



**KF**

**PROJECT  
PAPER**

Number RC8

July 1980

# **Health Education and Self Help**

**Christine Farrell  
David Robinson**

**HIE (Far)**

Based on working papers of the Royal Commission on the NHS

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

KING'S FUND CENTRE LIBRARY 126 ALBERT STREET LONDON NW1 7NF	
ACCESSION No.	CLASS MARK
18726	HIE
DATE OF RECEIPT	PRICE
5 AUG 1980	DONATION

Published by the King's Fund Centre, 126 Albert Street, London NW1 7NF. Printed in England by Trident Services, London SE1.

## **HEALTH EDUCATION AND SELF HELP**

---

by  
**Christine Farrell**  
**David Robinson**

3

July 1980

Price £1.00

King's Fund Centre  
126 Albert Street  
London NW1 7NF



**1929933866**

## CONTENTS

---

<b>EDITORS' INTRODUCTION</b>	<b>5</b>
<b>HEALTH EDUCATION</b>	<b>7</b>
by Christine Farrell	
INTRODUCTION	7
Definitions	7
Changing Behaviour	7
THE ORGANISATION OF HEALTH EDUCATION	
WITHIN THE NHS IN ENGLAND	9
Structure of Health Education in the NHS	10
HEALTH EDUCATION IN THE EDUCATION SECTOR	12
PUBLIC EXPOSURE TO HEALTH EDUCATION	13
Potential Public Exposure to Health Education	13
RECENT DEVELOPMENTS	14
CONCLUSION	16
REFERENCES	19
<b>SELF HELP AND HEALTH</b>	<b>21</b>
by David Robinson	
WHAT ARE SELF HELP GROUPS?	22
WHAT'S THE PROBLEM?	24
HOW DO SELF HELP GROUPS WORK?	26
Sharing	26
PROJECTS	29
SELF HELP AND HEALTH	32
REFERENCES	34

## INTRODUCATION

### GENERAL INFORMATION

of Chinese People

### INTRODUCTION

Definitions

Compound Definitions

### THE ORGANIZATION OF HERBAL MEDICINE

WITHIN THIS REGION

Structure of Herbs

GENERAL INFORMATION IN THE CHINESE

HERBAL MEDICINE

## EDITORS' INTRODUCTION

---

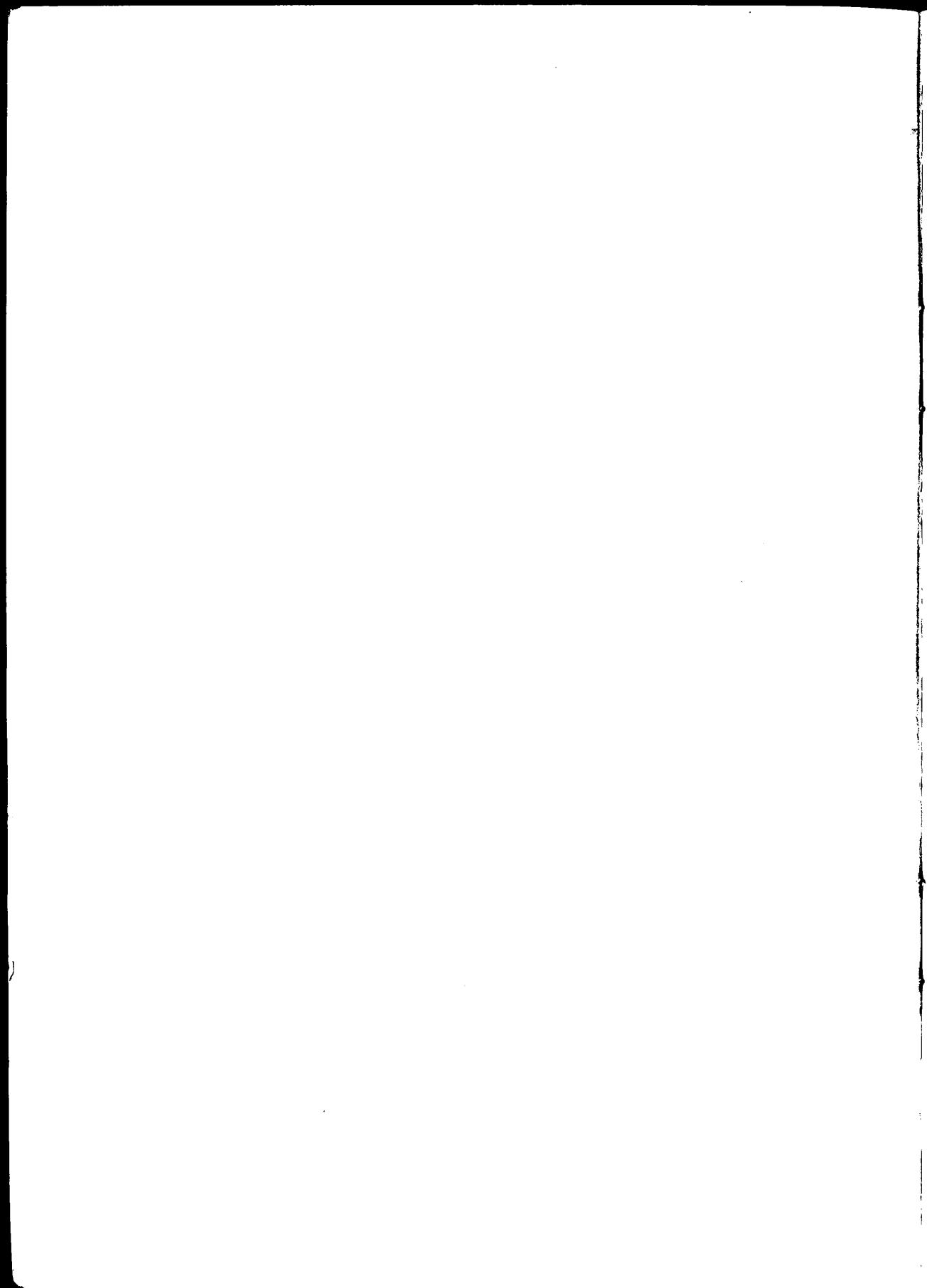
This is the eighth in a series of project papers based on the working papers of the Royal Commission on the NHS. The papers reproduced here complemented a wide variety of material made available to the Commission through evidence submissions, discussions with experts and papers by the secretariat and members on the topic of prevention and health: they should be seen in that context.

