findings
Social Care Research 60
November 1994

Self help groups and professionals

Self help groups run by and for people who share a common problem or experience are increasingly acknowledged as playing an important part in health and community care. Judy Wilson of the Nottingham Self Help Team examined their relationships with professionals in the health and social services with a view to identifying good practice for both parties. She found that:

- **Groups and professionals belonged to two different worlds. Good working relationships between the two did exist, but were patchy and inconsistent, depending on the individuals involved, rather than standard practice.**

- **The strongest concern of group members was that potential members should know that groups existed and what they offered. Lack of reliable information about groups was, however, a major problem for professionals and a strong feeling of responsibility for clients or patients often led them to be selective in their information-giving. Groups, on the other hand, felt that the decision on whether or not to participate should be left to the individual.**

- **Background support and practical resources from professionals were valued, particularly as groups started up. But helping groups was often a difficult task requiring particular attitudes and skills. No professionals had had any training in this.**

- **Groups and professionals welcomed the work of local intermediaries, such as self help councils and Councils for Voluntary Service. Their existence eased many of the constraints which group members and professionals identified on their own resources and skills.**

- **Some groups appreciated having informal opportunities to influence how services were provided. However, very few were formally involved in community care or health planning. None of the groups saw campaigning and influencing services as their main job and some took no part in this.**

- **The varied people taking part in the research all felt that groups, professionals and intermediary bodies could all do more to publicise and explain groups and to encourage good practice.**

JR JOSEPH ROWNTREE FOUNDATION

User involvement

Background

The study adopted the definition of self help groups used by the Nottingham Self Help Team, a local support and information agency which has pioneered work with self help groups since 1982. The definition's key elements are:

- groups are for people with the same problem or situation;
- groups are run by and for members;
- mutual support and information form their main activities.

Professionally-led support groups were not included in the study.

The benefits of self help groups

The people from varied groups, geographical areas and professions who took part largely agreed on the benefits that came from involvement in a self help group. These were mutual support, information of many kinds and increased confidence.

> *"They understand - and they are the only people who do understand."* (Chronic illness group member)

> *"They share information you can't put on a piece of paper."* (GP)

> *"Your own confidence increases and grows - just by being involved."* (Parents' group)

Not all professionals appreciated the degree of isolation and distress felt by many people or the extent to which self-helpers felt it was relieved by meeting others in the same situation. Nor did professionals always realise how much people gained from helping others, a recurring point made by self-helpers.

Obstacles in the way

The study found many examples of co-operation and many group members and professionals wanted to work even more closely together. But there were felt to be a considerable number of barriers and obstacles to closer co-operation.

The differences between their two worlds formed one important barrier.

Other obstacles to co-operation included:

- lack of interaction, knowledge and understanding
- traditions of professional authority and control
- professional attitudes to people as patients and clients
- knowledge gained through experience not being valued
- expectation of professionals having relevant skills
- problems and limits within self help groups

Putting people in touch

The most strongly expressed concern of group members was that potential members should know that groups existed and what they offered. The common use of the term 'referral' by professionals confused the issue: groups preferred the term 'putting people in touch'.

Professionals provided unique and often crucial access to the self-help world. Group members wanted professional agencies to have systems so that everyone could know what groups existed, and could make an informed choice on whether or not to join.

Many professionals did already put people in touch with groups. They could be closely or distantly involved in the process.

Groups and professionals generally agreed on what helped the process:

- clarity on the nature of the action
- reliable and accessible sources of information
- confidence that the new member would be welcomed
- systems in agencies rather than individual commitment
- interaction between groups and professionals
- local and national policies which endorsed practice

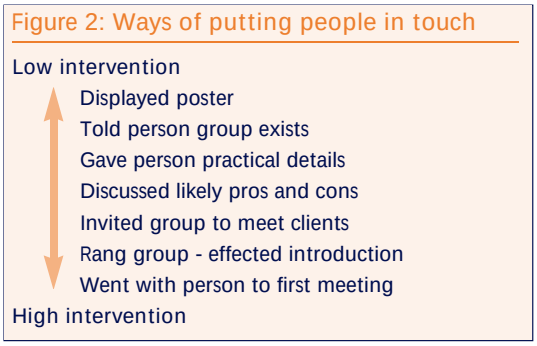
There were examples of systematic good practice.

> *"When the Health Visitor goes to visit new parents, she'll tell them about the group and then introduce them to us."* (Down's Syndrome group)

More often, however, good practice depended on individuals, not agency policy. Practice in some areas

Figure 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
How permanent	Uncertain	Long term
Resources	Volunteer help Members' homes	Paid staff Offices
Language	Everyday	Jargon and short-hand



was spasmodic or non-existent and very occasionally hostile.

> *"The doctor refused to put up our poster. He said people would pick up bad habits from each other."* (Women's eating disorders group)

Lack of reliable information about groups was a major problem for professionals, but not the only obstacle. A strong feeling of responsibility for clients or patients, resulting in professionals being protective and selective was quite common. Groups opposed this, feeling that you never could tell who needed a group.

