimes felt taken for granted. A diabetes group was finding that nurses were coming to them for talks on a common condition too often for comfort.

"We actually train nurses. Nurses come to us for talks. Why aren't they getting that through their own training?"

Special events

Two groups mentioned specially organised events, planned as training days for professionals. Mary, a member of an ME Association (Myalgic Encephalomyelitis), spoke warmly about their event.

"We have very good links with the occupational therapists. In fact, we went and did a training day and now the service is much better informed [about the condition] than it was."

Professionals took the initiative. Group members were involved in both the planning of the day and in contributions as speakers. Members of groups based on conditions which are not well understood, like ME, may have a special contribution to make in this way. A one-off event did not put a burden on a small group whose members by definition had little spare energy. They perceived that greater understanding of their situation and needs was probably an essential first step to getting better services, and they gladly took the opportunity to improve this.

Informal feedback

A handful of professionals mentioned attending group meetings to get informal feedback. They wanted to know whether the help and information they were providing were what was needed. Managing diabetes was one area where this seemed to be acceptable and to work without intruding on the process of the group meeting.

Some interesting questions arise. Does the nature of a condition like diabetes, where those affected are closely involved in their own treatment, affect the nature of the contact between the group and the professional? Did the ease with which professionals participated in this particular group result from their ability to play an acceptable role? Or was this group just happy to be used in this way?

Katherine, a physiotherapist working with arthritic children, was aware, however, that it could be more appropriate for her to be absent from meetings sometimes. She very much valued the opinions of parents in the group and had a close and effective working relationship with them. Providing a high quality service was very important to her.

"I use the group as a forum to discuss my ideas. Sometimes the group leader raises them in my absence and then feeds back the group's opinions. I've done questionnaires, but it's a more honest opinion when it's from the group."

She was aware of the difficulty that individuals could have if she were present when they discussed her service. They were in effect making critical comments on the work of someone whose help they both appreciated and depended on. A degree of anonymity was very helpful to get over this problem.

Common threads

Compared with the formal consultative procedures often used by health and social service authorities, these opportunities to influence services seemed relatively informal. Group members talking about them sounded relaxed about their involvement, comfortable with their style. There were other factors that seemed to help, summarised in Box 6.2.

Box 6.2: What helped groups influence services

Professionals showing they valued experiential knowledge
Professionals making time to listen
Paying groups for regular and sustained contributions
Joint planning of events, not top-down organisation
A scale compatible with the group and its other activities
Self-helpers having enough confidence to take part

Where these factors existed, group members welcomed the opportunity to influence how services were provided. Compared with their other activities, however, it was low down the list and for some was not of interest at all.

Threats and opportunities

Groups welcomed small scale activities compatible with other tasks of the group, seeing them as an opportunity. But the emphasis given by statutory authorities to getting users, and carers, views as part of a needs-led service, may well bring threats, as well as opportunities. The evidence in this study suggests that both can exist. Exploring the question with national self help organisations confirmed this feeling.

Threats

A consultative meeting with national self help organisations came to a firm conclusion. Their experience was that there was indeed a risk of self help groups being used by others to further their own purposes. It was agreed that there should not be an expectation that they were a resource, ready and waiting to be used for consultation.

A further threat, also confirmed by national experience, was to group members' energy and time. If groups were expected to put substantial time into meetings and reading papers, this could lead to a diversion from their main objectives and a (perhaps unwitting) co-option to further professional aims.

A third threat could be to professionals. Professionals who were confident about their role and welcomed client feedback had few problems. Groups, however, felt that this could be an issue. As many as a third of the groups speculated that their existence and activities generally could be seen as a threat. In theory this could be an issue in this aspect of the relationship. In practice, there was comparatively little evidence of professionals feeling threatened.

Opportunities

There are differences when self help groups, as opposed to individuals, take on the role of influencing professional practice and services. Some of the potential threats to both professionals and group members are diminished. Comments can be made impersonally, from the group as a whole. The high level of personal self-confidence and willingness to take risks that an individual needs are avoided.

Raising confidence levels was identified by group members in Chapter 2 as a valued benefit and the importance of raising people's confidence may be insufficiently appreciated. Fig 6.1 summarises the different levels of contribution there can be to influencing service provision. As levels of confidence increase, group members, it is suggested, are more likely to move up a pyramid of involvement. A self help group may well be very important as a seed bed for increased confidence. As members feel more in control of their own lives and learn new skills through participating in a group, they may then feel ready to take on roles such as those described above - giving talks and so on - in influencing how services are provided.

In Chapter 2 there was also discussion on the value group members placed on being helpful to other people facing the same situation. Preventing distress was a common theme. Recognising this motivation may be a first step. Providing appropriate ways for self-helpers to do something constructive is a second. Emphasis on involvement in planning may have meant less attention to users and carers commenting informally on how services operate on a day to day basis - and hence a missed opportunity. There is real potential for more of this to take place, involving more people and minimising threats to groups.

The pyramid of opportunity

This question of how self help group members might influence how services are provided is not easy to portray simply. Fig 6.1 sets out how it might be seen. There is a range of opportunities available which groups can choose to take. They require different levels of confidence, time and energy.

Fig 6.1 **The pyramid of opportunity: How self help groups can be involved in influencing how services are provided**