In its report, the Royal Commission stated that the NHS should 'encourage and assist individuals to remain healthy'.\* These papers describe two means towards achieving that objective: health education and the development of self-help health groups. The first paper written by the principal research officer of the Royal Commission offers one definition of health education and describes its organisation in England. The second paper submitted to the Commission by Dr David Robinson of the Institute of Psychiatry explores the recent development of self-help groups in health. The views expressed in the papers are those of the authors and do not necessarily reflect those of the King's Fund or the Royal Commission.

We are grateful to King Edward's Hospital Fund for London for giving us a grant to enable this series to be produced and to the Polytechnic of North London where this project has been based.

Christine Farrell  
Rosemary Davies

\* GREAT BRITAIN, PARLIAMENT. *Report of the Royal Commission on the NHS* (Chairman: Sir Alec Merrison) London, HMSO, 1979 *Cmnd 7615* para 2.6.



## HEALTH EDUCATION Christine Farrell

---

### INTRODUCTION

#### Definitions

There are probably as many definitions of health education as there are people who have tried to define it, and the exercise is not without risk of conflict. However, for the purpose of this paper it is defined as:— *the provision and reinforcement of information to enable individuals to assess risks to health and to use the health and social services when appropriate.* This definition deliberately excludes the notion of changing established behaviour, but emphasises the need to influence attitudes so that healthy behaviour becomes a positive life style. The issue of whether health education can or should aim to change established behaviour patterns is debatable. The World Health Organisation's definition emphasises this behavioural change aspect but excludes specific reference to use of health services:

‘Health education concerns all those experiences of an individual, group or community that influence beliefs, attitudes and behaviour with respect to health as well as the processes and efforts of producing change when this is necessary for optimal health.’<sup>1</sup>

Some readers may prefer this definition to the one on which this paper rests and reasons for excluding behavioural change should be given.

#### Changing Behaviour

Firstly, established health behaviour in adults is the result of a complex set of experiences and beliefs developed during childhood and adolescence which are then proscribed by environmental and personal circumstances. Experiments with and research into effecting behavioural change have indicated severe difficulties, even ethical

problems, in achieving long-term changes.

Secondly, for many adults who smoke or drink (two activities now known to damage health), the problem is not only one of changing behaviour but of dealing with addictions.

Thirdly, any suggestion that the individual right to choose should be restricted is often politically and socially unacceptable in a democratic system.

All these points may be challenged, particularly in the case of smoking, since individuals who smoke in company expose others to health risks. However the current climate of opinion is not one which would favour public intervention to force people to change their behaviour. Health education may in the long term help to change this climate of opinion and encourage individuals to modify their own behaviour but it cannot, by its nature and definition, change behaviour.

McKeown demonstrates convincingly that health behaviour has changed and can be changed, but not through medical intervention or health education *per se*. Rather it comes about through complex interaction between economic and social factors and scientific evidence. He says: 'Clearly there is no general answer to the diverse problems associated with modification of behaviour except perhaps that they should be considered individually and with imagination as well as tact. Broadly what is needed is a change in way of life rather than a commentary on it, which is all that is achieved by some of the traditional methods of health education.'<sup>2</sup>

The British Medical Association's evidence to the Royal Commission also supports the view that health education is not a way of changing behaviour they comment, 'there is little evidence that health education alone will be effective in changing an individual's life style'. They go on to emphasise the second part of the definition, which is the need for health education to inform and encourage responsible use of the health service. This is an aspect that until recently the Health Education

Council (the independent body responsible for health education) would not have seen as part of its definition of health education or of its work.

However, acceptance of this issue by a medical body does not mean that education in this area will necessarily lighten the burden of the NHS. It can be seen as a double-edged sword. One of the most common complaints from doctors is that a lot of their time is wasted dealing with minor illnesses which could be treated by the patient. This is no doubt the reason for the inclusion of 'responsible use of the service' in the BMA's discussion of health education. There is probably some justification for the doctors' complaints, encouraged, at a guess, by the need for sick notes to be signed by doctors. But there is also considerable evidence that people do treat minor ailments themselves<sup>3</sup> and that a fair number of people do not go to the doctor when they feel ill because they think he is too busy<sup>4</sup>. If health education is to provide information about which symptoms people should treat themselves and which they should take to the doctor, great care will need to be exercised with the nature of such information. When is a prolonged, severe headache a symptom of nervous tension and when is it a symptom of something more serious?

Health education campaigns in this area have so far concentrated on prevention and early warning signs, actively encouraging people to consult their doctor if they are uncertain. Most doctors admit that diagnosis of certain serious conditions at an early stage is difficult. How can patients be educated to make such distinctions? These are some of the problems and conflicts in the field of health education and there is little doubt that work needs to be done.

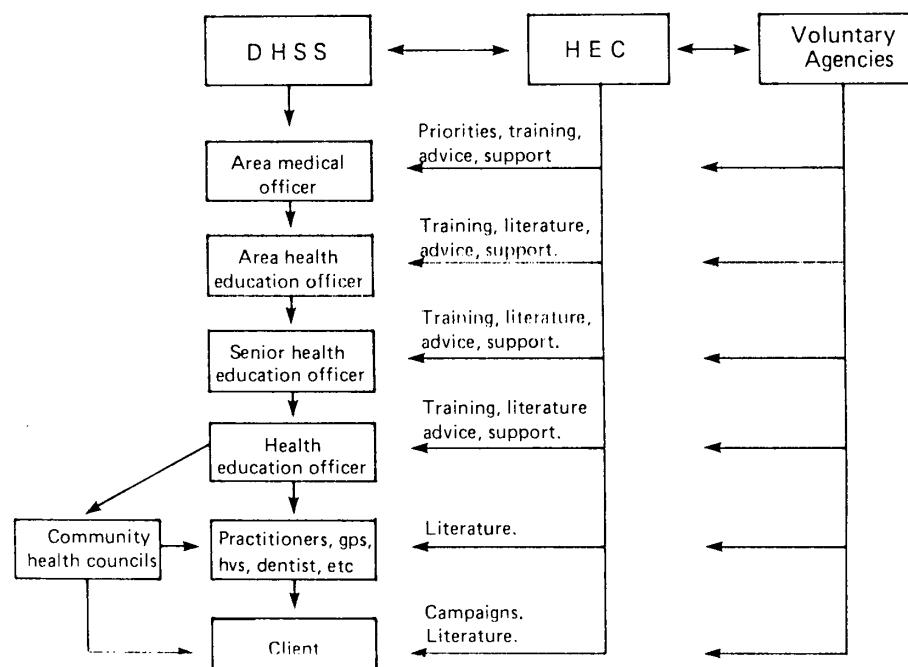
#### THE ORGANISATION OF HEALTH EDUCATION WITHIN THE NHS IN ENGLAND

The operational responsibility for health education within the health service lies, since reorganisation, with the area health authorities. The area medical officer is responsible for planning health education programmes 'as part of his wider role in developing preventive health

services<sup>15</sup>. The area health education officer is responsible for strategic planning and the provision of information, advice and materials for use by doctors, dentists, midwives, nurses, health visitors, pharmacists, chiropodists and others. Senior health education officers and health education officers are responsible for supporting the health education needs of these workers in the health services.