> *"How do they perceive one person to be in greater need than another?"* (Rare condition group)

Support and development

Professional support to self help groups was common and usually appreciated, if undertaken appropriately. Five ways of helping emerged:

- support when groups began
- continuing background support and help with change
- access to practical resources
- attending meetings and giving talks
- acting as a figurehead

Most groups wanted to run their group themselves.

> *"You get doctors and so on interested just to get it off the ground. Let's face it - once it's going, we can do it without them!"* (Cardiac support group)

Sensitive background support, based on community work, enabling principles and offered over a long period, was often welcome and needed. There was a wide variety of practice and no blueprint for appropriate supportive relationships emerged. Professionals in the study varied greatly in how skilled they were; many found the task very difficult and none had been formally trained to do this work.

Providing practical help and resources, and getting access to them, appeared a more manageable task, was highly valued and was often important to the success of the group.

Examples were:

- meeting rooms
- speakers at meetings
- access to grants
- use of noticeboards

Support and development seemed to work best when there was a sense of mutuality, with both sides helping and getting help.

> *"I ask the leader for advice on problems I'm coming across. She might ask me to recommend speakers."* (Social worker about an Asian single parents group)

Supporting without also controlling was difficult for professionals. As the group developed, roles needed reappraising and renegotiating. But support could work well and was valued by groups as much as a form of validation and encouragement as for its practical benefits.

Promotion of self-help groups

The most effective approach to promoting groups seemed to be three-pronged: work by group members, professionals' efforts and action by local intermediaries. First, self-helpers were keen to promote and sell their group, but identified lack of time, energy, resources and knowledge of the structure of professional agencies as real obstacles to this working well.

Second, some professionals, though not many, took a proactive role. For example they:

- invited groups to give talks to their meetings
- put up special noticeboards
- included information in handbooks
- created opportunities for fundraising
- challenged doubtful colleagues

Third, groups and professionals welcomed the work of local intermediaries, either specialist self-help projects or Councils for Voluntary Service. Intermediaries could both provide information and promote groups effectively. Their existence eased many of the constraints which group members and professionals identified on their own resources and skills.

Influencing how services were provided

None of the groups in the study saw campaigning and influencing services as their main job and some took no part in this. About a third of the groups welcomed informal opportunities to make comments, especially if these did not divert them from their main aims. Few mentioned formal involvement in community care or health planning.

A few professionals voiced their regret that groups did not do more, seeing them as ideally

placed to influence services for the better. Some had found ways to draw appropriately on the knowledge and experience of group members, whilst being aware of the risks of diverting the group from their original aims or commandeering their limited time and energy.

The following factors helped this work well:

- scale of activity compatible with the group
- professionals valuing knowledge gained through experience
- making time to listen
- paying groups for regular and sustained contributions
- joint planning of events
- confident self-helpers

Who gained and how

Good practice between self help groups and professionals existed in some places. Where it worked well, it was found that:

Groups gained:

more members
higher self-esteem
access to resources

Professionals gained:

access to a complementary form of help
opportunity to improve the quality of their work

Individuals in difficulty gained:

the option of an additional or alternative source of help

The professional system of care gained:

more help for people in need
prevention of some inappropriate demands
increased access to users' views

About the study

The study was carried out between 1992-3, across the Trent Regional Health Authority area. Members of 49 self help groups based on a wide range of health and social issues, and 50 professionals from health and social services took part. Interviews with four social policy specialists were also carried out. Two focus groups, held jointly between self help groups and professionals and a half-day with national self help organisations reviewed initial findings.

The researcher, Judy Wilson, is Leader and Research Director of the Nottingham Self Help Team, part of Nottingham Council for Voluntary Service.

Further information

The full report Two Worlds: self help groups and professionals, by Judy Wilson, 1994, is published by Venture Press, available from BASW, 16, Kent St, Birmingham B5 6RD, Tel: 021 622 3911.

Good Links: guidelines for self help groups on working with professionals, by Judy Wilson is published by the Self Help Team, 20, Pelham Rd., Sherwood Rise, Nottingham NG5 1AP 0115 9691212.

How to work with Self Help Groups: guidelines for professionals by Judy Wilson is published by Arena Publishing.

Related *Findings*

The following *Findings* look at related issues:

27 Involving disabled people in community care planning (Sept 92)
29 Self-advocacy and people with learning difficulties (Jan 93)
31 Involving disabled people in assessment (Mar 93)
37 The effectiveness of an Independent Living Advocate (Sept 93)
42 Citizen advocacy and people with learning difficulties (Nov 93)
45 Development and training for self-organised groups of Disabled people (Jan 94)
48 Evaluation of an independent living skills training project (Mar 94)
49 Disabled people and community care planning (Apr 94)
52 Evaluating a citizen advocacy scheme (Jun 94)
56 Independent organisations in community care (Sept 94)

For further information on these and other *Findings*, contact Sally Corrie on 0904 654328 (direct line for publications queries only).

JOSEPH ROWNTREE FOUNDATION

Published by the
Joseph Rowntree Foundation
The Homestead, 40 Water End
York YO3 6LP
Tel: 0904 629241 Fax: 0904 620072
ISSN 0958-3815