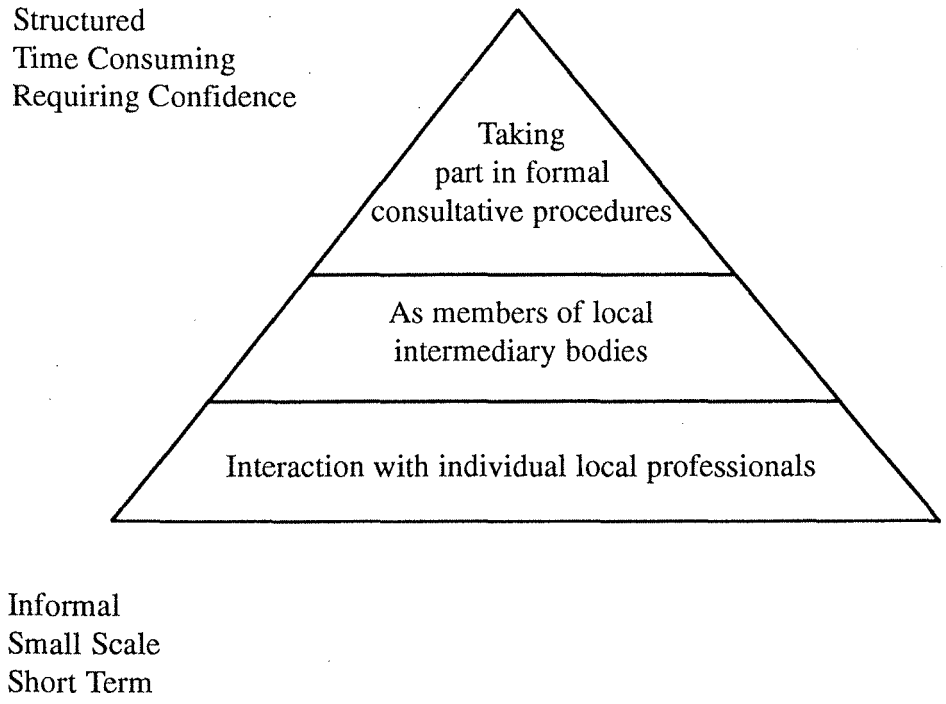
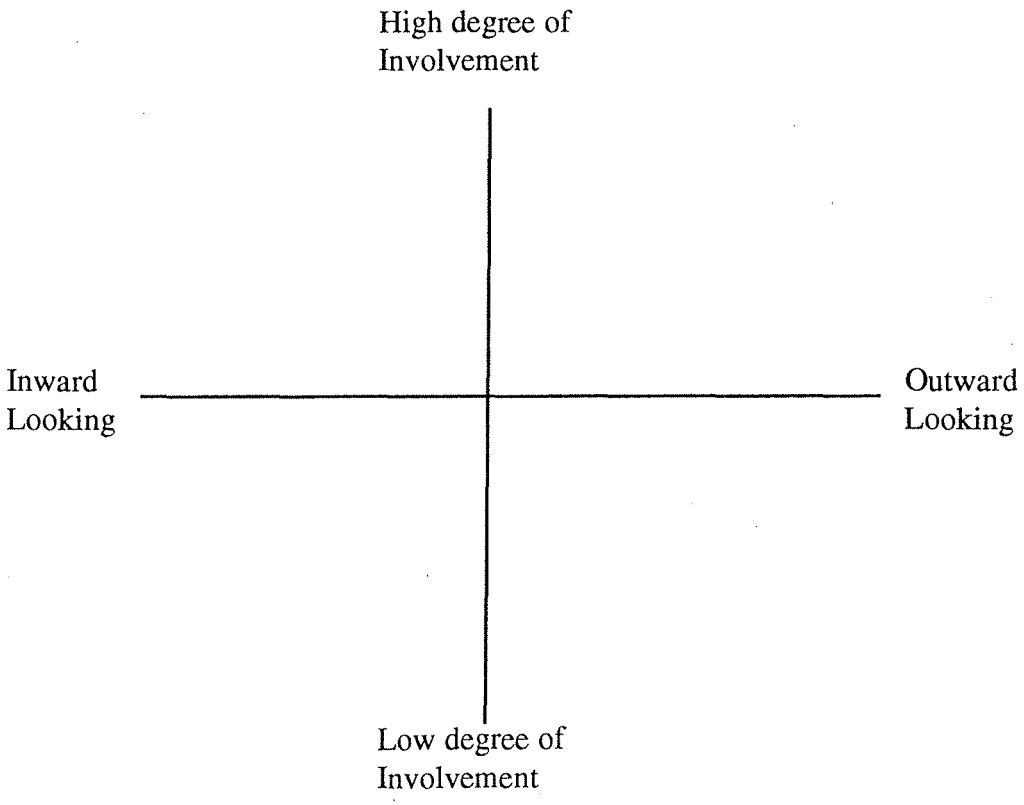


Fig 6.2 **The focus of self help groups and their degree of interest in influencing how sevices are planned**



The bottom segment of the pyramid, interaction with individual local professionals, has been described above. The middle one, groups as members of intermediary bodies, was only mentioned occasionally by groups in this study, but has been seen to work effectively in Nottingham and elsewhere. A long-established mental health forum, for example, is attended by a number of self help groups in the mental health field, few of whom would want to take on more-formal commitments. Carers' forums have provided the same intermediary function in many areas.

This again was not an issue which arose in the interviews for this study, but the top component of the pyramid, formal consultative procedures, may be attractive to some self help groups. Formally structured, well-established groups, whose members have developed in confidence, may well choose the top level of opportunity. District and specialist planning teams, special working parties and membership of Community Health Councils all provide opportunities which self-helpers have taken.

It is important to emphasise again the need for choice. There cannot be assumptions that this is what self-helpers necessarily want to do. The point, throughout, is to maximise opportunities and minimise threats.

Inward-looking and outward-looking

Many groups choose to concentrate their efforts on the needs of the individuals who actually come to the group, to focus on personal rather than political change. This has to be seen as a strength, not a limit, to be endorsed and supported. Anything which distracts a group from the role they have decided to take is co-option to someone else's objectives.

Other groups, however, move from one stage to the other. It is quite common for groups to begin with members sharing their personal situation. They then may change to having a wider vision, an awareness perhaps that "the personal is political". Individuals in a group vary. People who are coping with life better, for example, may welcome what might be described as a self help career, and find working for change in the outside world a fulfilling personal experience.

Fig 6.2 contrasts the focus of self help groups and their degree of interest in influencing how services are provided. Groups with a strong emphasis on being outward looking, and with opportunities to take part in consultative processes, are likely to be clustered in the top right quadrant for example. Understanding the nature of groups, and the character of any individual group, may well be essential for authorities who wish to involve groups more in consultation and comment.

Conclusion

Self help groups encompass members who join for individual self help, others who want to help other members, and yet others who want to influence services and campaign for change. With this proviso, they may be seen as part of a broad consumer

movement. Most members in this study would probably welcome the move to services with a greater emphasis on the needs and views of users and carers. There needs, however, to be greater awareness first of the threats such a change can present to individual and mutual help aspects of group activities, and second, of opportunities for informal involvement that may not be being maximised.

More could be done to increase opportunities at the bottom of the pyramid. Both groups and professionals could initiate action, recognising the need for it to be jointly planned and undertaken. Groups should feel, however, that they can turn down opportunities, both formal and informal, if they feel they prefer to focus inwards. Professionals should accept this as valid and constructive.

Intermediaries provide opportunities for greater involvement by self help groups without risks of co-option. Forums, joint planning officers and carers' development workers are all examples of intermediaries. They have led to the development of systems for using the experience of group members without diverting individual groups from their main job. While formal, staffed voluntary organisations may not need such support, it may well be necessary to have some sort of intermediary for self help groups.