The Health Education Council (HEC), an independent body financed by the Department of Health and Social Security (DHSS), has ten functions listed in an appendix to circular HRC(74)27. These responsibilities cover the provision of information, advice on priorities, campaigns, research and the promotion of training in health education. An organisational chart illustrates the structure.

### Structure of Health Education in the NHS



Although in theory this organisation looks good, there are practical difficulties and gaps in the system. Mostly these could be said to be caused by financial restraints and reorganisation. But some are more basic. What follows is a personally defined list of problem areas. There may be others.

- (a) The DHSS has established a good supportive structure for the innovation and practice of health education by practitioners. It is of little use if the practitioners do not use it or know how to 'practice' health education. The medical curriculum pays little attention to health education and preventive and community medicine is low on its list of priorities. In some medical schools it is actively resented. Far greater attention needs to be paid by medical educators to devising ways in which students can be trained to be effective health educators. In spite of statements about the need to improve teaching in this area<sup>6</sup>, community medicine is still underdeveloped in most medical schools.
- (b) If health education is to be a priority, the suggested structure set out by the DHSS in its circular in 1974 may have to become mandatory. Almost four years after its issue, 33 area health authorities had not appointed an area health education officer and 15 authorities had no health education staff at all. If legal obligation is not desirable, some system of incentives needs to be devised.
- (c) Provision of training for health education personnel is currently at a low level in terms of the number of places available and money to finance them. Only four courses exist in institutions of higher education; two masters degree courses at Nottingham and Manchester University take a maximum of 16 students (not all of whom will go into health education), and two polytechnics (Leeds and the South Bank) run diploma courses, with a maximum of 40 places a year. The HEC has only four fellowships a year to finance post graduate students and finance for other students is by secondment from AHAs, local education authorities, or through discretionary awards.

- (d) Very little research has been done on what health education workers actually do. This means that there is a great deal of uncertainty around for both the workers and the planners. Some overview of the activities of health education workers and practitioners is necessary before ways can be found either to improve their training or their effectiveness.

## HEALTH EDUCATION IN THE EDUCATION SECTOR

This view of the NHS organisation ignores the educational inputs to health education which are of equal, if not greater, importance. In many ways the education authorities are more blameworthy for their neglect of health education than health authorities. Their opportunities for influencing the next generation are greater than those of health authorities and the issue has never really been grasped. Partly, this has been due to the belief in education circles that the curriculum is the responsibility of head teachers and teachers, which means that individual schools can choose whether or not to teach health education. Since it is not an examination subject, it is often neglected. Also, health education is not a subject which inspires great enthusiasm in either teachers or pupils and there are many presentational difficulties. However, having said this, it is impossible not to feel critical of the failure of educational administrators and teachers, particularly head teachers, to seriously tackle the subject. In the one area of which I have particular knowledge, sex education, the evidence suggests that it is haphazardly and badly taught in many schools. In 1974 a national survey of teenagers<sup>7</sup> revealed that only nine per cent of young people remembered having any kind of sex education in primary school -- including lessons on animal reproduction -- and only one in four had had birth control lessons which dealt with contraceptive methods in secondary school. Maybe sex education is a bad example since it is often regarded as a 'delicate' subject, and it possible that smoking, drugs and teeth get a better deal.

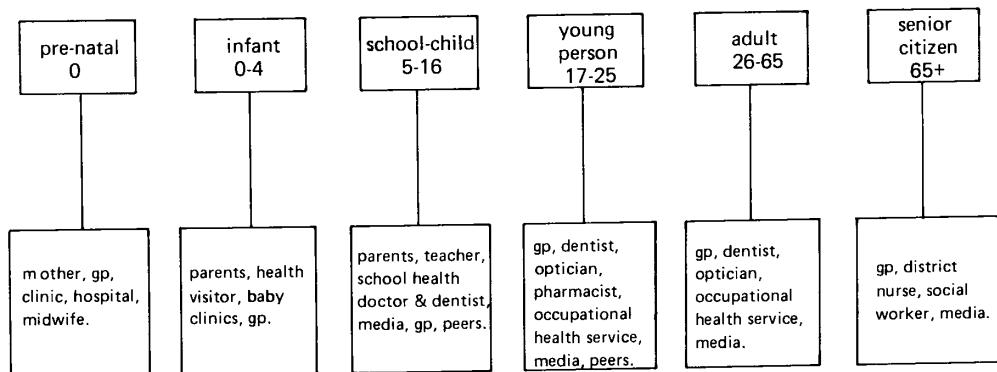
Even so, the general level of health education in the curriculum of both schools and training institutions is low. More attention needs to paid to

teacher training, particularly at the in-service stage, if improvements are to occur. There have been attempts recently to improve the quality of teaching in schools; with programmes like Nuffield Secondary Science Unit and the Schools Council projects, and their contribution should not be under-valued. Yet still in too many schools teachers teach badly, or not at all, a subject on which the future health of the nation rests.

### PUBLIC EXPOSURE TO HEALTH EDUCATION

This section looks at the public's potential exposure to health education in a 'seven-ages of man' type analysis . . . 'First the infant mewling and puking . . .' with a subsequent attempt to identify needs and gaps from the client's view. The chart below sets out the potential sources of health education from birth to death. The divisions may be regarded as slightly artificial but, unlike Shakespeare, my aims are not poetic.

#### Potential Public Exposure to Health Education



The chart excludes the HEC and community health councils because they are not face workers. It may also unwittingly exclude other face workers, but the important message is that the GP appears in every box. There is very little evidence about the role of GPs as health educators and this, in my view, is a priority for investigation. There is some evidence<sup>8</sup> that people regard their doctors as a first choice for getting helpful advice about health, with books and the media in second place. But this survey also found that half the people interviewed did not feel that their doctors had a duty to keep them well, as well as treating them when they were sick. Ways in which this apparent conflict can be resolved need to be given careful consideration.

Midwives, health visitors and baby-clinic workers could be a primary influence for mothers at the vital early stages of life. Although health education is an integral part of their work, some evidence suggests that it is not something that is done effectively or continuously<sup>9</sup>. More attention needs to be directed to finding ways for these workers to carry out their health education activities more effectively.

The chart also shows that adult contact with face workers will depend on their own referral habits, with the exception of the media. There are doubts about the effectiveness of media campaigns in health education and the HEC has been criticised for spending large sums on television and cinema propaganda. One alternative to this, since work is an activity in which most adults engage, is to encourage development and expansion of the health education content of occupational health schemes. Developments in this field would be welcome -- partly because the cost could be met by employers, but mainly because health education needs to be a continuous process to be effective and work could provide a suitable environment. However, there are practical difficulties and not everyone would see this as a suitable development. There is great scope for further thinking and ideas.

#### RECENT DEVELOPMENTS

During recent years in the press and in medical circles there has been an

increasing emphasis on health education as 'the saviour of the NHS'. The evidence to the Royal Commission also contained many pleas for more and better health education. Most of these submissions made unsubstantiated claims. They did not discuss the important issue of the effectiveness of health education, nor the problems involved in helping people to achieve a healthier life style.

In February 1977, the first report from the Expenditure Committee: Preventive Medicine, was published by HMSO.<sup>10</sup> The report provides a good balanced discussion of the problems of prevention:

- 1 cost-reduction to the NHS of preventive measures and health education (paras 25-30:)
- 2 legislation and freedom of choice (paras 34-38:)
- 3 health education in the NHS (paras 73-79): addiction (para 161),

as well as presenting case studies of areas where health education and prevention can make a positive contribution (alcohol, tobacco and family planning).

Although this report is an intelligent and readable analysis of the problems facing preventive medicine, it has one important flaw. The committee deliberately excluded consideration of three major areas where government action could make a positive contribution to prevention. They are:--- occupational health, environmental pollution and preventive mental health (para 16). In this way it ensures that the burden of action to improve health and to maintain a healthy life style is placed on the individual.

The individual's efforts to maintain and improve his own health are of prime importance. But it seems unreasonable that he should be encouraged to stop smoking, limit alcohol consumption, eat bran flakes or toast with margarine for breakfast, and then cycle or jog to a work place when, at work, he might inhale cancer inducing substances all day,

having breathed in diesel-polluted air on his way there. Other areas where government could make an important contribution, in terms of legislation, expenditure and encouragement, have been ignored.

There is not as yet a clear-cut policy for health (as opposed to illness) and the report on preventive medicine is a good example of the piecemeal way the problems of health are tackled. Health education could provide a good analytical case study leading to the design of an overall strategy for health. Even if the strategy could not be implemented because of limited finance, it could encourage development within a framework, which would have more chance of achieving a whole.

The consultative document, *Prevention and Health: everybody's business*: (1976)<sup>11</sup> also emphasises the individual's responsibility for ensuring his own good health. At the same time it considers the roles and responsibilities of central and local government and of professionals. Industrial accidents and diseases and environmental factors are considered (pp 34, 45, 53, 65-68) and the report discusses the interaction of individual, occupational and environmental factors in health. Disappointingly, its conclusion shies away from the implications of this discussion. Apart from recommending a continuing reassessment of the health needs of local populations and flexibility in preventive programmes to take account of changing knowledge and needs, there are no proposals for an overall framework for the development of preventive medicine or health.

Criticism of these two documents should not belittle their importance. Both of them should be seen as important stages in the development of preventive policies. One way forward would be for a discussion of the issues in these documents to evolve an overall framework for the implementation policies.

## CONCLUSION

At this stage it is important to emphasise five points.

- (a) Not everyone agrees or knows what health education is.
- (b) Short-term changes in established behaviour should not be seen as a realistic achievement of health education.
- (c) Spending more on health education will probably lead to long-term improvements in the nation's health but may not in the short-run (or even the long-run) reduce the burden on the NHS. Cost-effective studies of health education are few and far between, but an example of the problem is highlighted by the smoking issue. To help large numbers of people who already smoke to stop smoking would involve approaching it as an addiction problem. This would mean large amounts of money being spent on anti-smoking clinics and personnel. To make such a programme effective would probably mean attendance at clinics for several weeks, which could mean days lost at work and sick pay. The short-run costs would therefore be high and would involve many more people in using the health service. In the long run, fewer people would suffer from respiratory and heart disease, which would mean a reduction in use of services but they would live longer. As we know, the older people are, the more they use the health services, so an increase in the number of people living longer would mean increased costs. There is a strong possibility therefore that more money spent on health education could raise the burden on the NHS. Prevention is better than cure, but it is not necessarily cheaper.
- (d) It is important to consider the effects on individuals of asking them to look for early warning signs of disease and at the same time asking them not to take trivial complaints to the doctor.
- (e) Encouraging people to adopt a healthy life style should be seen as a wider campaign to reduce or eliminate other health hazards over which individuals have no control. The government needs to put its house in order by paying attention to and taking action on hazardous industrial processes (for example, asbestos, paint spray,

chemical processes) and environmental pollution (for example lead content in fumes and industrial effluent).

Health education is basically a long-term preventive measure and it is questionable whether it would be seen as a short-term solution to the problems of the N H S.

REFERENCES

---

- 1 WORLD HEALTH ORGANISATION. *Research in Health Education*: Report of a WHO scientific group, Geneva, 1969.
- 2 McKEOWN, T. *The Role of Medicine*, London, Nuffield Provincial Hospitals Trust, 1976, p. 110.
- 3 WADSWORTH, M. et al. *Health and Sickness*. Tavistock Publications, 1971.  
CARTWRIGHT, A. *Patients and their doctors* — Journal of the Royal College of General Practitioners Supplement, London, RCGP, 1979.
- 4 OFFICE OF POPULATION CENSUSES AND SURVEYS. General Household Survey, London, HMSO, 1971.
- 5 DHSS Circular H R C (74) 27.
- 6 GREAT BRITAIN, PARLIAMENT, *Report of the Royal Commission on Medical Education 1965-68*. (Chairman: Lord Todd), London, HMSO, 1968. *Cmnd 3569*
- 7 FARRELL, C. *My Mother Said — A study of the way young people learn about sex and birth control*, London, Routledge and Kegan Paul, 1978.
- 8 PIKE, L. A. 'The Consumer demand for health education', in *The Journal of the Royal College of General Practitioners*, 1971, Vol 21, pp. 156-160.
- 9 GRAHAM, H. (1977). The effectiveness of health education for pregnant mothers — private communication.