Who should initiate this aspect of good practice? Where the atmosphere in the professional world is friendly and co-operative, it may well be easy for the initiative to come from the group members. Where there is tension and lack of contact, it will be unlikely that they will have the confidence or wish to risk rebuffs. Generally, it is suggested, initiative is more likely to have to come from the professional world.

Are professionals being asked, however, again to take on a task for which their training and skills do not equip them? This could be another example of expecting close co-operation between the two worlds, without recognition of their differences and the skills needed to work together.

CHAPTER 7: OBSTACLES TO GOOD WORKING RELATIONSHIPS

The last four chapters have illustrated the range of good practice in the field. In a variety of settings - in hospitals, in communities, in drug counselling centres and so on - professionals and self help groups are working effectively together. In one town, professionals and groups expressed particular satisfaction with their relationships. Groups based on mental health, chronic illness and disability echoed each other's endorsement of what was going on. It was a view expressed honestly, not a generalisation that glossed over difficulties. But such warmth was unusual. In most places, the good practice went side by side with some poor practice, and in some cases the constraints on good working relationships were considerable.

In this chapter I shall draw together the main obstacles to developing good working relationships. Defining obstacles is the first step. Discussing ways of overcoming difficulties, or accepting that some problems are part of the relationship, is the second. For living with constraints, rather than solving them all, may be a more realistic objective.

A range of different obstacles appeared, summarised in Box 7.1.

Box 7.1: Obstacles to good working relationships

Lack of awareness of the two different worlds
Traditions of professional power and control
Professional attitudes to people as patients and clients
Professional attitudes to experiential knowledge
Lack of interaction, knowledge and understanding
An expectation of professionals having relevant skills
Problems and limits within self help groups.

Two worlds

A theme interwoven in the report so far has been that self help groups and professionals inhabit two different worlds. The difficulty is not so much that they are separate and different, but rather that the degree of difference is not recognised. Fig 2.1 summarised some major characteristics. Not acknowledging how different the two are can be an obstacle to co-operation.

For some groups it may be a conscious decision that the two worlds should not overlap. One of the limits to this research was that people who took part were by and large already interested in working together. The opinions of groups who wished to be strongly independent were not heard so clearly, but the option of separation has to be there. The concept of partnership is not one which sits easily with the relationship between self help groups and professionals (Wilson 1993b). Instead there has to be

choice by group members on their relationship. A reason for limited working relationships may be simply that groups choose separation rather than co-operation.

Professional power

Access to power, a second obstacle to co-operation, is a further example of differences between the worlds. Charlotte Williamson, writing about consumer and professional standards in health care, sees health care professions as long-established, strong and cohesive. "All have exceptional power to define their patients' situations and interests." (pp 4-5, Williamson 1992). A strong sense of power may well lead to an assumption by some professionals that the only way to meet needs is through professional diagnosis and treatment. As patients and clients, we may well go along with this, endorsing the power imbalance, even if feeling uncomfortable about it.

Knowledge is part of the basis of power. Self-helpers in this study contrasted those professionals, often doctors, who saw themselves "as God", with those who were not afraid to say that they did not know. It is an issue which often comes up in discussion with medical students in Nottingham. Only when professionals are able to accept and speak about the limits to their own knowledge will they recognise and accept other sources of knowledge which may be helpful to their patient or client.

While the question of power and hence control is one seen most clearly with doctors, it is an issue running through all professions. Even those, like social workers, with traditions of co-operation with clients, are increasingly being thrust into a relationship of antagonism and mistrust because of the power they are required to exert over their clients (Jones and Novak 1993). Social workers and other even less clearly defined professions may be tempted to strengthen their position of power as part of achieving an identity.

Power, how it is exerted and accepted, is a large question. It can only be touched on here, but has implications for practice. Where people are excessively conscious of needing to maintain power, and are resisting encroachment on their territory, there would seem to be a real obstacle in achieving good relationships between self help groups and professionals.

Professional attitudes

Associated with power is another complex problem area, that of professional attitudes to individuals. Groups pinpointed this as an important issue and recounted a number of stories of inappropriate general attitudes. Many had felt diminished by how they had been treated as individuals. In contrast they spoke warmly about people who could listen and communicate, were 'forward looking', were approachable, patient and tolerant. Many self-helpers made a clear link between general attitudes to them as individual clients and attitudes to their group.

Sometimes professional attitudes were related to a blinkered focus, as self-helpers saw it, on the physical illness - not seeing the whole person. Lucy, in a carers' group, linked an emphasis on curing and medical training to a lack of awareness of emotional needs.

"They are trained to cure, and when they can't do that, they don't know how to deal with it. They are not trained to deal with emotions, they are trained to deal with the body."

Attitudes to individuals may be more of a constraint than attitudes to self help groups themselves. An extensive study in Canada (Cardinal and Farquharson 1991) put it even more strongly. Positive attitudes to individuals were seen as an essential preliminary step to effective practice with self help groups.

I tried, and failed, to interview some professionals who were overtly hostile to self help groups. While their views would have been interesting, underlying attitudes to individuals may be more useful to consider. Nor may there be that many professionals who are really hostile. Overbearing rather than hostile attitudes may be an obstacle, but hostility to self help groups should not be seen as a common barrier to relationships. Overbearing attitudes to individuals do exist however and do inhibit co-operation.

Attitudes to experiential knowledge

Knowledge gained from experience, acquired by people from having and living with a problem, was touched on in Chapter 3. It was seen as one of the obstacles to developing systems for putting people in touch with groups. Fig 7.1 summarises the range of attitudes to experiential knowledge that exist and the implications there may be for co-operation with self help groups.

Thomasina Borkman, (Borkman 1990) an American sociologist, suggests that the importance of this source of knowledge is underestimated. She makes a distinction between three forms of knowledge. First, professional knowledge, gained initially through training, is grounded in theory and scientific principles. Second is a form of lay 'folk knowledge', common sense acquired from family and friends. Third, she identifies knowledge held, distilled and shared in a self help group which becomes part of the organisation's knowledge, passed on even when the initiators of a group leave.

Borkman sees self help groups as learning communities. They first develop knowledge about their problem and how to resolve or cope with it. Then their members apply that knowledge. Reservations by professionals about this practice, or just lack of awareness of its value, as Borkman suggests is common, may well be another obstacle to good working relationships. She points out that experiential knowledge is largely unrecognised and unnamed by professionals. It needs to be singled out and discussed so it can become visible and understood. Lack of awareness of the value of knowledge gained through experience would appear to be one of the important underlying issues in this study.