- 10 GREAT BRITAIN, PARLIAMENT. First Report from the Expenditure Committee, *Preventive Medicine*, Vol 1, London, HMSO, 1977.
- 11 GREAT BRITAIN, PARLIAMENT. *Prevention and Health* London, HMSO, 1977. *Cmnd 7047*

## SELF-HELP AND HEALTH<sup>1</sup> David Robinson

---

It does not require Ivan Illich to persuade us that the complex relationships between health professionals, laymen and governments are changing. Nor do we need anyone to remind us that money is tight and that in many countries the range and scale of professional health and social services are being refocussed, reorganized and generally rethought. Among others things there has been a concerted effort on the part of many nations to ensure not only a fairer return for their natural resources but a more equitable distribution of other aspects of the world's wealth, including health facilities. But, as Dr Mahler, Director General of the World Health Organization, pointed out recently, no one should be misled into thinking that because the developed countries have highly sophisticated medical services they also have high levels of health. 'Medical affluence', he said, 'should not be confused with health abundance'.<sup>2</sup>

It is certainly true that medicine, as practised by the medical establishment of developed countries, is increasingly being seen as a major threat to health, not merely in the technical sense of malpractice, clinical iatrogenesis and inappropriate treatment, but in the wider political sense of diverting attention from the social-structural and environmental conditions which are the cause of ill health. There is growing reluctance to accept a medicine which sees as its main task, in the words of the British Royal College of General Practitioners 'to assist the patient's own adaptive and homeostatic mechanisms to meet challenges presented by the patient's total environment'.<sup>3</sup> People are becoming less inclined to adapt to the challenges of their environment. It is the environment, not they, which must change and it is they who want to change it. Not surprisingly, then, there is widespread hostility toward a professional and physician-based health-care system which undermines the power of the individual to heal himself or shape his own environment. Nor surprisingly, in addition, there has been a rapid and substantial growth of self-help groups and organizations which, taken together, now represent a significant feature of contemporary life.

A good deal of attention has been given to self help by both professionals and governments as well as by interested laymen and the media. In fact, there is hardly any wide-circulation newspaper, magazine or professional journal which has not carried an article on some aspect of self help or on the activities of some particular group; from *Alcoholics Anonymous* to *Little People* groups; from *Gamblers Anonymous* to *Relatives of the Depressed*, and hundreds more.

As well as the main stream of self help groups there are other related developments which are often referred to as part of the self help movement. Among them are the various volunteer schemes; the 'integrity' and other small groups; the growing number of self-treatment groups, self-examination and self-care programmes which aim to lessen dependence on the medical professions, and, finally, the 'health by the people' and other self-health projects in the developing world which are, at last, being reported.<sup>4</sup> In fact the rhetoric of self help is all pervasive. But what are self help groups, and how do they work?

#### WHAT ARE SELF HELP GROUPS?

Over the past few years, there have been a number of attempts to analyse the nature of self help and its place in today's world. Writers such as Alfred Katz,<sup>5</sup> and more recently Gerald Caplan and Marie Killilea,<sup>6</sup> have been gathering together the scattered literature in order to discover what self help is taken to be and begin to describe what in practice self help groups do. Killilea, for example, picks out certain characteristics of self help groups which tend to be stressed. These are: **Common experience of members**, the belief that among the primary characteristics of self help groups is that the care-giver has the same disability as the care-receiver; **Mutual help and support**, the fact that the individual is a member of a group which meets regularly in order to provide mutual aid; **The helper principle**, which draws attention to the fact that, in a situation in which people help others with a common problem, it may be the helper who benefits most from the exchange; **Differential association**, which emphasises the reinforcement of self concepts of normality which hastens the individuals' separation from

commitment to their previous deviant identities; **Collective will-power and belief**, the tendency of each person to look to others in the group for validation of his feelings and attitudes; **Importance of information**, the promotion of greater factual understanding of the problem condition as opposed to intrapsychic understanding and **Constructive action toward shared goals**, the notion that groups are action oriented, their philosophy being that members learn by doing and are changed by doing.

That, however, is how 'outsiders' see self help. What do the members of self help groups themselves think? On the basis of the literature produced by the groups, they most typically see themselves as fellowships, while great stress is put on the common problem, position or circumstance colloquially expressed as 'being in the same boat'. 'Being in the same boat' means, first of all, understanding the problems of others, that is: 'knowing what it's like'. It is said that only those experiencing the problem can really understand.

'The organization consists in the main of cancer patients – people who know what it is like to have cancer, who know the problems, mental and social, associated with the disease. These people we feel are best fitted to give moral assistance and help to patients and families before and after treatment.'

*CARE, Cancer Aftercare and Rehabilitation Society.*

It is this understanding based on common experience, say the groups, which produces the necessary common bond of mutual interest and common desire to do something about the problem. And the basic ingredient of this 'doing something' is collectively helping oneself. As *SHARE*, a self help group for the disabled, say; to help others is to help yourself.

'SHARE differs from practically all other organizations in the disablement field in that it

aims not so much to do things *for* the disabled, as to help them to help themselves . . .'

In addition to collectively helping oneself and helping yourself through helping someone else, there is the repeated stress on the importance of 'example' in the sharing of experiences and coping. A point succinctly expressed by *CARE*.

'What better therapy than seeing someone who has had exactly what you have got, and who is . . . participating in all the normal activities of work and social life.'

What better therapy indeed. But being in the same boat, sharing experiences, and helping yourself by helping others, while excellent statements of what self help is, give little indication of how self help groups actually do their self help.

#### WHAT'S THE PROBLEM?

Before looking at how the groups actually do the 'it' that they do alone, together, altruistically for themselves, it may be useful to consider why there is any need to do anything at all. In short, what is the problem? Clearly, the range of problems, any one of which is shared in a particular self help group is immense. They may be physical, practical, mental, emotional, spiritual or social. Here they are discussed under two heads; technical abnormalities and social stigma.

In any aspect of physical condition, mental well being or social position or activity, there will be those who are technically abnormal. There are those with illnesses such as cancer, or disablements such as amputations, colostomy, stammering, skin blemishes or blindness. There are those with abnormal mental attributes such as feelings of chronic depression, guilt or fear. There are those whose interpersonal behaviour is abnormal, such as those who batter children, make love to them, or choose not to have them; and there are those with some social-situation abnormality

such as being a single parent, or homeless, or a mental patient, or divorced.

Such **technical abnormalities**, however, are not necessarily a major problem. While there may be practical difficulties they may not be insurmountable. As an article in a popular magazine explained, under the heading '**Big Problems for Little People**';<sup>7</sup>

'The physical limitations of restricted growth are relatively easy to overcome — or at least learn to live with. Clothes can be made to measure and household appliances, and even cars, can be specially adapted to suit the little person's need. Telephone kiosks, door handles and shaver points can of course present problems, but Mr Pocock carries a neat briefcase which opens into two steps for just such eventualities.'

Clearly, what turns technical abnormalities into major problems, is the way they are interpreted by the people themselves, or by others. To return to the magazine article;

'What is distressing for people of restricted growth is the way in which people don't respect the fact that little people have an opinion, a view on life and that they want to contribute.'

Despite efforts to discount the attitudes of others, for example by saying that 'society doesn't understand', it is easy to see how, for many people, the combination of technical abnormality and social stigma assumes central and overwhelming importance. Listen to how a member of *Weight Watchers* described it.

'Well, I grew very, very, fat over the years and inside me was the slim person that I had always been. But when I was slim I wasn't aware that I

was slim . . . The only thing I wanted was to be slim again. It mattered, it was the only thing that mattered to me. The only thing. It mattered to me passionately. It meant that when I was fat, wherever I went, I was conscious not of being a woman, nor of being a nothing, or of being a something, or of being a friend, or of being a stranger. I was conscious only of being a fatty . . . Day and night for years it got me that bad.

Not surprisingly the end result is to lose all sense of personal value. People describe themselves as feeling guilty and ashamed, feeling inadequate, having no identity, no place in life, distressed, angry and, finally alone; since in the end there may be a gradual slide into secrecy, seclusion and isolation. How, then, does self help work for people like these with problems of technical abnormality and social stigma?

#### HOW DO SELF HELP GROUPS WORK?

At first glance, self help groups appear to do so many different activities for so many different purposes that any attempt to generalize seems futile. On closer inspection, however, it becomes possible to draw out a number of dominant themes and practices which, for the sake of convenience, can be summarised as 'sharing' and 'project work'.

##### Sharing

Sharing is the sharing of information and common experiences. The mechanics of sharing range from formal group meetings where, as in *Alcoholics Anonymous*, a crucial part is taken up with the telling of life stories, to no less important informal meetings between group members; telephone contact networks, correspondence and newsletters, or tape exchanges and radio contacts when the members are geographically dispersed or prevented by their shared problem from meeting face-to-face. *In Touch*, for example, a self help group of parents of mentally

handicapped children, has a network of correspondence magazines. In these, parents of children with a similar condition take part in a magazine which consists of letters from each of them. As each mother receives the magazine she reads all the others and replaces her last letter with a new one commenting on the points raised. These magazines circulate continuously and so each member gets up to a dozen letters every few weeks whilst writing only one. Some of the magazines have been circulating for several years.

The degree to which 'sharing' is explicitly recognized as a major feature of self help activity varies from group to group. But irrespective of this, the crucial question is what does sharing mean? How does it actually feature in the day-to-day working of self help groups? Needless to say *Alcoholics Anonymous (AA)*, an archetypal self help group, has recognised the importance of these questions. *Box 514*, the AA newsletter, put this way:

'Sharing is truly more than a word . . . Perhaps we should from time to time, re-examine what we really mean by sharing — and what it is we are offering to share. What, in other words, is the reality behind the symbolic concept of sharing? What do we really mean, for example, when we say that we share "experience, strength and hope?" The problem is not that it is inaccurate to say that we are offering experience, strength and hope -- but that the words alone fail to convey the total sense of what we are offering.'

The 'symbolic concept' of sharing is translated into action in terms of *de* construction and *re* construction. *De* construction emphasises the group's attention to specific aspects of their common problems and how these are settled on, and defused, dispersed, and generally coped with. *Re* construction emphasises those activities geared to the production of a new way of everyday life.

Paradoxically, perhaps, the deconstruction of the problem initially involves concentrating on it. For, a familiar part of self-help group work is to help people to settle, from among a whole complex of everyday problems of living, upon one clearly defined set of problems and agree to their centrality; admitting that one is an alcoholic, for example or a child abuser. Once the problem is settled on, admitted, acknowledged or brought out into the open, a second stage of deconstruction can begin: the sharing of information about practical solutions to technical difficulties. This may be at the level of physical aids, dietary advice, information about official agencies and rights, in short anything which makes it more possible to handle the technicalities of the shared problem. Clearly, the range of specific practical aids being used in self-help programmes is immense.

The third level of deconstruction, the most difficult, aims at destigmatisation: dispersing the perceived social discredibility of the members and their shared problems; a position nicely summarised by the *Association of the Childless and Childfree*.

‘The childless are under the same pressure as the childfree and their **common interest lies in trying to make it quite an unremarkable thing not to have children.**’

One way of destigmatising the problem is by changing members' self-perception, a feat partly achieved by meeting others in the same situation and, therefore, feeling less odd. “The self help groups” said the Director of the *National Council for One Parent Families*, “. . . have a double value to lone parents and their children in providing the mutual support that is so helpful to them and also helping the children to have a sort of social identity by realizing that there are many lone parents and the children are, therefore, not in any way unusual”. It is common for nearly all groups to direct their destigmatising efforts towards changing those who are seen as the **cause** of the stigma; the general public, or society, or just all those who do not understand. *The Society of Skin Camouflage* says that it, “aims . . . to develop a greater

understanding and awareness of (our) needs and problems in both the public and the medical and allied professions". In short, self help groups aim to destigmatise the problem by changing both their members and outsiders. *CHE* sum it up this way:

'The Campaign for Homosexual Equality provides a framework within which all women and men — whatever their sexual preference — can work together and change this situation and end all forms of discrimination against gay people . . . And while emphasizing the special needs of gay people that must be catered for, we wish to encourage people of different sexualities to integrate freely and to end the gay ghetto situation'.