Fig 7.1 **Professional attitudes to knowledge gained through a self help group**

	Hostile	Threatened	Unaware	Accepted	Valued highly	
LOW CO-OPERATION LIKELY	to self help group as source in principle	by knowledge gained	of value of knowledge gained self help groups	as useful complementary source	as means to dialogue with professional	HIGH CO-OPERATION LIKELY

Many self-helpers however talked about the importance of this aspect of their group. It seemed particularly important when people were having to live with a chronic condition, as Lilian from a carers' group suggested:

"Their attitude was - there isn't a cure, there's nothing can be done. So that's it - they just wipe their hands of you."

The experience of a Canadian self help worker was that where doctors knew that there was very little to be accomplished by medical intervention, and that the illness could go on for a long time, there was some relief in being able to tell a patient about a self help group (Lori Dessau, personal communication). In Britain perhaps this stage has not been reached.

Lack of knowledge and interaction

Also in Canada (Cardinal and Farquharson 1991) research indicates that knowledge about self help groups is the second essential preliminary step, after attitudes, if good practice is to come about . In Chapter 3 it was suggested that access to both hard information, and to ways of getting the feel of a group were necessary as part of the process of putting people in touch with groups. Where information and knowledge were absent, this was a constraint on practice.

Lack of knowledge may not be the only problem. It may be that a myth supplants knowledge. The influence of myths was highlighted in the first of Marina Warner's 1994 Reith Lectures (Cardinal and Farquharson 1991). Warner describes myths as "a kind of story told in public, which people pass on to each other". They can lock us up, she suggests, in stock reactions, bigotry and fear. One myth may stem from professionals' experience of contact with self help groups which pursue a particular cause or treatment. It can lead to a myth that all self help groups are likely to do this.

Bracketed with limited information would seem to be unsatisfactory interaction and contact. Another American researcher, Judy Haran, put lack of interaction and contact as a key influence on poor understanding and co-operation (conversation). The cause of this may not be solely professional hostility or indifference, it may come from self help groups. They may not think about creating opportunities for interaction, or simply not have time, capacity and confidence. Both direct and indirect contacts may be missing. General lack of visibility of groups may prevent professionals becoming knowledgeable about self help groups as much as lack of direct contact with specific groups.

Some negative opinions expressed were based on regular contact, not on myth - for interaction can also lead to seeing some of the limits to self help groups. A nurse, for example, observing the very cliquey nature of a diabetes group, was rightly critical about the effect this had on new members. For she also had experience of another, more open, group and was able to make a fair comment. On the other hand, sometimes it appeared that assessment was based on myth rather than knowledge.

Expectations of appropriate professional skills

Most self-helpers in this study wanted links between their world and the professionals' world. They were warm in their appreciation for the people who gave appropriate support and regularly told their clients about groups. Group members did not always recognise, however, that this was often a very difficult and challenging task for professionals, trained to do a different job. In the discussion in Chapter 4 on support to groups , it was suggested that professionals were being expected to have and use community work skills. This can be a false expectation. While some in-service training exists and may enable experienced professionals to acquire such skills, there was no evidence that this subject was included regularly in pre-qualification training.

The specially skilful professionals seemed to have these skills instinctively. In general, however, one cannot expect the average professional, trained to be a case-worker, to be a community worker. Not recognising this, and so expecting that they can support self help groups, may well be an obstacle to effective practice.

Problems and limits within self help groups

A final set of obstacles do not lie within the professional world, nor are they due to lack of interaction. They may rather be due to problems and limits within self help groups themselves. I see three different types of constraints, relating to effectiveness of groups, limits of time, energy and conflicting priorities and lack of knowledge and support.

Effectiveness

Self help groups are not easy to run. There are a number of reasons for this. First, lack of experience. Many people who start them have 'never done anything like this before'. Any activity learnt on the job takes time to settle down. Lack of experience may also lead to unawareness of the need for confidentiality and for ground rules needed when very personal problems are being aired.

Self help groups face the similar problems to other small voluntary organisations. They are vulnerable, for example, to domination by powerful individuals who may not be very good at running a group, however well motivated. 'Founder syndrome', hanging onto an office in a group long after it is appropriate to let go, is not unknown. Cliqueyness, a problem mentioned by people in this study more than once, can be a problem for groups which are apparently 'open' but to a newcomer feel 'closed'.

Despite such challenges very few groups, in the Nottingham experience, are ineffective. Occasionally attending them can be a bad experience, but one usually solved by people stopping attending, voting with their feet, rather than their lives being ruined.

Limits within a group

Groups are limited in the resources available within their group for developing better relationships with professionals. People join a self help group because they have some difficulty in their lives. When they are coping better, they may leave the group as part of the process. While a few join to be helpful when their lives are less stressful, they are a minority.

The actual issue on which the group is based may make liaison specially difficult. There was evidence in this study of lack of mobility, energy and caring responsibilities, as well as limited time - all of which constrain groups' ability to develop contacts.

Even without personal difficulties people in self help groups might choose, anyway, to spend what time they had for the group on other aspects of its activities. This was specially true for groups which had had experiences of being rejected, rather than welcomed, by professionals.

Lack of knowledge and support

Last, groups might simply not know how to go about developing their links with professionals. Cancerlink's guidelines to groups on working with professionals is a recent publication which aims to get over this problem. On the whole, though, the evidence from this study was that groups were not being guided by national organisations.

Not all groups are linked with a national organisation. Nor, in most parts of the country, is there an easily accessible local source of support and information about starting and running a self help group, and how to link it with other parts of a community. While government policies in the mid-1980's led to seed funding for 18 local self help projects under the Self Help Alliance programme, funding cuts and low priority given to supporting self help meant this did not lead to a consistent pattern of local support.

In summary, these constraints do lead to problems and limits within the self help world. Some professionals recognised this and were able to distinguish between groups which were just a bit ineffective and the few which were, as they saw it, harmful. Self-helpers too saw some of their limits, stressing quite rightly how these held them back from developing relationships as much as they would have liked.

Conclusions

Consideration of all these obstacles to co-operation leads to a broad conclusion that there are substantial constraints on the development of good working relationships between self help groups and professionals. Wishes for co-operation cannot easily be translated into action. The major differences between the two worlds suggest that there will always be some constraints, in some areas of need more than in others. There is likely in some fields at least always to be some inbuilt tension and untidiness.

For groups, taking on the whole weight of professional power and traditions would seem ambitious. A sense of realism may well be needed for people in groups seeking to change practice, especially at a time of uncertainty and lack of resources for statutory services. Some obstacles do seem to be surmountable, however. In this next and final chapter I shall suggest some of the ways in which this may be achieved.