As well as the *de* construction and relief of stigmatised problems, self help groups can also provide recipes for an altered or *reconstructed* life. At the same time they constitute a forum for putting those recipes into action. The 're structuring of life' may be more or less explicit and more or less detailed, but at whatever level the enabling and encouraging of a new way of living, a new way of seeing one's self and one's place in the world, is a core aspect of self help activity. In most cases this re structuring is accomplished through project work.

## PROJECTS

It is difficult to generalize about projects, but basically they can be defined as cooperative activity, planned and organised by the members to achieve certain predetermined goals, and more or less explicitly depending upon the particular group. *Breakthrough Trust*, for example, talk of 'integration projects with hearing people' such as going on outings, charity walks, holidays and holding jumble sales and dances. But no matter how elaborate or involving is a project, it is essential that it is important to the members. And clearly the most important thing to the members is their problem and so, naturally, most self help project work is based on the core task of helping fellow members with

their problems.

Indeed, *Alcoholics Anonymous*'s whole programme can be seen as a collection of 'projects' designed to help fellow alcoholics.<sup>8</sup> From merely telling his own drinking story at a group meeting, to twelfth stepping and sponsoring newcomers, the AA member is actively helping fellow sufferers. In learning to tell his story appropriately, for example, the newcomer in AA is transforming past experience into experience of value to be put to constructive use. His story provides another story for the group to draw on and identify with. It is a means of distancing the storyteller from the experience, and it is a personal example to use in the individual work of 'twelfth-stepping' and 'sponsorship'. As time goes on, the problem experience becomes only a part of a member's story. It is added to by reportable stages in AA group life, and by aspects of life outside the group which are contrasted with the 'problem' time before AA.

An integral part of project work is the use of time. Time, and in particular the concentration on particular units or periods of time, is a recurrent theme in much self-help activity. Explicit distinctions are often made between time now and time past, between the member and his life now and in the past. While references to origins and 'the first time' are frequently made. Time is often formally structured in 'steps' and tightly maintained by group members and related to time targets which may be formally celebrated as in *Gamblers Anonymous*'s 'Pin Night' or *Weight Watchers*' measuring of 'Goal Weight'. Time in the future is devalued while learning to live in the present, 'one day at a time' is stressed. Particular problems may be there for all time and since relapses can happen at any time, self help commitment must be full time. To ensure self help commitment is full time, it is not enough for project work to be restricted to formal group meetings; it has to carry over into everyday life, and life outside the group. This is a major feature of self help activity.

Successful self help groups are much more than huddle-together sessions for people who feel discriminated against or overwhelmed by a

common problem or by some aspect of late twentieth-century life. The groups which offer most to their members are those which manage to combine mutual support for those who share a common problem with projects which enable people to build up a new set of relationships.

The women's self-health groups provide a good example of the way in which self-help can be an opportunity for growth rather than just a refuge from an unacceptable world. An important feature of self-health groups is for women to get to know, understand, monitor, respond to, control and appreciate the nature of the functioning of their own bodies. But in the good groups this is only the beginning. The speculum is the instrument for opening up the passage not merely to one's cervix but to a new way of life. Linda Dove, in a familiar declaration, succinctly makes the point.

'Sometimes it seems that doctors and lovers have had more access to our bodies than we have. We must have power over our own bodies to control our lives'.<sup>9</sup>

That is the core of the self-help project method; to settle from among all the problems that one faces on a clear, understandable and manageable one, to 'find' that one can manage it and then to build a new life as a person who can control one's everyday problems and, thus, one's destiny.

The project method, based on a shared appreciation of the need to structure time and transmitted through 'group talk', is not just a matter of doing, it is a matter of being. It is a matter of being in the group but it is also a matter of being outside the group. Self help is a way of life. As the founder of the *Association for the Childless and Childfree* put it:

'... just being together improved morale and made us realise that being childless is not just a case for feelings of misery and hidden inadequacy, but a chance for another kind of future based on finding the best in

ourselves and offering it to others in whatever way appropriate.'

### SELF HELP AND HEALTH

Some have seen the rapid growth of self help groups as a movement or even as one manifestation of a new era of self determination. Others have waxed quite lyrical and seen the self help phenomenon as a sign of the new Jerusalem. Vattano, for example, in his much quoted essay **Power to the People** sees self help groups as 'signs of an evolving more democratic society'<sup>10</sup>, while Dumont feels they represent:

'... a reification of the aspirations of the Founding Fathers, with their concern for individual rights, balance of power and decentralisation of power within pluralistic structures.'<sup>11</sup>

Such rhapsodical claims, however, do a grave injustice to the variety of self help groups; with their differing origins, activities, aims, philosophies and political stances. To suggest, as Vattano does, that self help groups as a whole represent a form of counter-cultural protest with a 'power to the people' political stance is a gross and unhelpful simplification. As Katz puts it, such a claim:

'... does not stand a moment's analysis for example of the philosophy, values or internal operations of groups like *Alcoholics Anonymous* or *Recovery Inc.*, two of the largest, most influential and, in many respects, most useful of the self help groups... the aim of groups like *AA*... is exactly that of assisting their members to conform to the values of the dominant middle-class society.'<sup>12</sup>

Whether or not we agree with Katz's assessment of *AA* he is absolutely right to call for 'sharper' analysis, which attempts 'to understand the phenomena with which we are dealing in their many sidedness'. For it