CHAPTER 8: LESSONS FOR POLICY AND PRACTICE

In this final chapter I set out lessons that have emerged for policy and practice. Its emphasis is more on highlighting principles than specifying actions. The chapter is designed to enable a range of people and organisations to reflect on their situation, and to begin to think what might need to be done in their particular setting. Two other publications arising from this research will suggest practical steps for self help groups, (Wilson 1994), and set out guidelines for professional practice (Wilson forthcoming).

The lessons summarised here are for both worlds, the self help world and the professional world, and for organisations which may be able to play an intermediary role between them. Local self help groups and national self help organisations, local professionals and national and local policy makers will all be addressed. Change is needed at a variety of levels and by various organisations if there is to be greater co-operation and understanding.

I first return to the questions raised in the introductory chapter. They covered the issues of partnership, what degree of involvement might be appropriate, whether there were risks of co-option and involvement and what barriers to co-operation existed. I then suggest some broad lessons for policy and practice and finally make my own recommendations of action that might be taken.

Answers to questions

Partnership or co-operation?

In Chapter 1, I asked how much partnership there could be between the two very different worlds of self help groups and professionals. Self-helpers varied in how they saw this. Group members in the study all wanted to co-operate in some way. Some were happy with a very close degree of collaboration, even at times welcoming semi-integration into the professional system of care. However, more group members wanted clear separation, and choice on the degree of that separation as the basis of the relationship.

The term 'partnership' is a word often used when talking about the relationship between sectors, whether private, voluntary or public. Partnership between the voluntary and statutory sectors tends to be put forward as an accepted principle, a "good", like apple pie or motherhood. It is the wrong word to describe the relationship, actual or desired, between two sets of organisations with so many differences and with such disparate amounts of power.

Co-operation, however, was wanted and is a term that feels appropriate. Both groups and professionals in this study largely wished to co-operate. Co-operation is a manageable target to work towards and one which does not risk smothering or distorting self help initiatives. The evidence from this study suggests it is also achievable. When beginning this project, it was felt that people had probably already found effective ways

of working together. A variety of good practice was found, largely based on principles of co-operation, but allowing an appropriate degree of separation.

Must support mean involvement?

A second question put forward in the introductory chapter related to the degree to which professionals could become involved in initiating and supporting self help groups, without distorting the nature of the group. Self-helpers, again, did not always come to the same conclusions. There was a continuum, at one end a wish for support through close involvement, at the other a desire for acceptance of the group's role and value but very little direct contact. Most groups could probably be seen in an extended cluster around the middle of the continuum.

Choice on what was appropriate would seem again to be an important issue. Ability to change the degree of involvement as the group changed was another, for what might have been needed when the group began could be entirely inappropriate some years later. There is a need to recognise the importance of monitoring and jointly reviewing the relationship, enabling change to take place without acrimony.

Risks of co-option and diversion?

The third question raised concerned the risks of co-option and diversion. There was little direct evidence in this study that this had occurred. There were more complaints about being ignored. There were, however, some undercurrents, some stories of groups moving meeting rooms to avoid too much contact, and so on. There were also a few anecdotes of other groups where people had been dominated by the professionals trying to help them. These all indicated there are risks of too great an imposition of the targets of the professional world, and that there can be too little willingness to accept principles of self-determination.

It is all too easy for the professional world to come with clear goals and expect groups to fit in with them. This may not be through consciously setting out to exert power, but rather through the strength of their position and clarity about the purpose of their professional role, as they perceive it.

A distinction can be made between groups which change to become more closely integrated into the professional world as part of a natural process of development, and those which are diverted, maybe without realising this is happening. It is this process of invidious co-option that is dangerous. While they are probably rare, co-option and diversion can occur. Groups need to be aware that this can happen and have the confidence and ability to challenge it if it does. But there need not be an expectation that it is common or inevitable.

In the self help world, lack of confidence and self esteem with which many people have to battle, means it is not always easy to resist professional influence. While belonging

to a group is one way that individuals can increase their confidence, groups may well need to develop a more-conscious sense of identity and self-worth, as groups. It is only then that they will feel able to choose from the opportunities that arise, and resist attempts at co-option and diversion.

Surmountable barriers?

The final broad question posed in the first chapter raised the question of the barriers created by professional power and traditional attitudes. Did these barriers, and other obstacles, mean co-operation could not succeed? As Chapter 7 explored in detail, substantial barriers do exist, probably more than many people realise. Groups which did not perceive these difficulties clearly were more likely to feel discouraged, even failures, than those who understood some of the structural and personality issues which influenced the relationship.

Both groups and professionals need to understand that barriers exist, and that they vary in different settings. While some barriers can be scaled, others are part of the relationship. Acceptance of some obstacles as inevitable rather than removable, first, and ability to distinguish one from the other, second, are both needed. Where barriers do exist, it may be possible to approach them as being opportunities for growth and change rather than dead ends.

General principles of good practice

Moving on to what might underlie good practice, four general principles would seem to underpin the relationship between self help groups and professionals: valuing, self-determination, interaction, and clarity.

Valuing the special contribution

Members of groups had a strong sense of the value of their groups and of their own ability to run them, as set out in Chapter 2. This was a consistent thread throughout the study. It was not such a constant theme with professionals. While many professionals appreciated groups' achievements and their contribution, valuing self help groups, as groups wanted, was not universal in the professional world. Part of good professional practice should be valuing the special, different contribution of self help groups.

This awareness of the different contributions of self help groups was one of the features of the specially skilful professionals described in Chapter 5. Once professionals were aware of the difference in contribution and organisation, then valuing followed more easily.

Respect for individual patients and clients is part of the general approach which is needed. Professionals increasingly value their clients as people with the potential and

ability to identify their own needs and contribute to their own care. Respect for individuals would seem to be an essential first step to valuing self help groups.

Allowing self-determination

A second principle is one of accepting self-determination. In valuing the groups, and in trying to work more with them, it is important that the professional system does not impose its own style and expectations on them. Anyone working with self help groups should be prepared to make special efforts to learn and understand their nature. Action that strengthens the capacity of group members to make their own decisions and to run their groups is needed. Enabling people to learn and develop skills, with a lightness of touch in the support that is given, is preferable to direct leadership and imposition.

The principle of allowing self-determination by groups is one which will bring particular challenges for professionals whose tendency is to dominate the relationship with individual clients and patients. Other professionals may find it easy to avoid domination, but in putting the best interest of their clients first, as they see it, they may face real dilemmas. The discussion about 'referral' in Chapter 3, for example, shows the complexity and implications of a principle of self-determination.