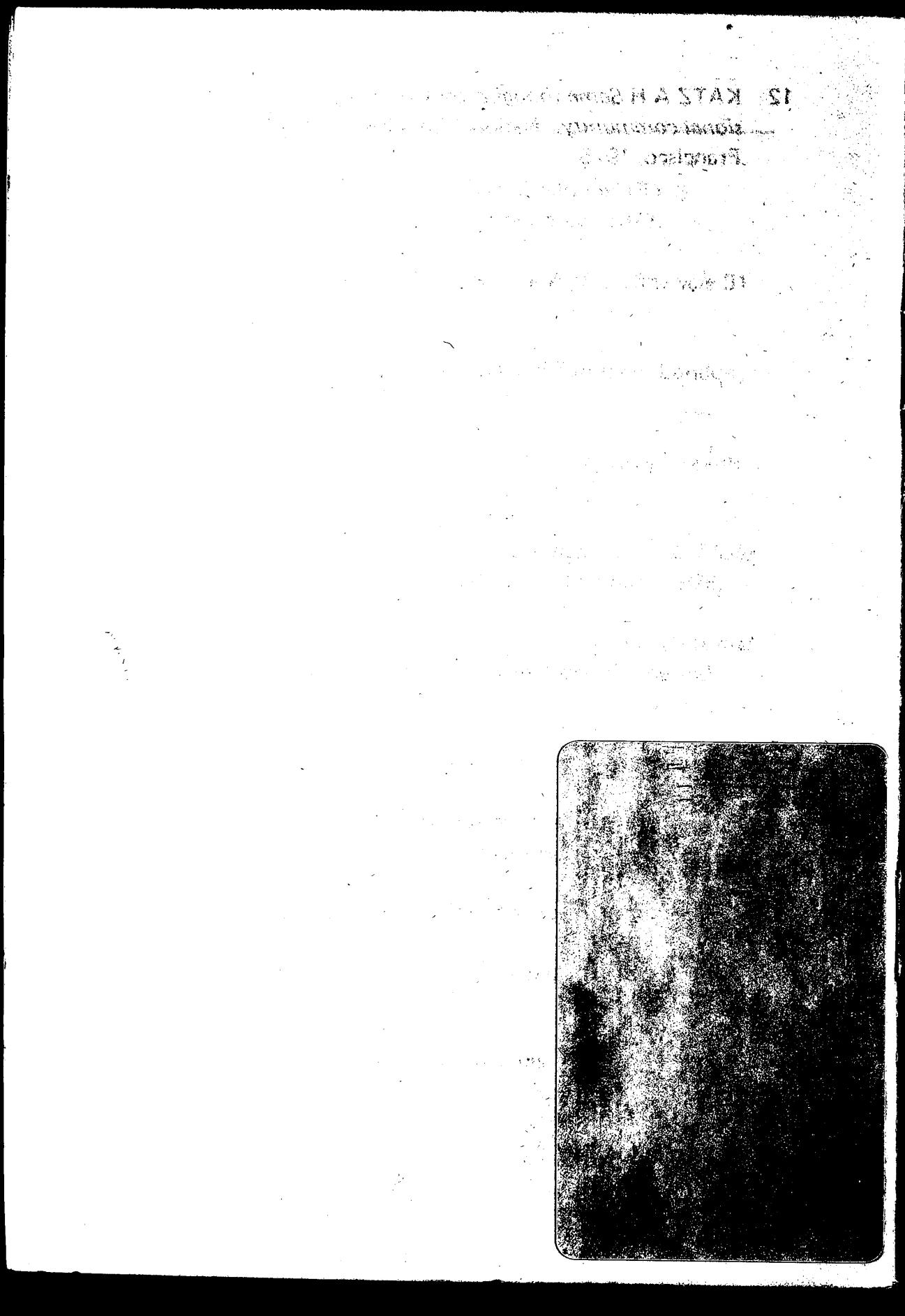
is only by looking at what particular self help groups actually do that we can hope to get away from catchy but unilluminating slogans and begin to appreciate what, at ground level, self help is for particular people with particular problems. For self help groups are of interest today, not merely because governments are short of money — which, of course, they are — or because the groups are symbols of anti-professionalism — which, of course, they may be — but because some of them actually work. And the sooner professionals, laymen and governments rediscover the simple fact that those who share a certain illness, disability, problem or position in the world have something to offer each other, whether that 'something' is emotional support, technical expertise, a refuge from the discrimination or stigma, or whatever, the better it will be for all of us.

REFERENCES

---

- 1 The full study is reported in ROBINSON D and HENRY S *Self Help and Health*, London, Martin Robertson, 1977.
- 2 MAHLER H Problems of Medical Affluence *W H O Chronicle* 31. 8, 1977.
- 3 *The Future of General Practice Learning and Teaching*, London, *British Medical Journal* 1972.
- 4 NEWELL K W (ed) *Health by the People*, Geneva, World Health Organisation, 1975.
- 5 KATZ, A H and BENDER, E I (eds) *The Strength in Us: self help groups in the modern world*, New York, Franklin Watts, 1976.
- 6 CAPLAN G and KILLILEA M (eds) *Support Systems and Mutual Health: multidisciplinary explorations*, New York, Grune and Stratton, 1976.
- 7 BROWN A *Big Problems for little people*, Honey, 10, 1976.
- 8 ROBINSON D *Talking out of Alcoholism: The Self Help Process of Alcoholics Anonymous*, London, Croom Helm 1979.
- 9 DOVE, L Self Help Centres in Los Angeles, *Spare Rib* 55.26 1977.
- 10 VATTANO A Power to the People: self help groups, *Social Work* 17. 7, 1972.
- 11 DUMONT, M P Self help treatment programs. *Amer J Psychiat* 131. 6, 1974.

12 KATZ A H *Some thoughts on self help groups and the professional community*. National Conference on Social Welfare, San Francisco, 1975.



King's Fund



54001000065592

JG?



CHRISTINE FARRELL worked for a number of years in educational research at the then Ministry of Education and the London School of Economics. In 1973 she joined the Institute for Social Studies in Medical Care and conducted a major survey on the way young people learn about sex and birth control. She was Principal Research Officer at the Royal Commission on the National Health Service and is currently Reader in Applied Social Studies at the Polytechnic of North London. She is a member of the Health Education Council.

DAVID ROBINSON is currently senior lecturer in sociology at the Institute of Psychiatry, University of London. His main interests are general medical sociology and the addictions.

## LIST OF TITLES IN THIS SERIES

---

### Paper No.

---

RC1 Conflict and Consensus: An analysis of the evidence submitted to the Royal Commission on the NHS

---

RC2 Essays on Nursing

---

RC3 The Expanded Role of the Nurse

---

RC4 Ideology, Class and the NHS

---

RC5 Consumers, Community Health Councils and the NHS

---

RC6 NHS Finance and Resource Management

---

RC7 Deputising Services, Prescribing in General Practice and Dispensing in the Community

---

RC8 Health Education and Self Help

---

RC9 International Comparisons of Health Needs and Services

---

RC10 Health Service Objectives

---

RC11 The NHS and Social Services

---

RC12 Multi-disciplinary Clinical Teams

---

RC13 Aspects of Dentistry

---

RC14 The Nation's Health and the NHS

---

and Further papers prepared by the Secretariat and Members of the Royal Commission on *Hospitals, Management and Manpower* in the National Health Service

---