Interaction

A third general principle is the need for some form of interaction. Contact between groups and professionals is generally useful and appreciated, but may not always need to be direct. There was plenty of evidence in this study of successful contact between self help groups and professionals which did not involve close or continual association.

The degree of contact will depend on a number of variables. Groups which rely on the professional world for a constant supply of new members, for example, are more likely to work towards close and frequent interaction. Professionals which consciously rely on groups' services for people leaving professional care will be motivated to develop and maintain close links.

But all groups can benefit from some form of interaction. Absence of contact can lead to misunderstandings, continuation of myths and missed opportunities, as discussed in Chapter 7. Interaction should not be left to chance, nor taken on entirely by self help groups, though they could well think of how their particular group could achieve more. Creating chances for more contact may well be a task for a range of organisations, including the professional and self help group worlds. Intermediary bodies, however, national self help organisations and community leaders can all also take a lead and play a major part.

Clarity on aims, roles and structures

In recent years hospitals, social services and other professional agencies have tried harder to clarify and communicate their aims and values. In the self help world, some groups put themselves over very clearly, but others do not. People outside a group cannot be expected to guess its function. They need to be told what the group is trying to do, for whom it exists and what the benefits of membership are.

Clarifying aims, values, benefits and membership helps any group activity. It is essential if there is to be co-operation with other organisations. While the group itself must make the decisions on aims and activities, people outside the group can assist the process of both making decisions and publicising what they are. Self help projects, national organisations and supportive professionals, as touched on in the discussion on support and development in Chapter 4, can all help and encourage the process of achieving clarity and communication.

Benefits to both worlds

Greater awareness of benefits can only help improve the relationship between self help groups and professionals. Two threads emerged in this study - the question of mutual benefit for both worlds, and the need to highlight the way in which membership of groups can benefit individuals. Underlying these issues is the complex issue of evaluation.

Mutual benefits

The examples of good practice identified in this study suggest that mutual benefit is possible. Both sides gain when the relationship works well - groups are not the only winners. Fig. 8.1 summarises who appeared to gain, and how, when there was effective co-operation and understanding between the two worlds.

Accounts in Chapter 6 are examples of how professionals benefited from groups' comments on professional services. The same professionals in turn helped the groups by having effective systems for putting their clients in touch. Recognition of the possibility of substantial benefits for both worlds is needed.

If both sides can gain, a degree of mutual dependency also needs to be recognised. Interdependency is a theme underlying good working relationships. The specially skilful professionals described in Chapter 5 understood this. Others, however, may need to learn about the benefits of co-operation. For it is not enough to simply urge people to work more effectively with self help groups. Clarifying and appreciating benefits that result from co-operation could be a way to lead professionals to change their practice. There has to be some incentive, some clear benefit for clients, individual professionals and for the professional system before most people act differently.

Fig 8.1 Who gains and how, when there are effective working relationships

Who	How
Individuals in difficulty	Option of an additional or alternative source of help
Self help groups	More members Higher self esteem Access to resources
Individual professionals	Complementary form of help available Quality of own service improved
Professional system of care	More help for people in need Prevention of some inappropriate demands. Access to users' views

Highlighting benefits

Self help groups need not wait for scientific evidence. They have the opportunity for effective personal testimony. Groups may well be able to do much more than they do at present to identify and highlight the benefits members feel they have gained from belonging. Individual members are well placed to go back to their doctors and social workers and tell them about their experiences. Groups could well think of systematically encouraging people to do this.

Evaluation

How does one measure the extent to which people feel better about their situation, and whether this can be attributed to membership of a group? Wann and Coote's forthcoming study touches on the difficult question of evaluation of the results of taking part in self help groups. It was not a major issue in this study, but one which may need more attention. For in this country, compared with Germany and the USA, little research has been undertaken to provide evidence of either benefits or disadvantages to group members.

There is a dilemma here. Small qualitative studies, focusing I suggest on specific areas of need, may be required in order to provide professionals with evidence and so the incentive to change their practice. On the other hand, people set up groups to meet their own needs and unless demanding substantial financial support should not be required to provide evidence.

While research evidence may help, trust is important too. The thoughtful professionals in this study who understood and worked effectively with self help groups had trust in the benefit of membership. There has to be a more general acceptance that groups can work, as well as evidence that they can, before practice can change.

Policies which give opportunities

A further general question related to policies in health and community care in the mid-1990s. Some groups had been alerted by their national organisations to relevant legislation and policies. The question of overlap between government policies and the activities of self help groups is an interesting and relevant issue. The conclusion from this study is that a number of strategies, in some cases actual legislation, give opportunities for better working relationships between self help groups and professionals. Groups may choose to take the opportunities. Professionals ought to pursue them as methods of implementing policies. Four specific policies can be identified: community care, information for parents as outlined in the 1989 Children Act, the Patients Charter, and the Health of the Nation's target for improving mental health.

Community care

Community care encompasses a variety of strategies for helping people live fulfilled lives in the community. Discussion about it has tended to emphasise living arrangements and practical care rather than coping mechanisms and preventing isolation. Logically, however, implementing the vision of community care should include effective working relationships between self help groups and professionals. It certainly could include appropriate ways of enabling self help groups to influence how services are provided. Hospital discharge is a particularly appropriate opportunity for co-operation. A recent Audit Commission report (1993), for example, proposed that telling patients about groups should be an automatic, and, in their view, a relatively easy procedure as part of hospital discharge.

The Children Act

The 1989 Children Act requires that parents are given information about services. Groups for parents with children with a disability have particular opportunities under this legislation but other parents' groups, twins groups for instance, have also successfully used this legislation to improve systems for putting people in touch with their groups.

The Patients Charter

The impact of the Patients Charter and its emphasis on patient information was beginning to influence practice at the time of the field work for this study. The Patients Charter has led to the establishment of regionally organised Healthlines. In the Trent Region, Trent Healthline has made self help group information a feature of its work a model, it is thought, for other Healthlines in the country.

But many organisations are required to implement the Charter; phonelines are not the only method. Purchasers of care can build into contracts requirements that hospitals and community services as providers of services put its principles into operation. To do this effectively, they need information about self help groups and systems to make sure details are passed on. Groups, again, have opportunities and professionals, obligations.

The Health of the Nation

Last, the Health of the Nation includes targets for improving the country's mental health. A broad approach, seeing the potential of many self help groups, not just those based on mental illness, as contributing to policy implementation is needed. There is little evidence so far that any connection has been made between policies encouraging self help groups and achieving Health of the Nation targets.

In Chapter 2, group members' experience of the frequency of feelings of isolation and the importance of support, suggest that they provide an important resource for dealing with what may be a submerged problem. A strategy about self help groups could be developed as part of implementing Health of the Nation.

A thread running through these strategies is quality of care. Working effectively with self help groups should be seen as one way of increasing the quality of care received by people in need. There are, however, also potential problems. The growing number of policies which appear to give opportunities to self help groups may also contain threats. Not appreciating the nature of small informal groups could lead to inappropriate assumptions about them, resulting in over-integration into policy.

While groups were largely ignored, this was not a problem. Now policies are beginning to include them. The possibility of co-option and the risk of diverting their energy, time and resources are issues which need debating. National self help organisations and intermediary bodies are well placed to focus attention on the threats as well as opportunities which self help groups may face, and to inform and educate statutory authorities about them.

Creative tension

A final reflection relates to what might seem to be a major difficulty. Running through these studies is the theme of tension. While tension can and does bring stress, it can also be creative. Seeing the relationship between self help groups and professionals as one of an opportunity for creative tension, rather than a cosy partnership, may be essential. This research suggests that in Britain both the problems and the openings tension brings have been underestimated. Policies and strategies to be considered by anyone concerned with the self help world could usefully integrate the concept of tension as a reality, not an issue to be ignored or smoothed over. It can, however, lead to benefits for all concerned.

Recommendations

I end this report with a number of recommendations. They have been reached as a result of my analysis of this research, but also draw on experience in the field and on other authors' conclusions. Some recommendations suggest specific action, others highlight priorities. My four recommendations cover the subjects of organisational, rather than individual, change, the development of specific research projects and good practice guidelines, the role of intermediaries, and the need to appraise the consultative role of self help groups.

1. Achieve organisational change

Individual practice, however good, is not enough. Agencies and organisations need to evolve and adopt policies and help staff to implement them. Common elements to any action are likely to include increased clarity of aims and relationships, interaction, systems of getting and giving information and spreading good practice through pre-qualification and in-service training. Few organisations will have to start from scratch. Identifying and using skills likely already to exist among some of their staff would be an easy first step.

My recommendation is that organisations, in both the statutory and voluntary sectors, which provide services for people in need should examine their practice with the help of self help groups. They should develop, promote and maintain conscious strategies to be adopted by all their staff.

2. Develop good practice in specific areas

The situation and solutions to problems will be different with particular groups and specific professionals. While this study has drawn out broad principles, more specifically focused research is needed. Some of this could be to improve on areas where there is already evidence of co-operative working. Families of children with special needs, for example, provide an example of substantial good practice.

There are, however, a number of areas where the potential of the self help group contribution is not yet, in my view, sufficiently perceived. Three specific areas where conscious action is specially needed are the management of less-common chronic illnesses; mental health and isolation; and bereavement and traumatic accidents. Research which highlights the benefits for people in self help groups in these areas in particular should be undertaken.

My recommendation is that national voluntary organisations with an overview in these and other areas could initiate action. They could work in alliances to commission research and to develop and share good practice, enabling specific guidelines to evolve which are relevant to the particular area of need.

3. Develop and strengthen intermediaries

The value of people and organisations who acted as intermediaries emerged as a recurring underlying theme in all four aspects of good practice. For example, putting people in touch with groups was greatly helped by the availability of directories produced by local self help projects. To put all aspects of good practice into operation effectively, an individual or an organisation is needed to play an intermediary role.

There is no blueprint. No one form of intermediary is right and proper everywhere. There are examples in both the statutory and voluntary sectors, and of organisations working at national, regional and local levels. Some intermediaries work specifically with self help groups, others have a broader base to their work but include self help groups.

Three particular forms of intermediary can make substantial impact on improving good working relationships: local self help projects, statutory sector resource and development workers, and local consultative forums.

Local self help projects

There was evidence in this study that self help projects, locally based intermediary organisations working across the range of self help groups, helped bridge the two worlds. This was clearly evident in a number of areas of good practice. The experience of cities where projects have been established confirms how effective they can be.

Self help support workers are recognised by funders as playing an important role in improving contact and practice; in providing information and support; and in giving credibility to groups. The interest in their work waned after the end of the national Self Help Alliance programme, a funding programme in operation in the mid-1980s. After a substantial dip in the numbers of funded projects, more are now starting, particularly in the Trent Region where nine projects now exist.

My recommendation is that local self help projects should be seen as a crucial link between self help groups and professionals. CVS and other general intermediary bodies should consider initiating schemes and district health authorities in particular should support initiatives. A national co-ordinating body for a network of local projects should be initiated and funded.

Intermediaries in the statutory sector

Intermediaries in the statutory sector can also play a role. Community and resource workers employed by local and health authorities have a brief wider than self help projects, but they are a resource for new groups and provide information about them. They have the advantage, too, of being within the professional system, and so having the chance to raise the credibility of groups within their particular agency.

I recommend that community and resource workers employed by local authorities and NHS trusts should have their role strengthened and recognised.

Local forums

Groups' limits in influencing how services were provided were set out in Chapter 6. Evidence from the literature and from experience in Nottingham suggests that local forums can be effective in enabling small self help groups to influence service provision, without having to take on a major role. The benefits of carers' forums, mental health co-ordinating groups, and alliances of disability organisations are well documented.

I recommend that the role of specific forums be recognised and developed as part of a good practice strategy.

National self help organisations

National self help organisations based on a specific need, can also play an intermediary role. The Twins Association, Cancerlink and the Eating Disorders Association are all examples in this study where the national association had provided the bridge and resources for improving understanding and working towards better relationships. National organisations' information services, too, were a way of linking local professionals with local groups.

Some self evaluation is recommended. Some organisations may need to review their rules and consult with local groups. Their view from the centre may be based on long traditions, appropriate 30 years ago, but not in the 1990s. Current policies may provide opportunities which organisations are not taking up to the full.

Generally, the role of all such intermediaries needs to be recognised and financially supported. They all perform a number of functions which make it more likely that professionals and self help groups will work co-operatively together. Without their contribution, getting over the obstacles to a good working relationship may be impossible.

4. Review consultative role of self help groups

People concerned with providing health and social care are much more willing to listen to those who receive it compared with a decade ago. Self help groups are part of this change, in some cases having substantially contributed to the shift in attitude. This research indicates two problems however: one the risk of overusing them in consultative procedures, and the other apparently underusing self help groups, and not appreciating their potential.

Formal consultative procedures for established, funded voluntary organisations may work for groups with staff and offices. They can be inappropriate or distracting for small self help groups. Bodies undertaking consultation on planning services in health, education and social services need to be aware of the difference. They need too to be aware that extra staff time, finance, resources or the use of funded intermediaries may be required.

Providers of services, however, may well be underusing the experience of people who receive them. The contribution of self help groups in educating, feeding back and developing ways of coping may well be insufficiently appreciated and used. Low key, appropriate techniques need to be developed, to use groups' potential without diverting their energy.

My recommendation is that further research is needed to explore the special contribution of small self help groups in influencing how services are provided. A principle to be built into any strategies should be choice of whether to take part or not, enabling the principle of self determination to be upheld.

Conclusion

I end this study optimistic that the two worlds of self help groups and professionals can find ways to co-operate for their mutual benefit. The warmth and willingness to work together, and acceptance of the different strengths and limits of both worlds, alongside difficulties and tensions, were marked. Action now seems possible in a way it was not a decade ago. There are opportunities both to crystallise and share the good practice there is already - and to challenge attitudes and address the lack of knowledge that holds co-operation back.

The underlying issue is that there are two worlds. Too much attention by the professional world to the self help world may be as bad as too little. Co-operation may well be difficult and at times uncomfortable. The challenge is to acknowledge and integrate the contribution of self help groups, but not the self help groups themselves. The autonomy of the groups, and the need for them to have choice on how much they should be integrated are the principles underlying this challenging question. But if these principles can be accepted, then the potential of self help groups can be developed to the mutual benefit of both worlds.

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FURTHER READING

Adams R. Self-help, social work and empowerment. Macmillan, 1990

Adams sets out to examine the much neglected relationship between social work and self-help, drawing on a range of other important writing from the 1970's and 1980's. He takes a wide view of self help, including groups where professionals take a leading role, setting out the different sorts of groups and hence the varying relationships.

Bradburn J. et al. Community based cancer support groups: an undervalued resource? Clinical oncology (1992) 4: 377-380

A pilot study in a specialist cancer centre suggested that local support groups played an important supportive role. Hospital staff were not well informed about them and felt uncertain about their use. The authors identify a number of difficulties and put forward proposals for strategies and action.

Evans L. et al Working with parents of handicapped children - a guide to self help groups and casework with families, Bedford Sq. Press 1986

The main focus of this illuminating study is on the formation of self help groups and how they may be encouraged and guided towards independence. The dilemmas that accompany professional intervention are explored and guidelines set out for use by professional and voluntary workers and parents themselves.

Gay P. Getting together: a study of self help groups for drug users' families. PSI Record Report 695, Policy Studies Institute, 1991

Gay recommends strongly that good links be forged between these groups and professionals. Her survey gives detailed information on how 42 groups ran and how they see their role. Creative collaboration is one of the features described.

Hasenfeld Y. and Gidron B. Self-help groups and human service organisations: an interorganizational perspective. Social Service Review June 1993, 217 - 236

The authors examine the conditions and forms of relationships between professional human service organisations and self help groups. They compare them, explore some of the tensions between them and discuss the alternative competitive and co-operative relationships that can exist. The setting is largely American, but raises important basic issues which are universal.

National Self-help Support Centre. Self help groups - a way to health: developing partnerships between self help groups and health promoters, National Self Help Support Centre, NCVO, 1990

A report of a seminar sets out the issues involved in forming partnerships between health promoters and self help groups, in order to improve health in its broadest sense. It provides practical guidance and raises issues for policy, stressing throughout the benefits of partnership.

Shakespeare J. Empowerment through self-help - an experience group for families living with Huntington's Disease. Health and Social Care in the Community, I.1 January 1993, pp 58-61.

A social worker outlines her experience of initiating and maintaining a successful support group. Her conclusions emphasise the need for a long time-span, the importance of the supportive/facilitative approach and the need in this case for ongoing professional involvement. The experience had changed them all and resulted in a group directed by its members.

Unell J. Wilson J. and Marsden K. Self help groups and professionals: an annotated bibliography of literature published in the UK between 1982 - 1991, The Self Help Team, Nottingham 1992

Summaries of a wide range of publications are brought together, showing the different perspectives to this question. Both findings of major research projects and smaller but illuminating case-studies are included. The lack of contributions that focus on policy is revealed.

A SUMMARY OF RESEARCH METHODS

This study was a qualitative, good practice research project. Three main research methods were used: a literature review, group interviews and individual, one to one interviews. Three types of group interviews were carried out. Interviews were carried out between June 1992 and September 1993.

Literature review
A literature review was based on a recently published bibliography (1). An article published in 'Health and Social Care in the Community' summarised conclusions about what had been written to date (2).

Group interviews with self help groups
The first were with members of self help groups, in nine different places in the Trent Regional Health Authority area. A total of 49 members of groups took part, from a total of 39 different groups.

The types of groups represented included groups concerned with:

- common chronic illness
- rare chronic illnesses
- traumatic medical conditions
- disability
- carers needs
- addictive and compulsive behaviour
- bereavement
- mental health
- single parents
- isolation and social problems

Interviews with professionals
Four group interviews with professionals were arranged, one, a group of health visitors, was specially convened and the others, all multidisciplinary teams were carried out as part of a team meeting. The teams were concerned with mental health, visual impairment and learning disabilities.

Group interviews were complemented by individual interviews carried out by phone. Ten professionals from a variety of professions and areas of work were interviewed in this way. Some worked in institutions and others in the community.

Altogether interviews included people from the following professions:

- Hospital nurse
- Health visitor

Community psychiatric nurse
Social worker Social work assistant
General practitioner
Psychologist
Physiotherapist
Occupational therapist
Community nurse

Joint discussions
A preliminary analysis led to further group interviews and discussions. Two additional group interviews included an equal balance of self-helpers and professionals. A half day consultation with a selection of interested national self help organisations was arranged in London. The purpose of this was to see how typical the experience of groups in one part of the country was and to develop thinking on some difficult issues.

Interviews with researchers
Finally four telephone interviews were carried out with experienced researchers based in universities and research institutes, to get an overview on the subject.

Analysis
A detailed analysis of transcripts and notes was undertaken. Two working papers were written and discussed with the project's advisory group and other researchers. Drafts of this report were circulated and discussed in depth.

Sponsor and staffing
Judy Wilson, B.Soc.Sc., M.Phil. undertook all the research work. Dr. Jill Vincent, Centre for Research in Social Policy, University of Loughborough acted as adviser.

The project was sponsored by the Nottingham Self Help Team, part of Nottingham Council for Voluntary Service.

Support
This project was supported by the Joseph Rowntree Foundation. The advisory committee for the project was chaired initially by Tessa Jowell MP and more recently by Dr. Janet Lewis, Research Director of the Foundation.

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