Professionals and Volunteers: Partners or Rivals?

Report of a seminar organised by the
World Federation for Mental Health

Edited by Pat Gordon

King's Fund

The World Federation for Mental Health was founded in 1948 to promote the highest possible level of mental health among peoples and nations. Its 1983 Congress in Washington, DC is on the theme of collaboration between volunteers, professionals and governments in the formation of mental health policy and the delivery of services. Further information from:

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PREFACE

Stijn Jannes
European Vice-President, WFMH

The seminar on "Professionals and volunteers: partners or rivals?" continues the present European WFMH programme. This started in 1979 with a study visit in London on volunteers in mental health. In 1980 a workshop in Gent, Belgium focused on alternatives to mental hospitals, and one in Newcastle, England in the same year on transmitted deprivation, its nature, prevention and treatment. Helsinki, Finland was the location of a symposium on mental health and old age in 1981. The seminar on which this report is based differed from the others by including participants from North America who have special interest and experience in the subject.

As current European Vice-President of WFMH, I have much pleasure in expressing warm thanks to all those who contributed to its undoubted success:

- to Professor Eugene Brody, current President of the World Federation for Mental Health, who launched the idea for the seminar and gave support and help throughout its preparation.
- to the organisations in Britain which co-sponsored the seminar and generously contributed resources, staff time and money: the International Hospital Federation, the King's Fund Centre, MIND (the National Association for Mental Health) and the Volunteer Centre. Additional thanks are due to the King's Fund Centre for publishing the report.
- to Edith Morgan, my predecessor as European Vice-President of WFMH, currently a member of its Board and Executive Committee and Director of the Good Practices in Mental Health Project, who developed the idea and was principal organiser of the seminar.
- to Pat Gordon who as reporter of the seminar had the difficult task of drawing together three days of discussions between 47 people from 14 countries.
- to Kina Avebury, William Bingley, Simon Hebditch, Kevin Richards and David Towell who made notes of the discussions, to Maureen Eldridge and Margaret Phillips who typed them and to Philippa Hannay who typed the final manuscript.
- to the seminar organising committee, whose names are listed on page 51.
- to Patrice Leavold and Kevin Richards of the Good Practices in Mental Health Project who made the administrative arrangements, and to Marian Rockes (MIND) who helped during the seminar.
- to Mr Eric Moonman, Chairman of the Islington Health Authority and his fellow members, for an enjoyable evening reception which enabled participants to learn something about the health district in which the seminar took place.
- to Mr Tom Benyon, MP who hosted a farewell dinner party in the House of Commons, and to Lord Trefgarne, Parliamentary Under-Secretary of State in the DHSS, who made a thoughtful speech.
- to E R Squibb & Sons Ltd. for financial support.
- and finally, my sincere thanks to the participants - all busy people - who found the time and means to travel long distances to bring the seminar to life. It is my hope that this is the start of a series of study meetings which will examine in greater depth a subject which in the 1980s is of utmost importance to every country in Europe, and probably the world.

FOREWORD

Eugene B Brody, MD
President, WFMH

This seminar continued the European World Federation for Mental Health tradition of close examination of relevant mental health issues by multinational and multidisciplinary working groups. At the same time it was a landmark for the Federation. For the first time since our founding in 1948, we have explicitly confronted the issues of paternalism and elitism in the relations of professionals to the citizenry at large. These broad issues which must be met in any philosophy of health care are translated into operational questions: Whose knowledge is most crucial to health-relevant decision-making - that of citizen or professional (or the institution which employs the latter?). Which group writes the rules upon which the social contract between help-seeker and help-giver is based? How do these groups work effectively to combine their knowledge and resources? How do citizens banded together in voluntary associations relate most constructively to the organised professionals whose assistance they require - whether the professionals are organised into their own guilds, or are leaders and practitioners in government health services?

The traditional citizen-based source of protection, of service provision and of advocacy for the mentally ill, has been the voluntary mental health association. A newer development in North America and Europe is the development of self help groups. Sometimes led by organisations of former mental hospital patients, these are beginning to threaten the voluntary mental health movement's claim to represent the consumer in this area.

Our Federation is vitally involved in these matters. Mental health, in our view, is not the exclusive province of government or the professions. It must be a concern of the citizenry at large. At the same time we recognise that individual professionals (psychiatrists, psychologists, social workers, nurses and others) are also citizens. As volunteers they are free to act in ways not possible when they represent their institutional employers or professional trade unions. WFMH which, in addition to individual members, includes both professional and voluntary associations has been a unique linking mechanism, a bridge between these two groups. Our inclusion of self help and ex-patient leaders in this seminar, marks a major extension of our usefulness as a linking association. It also adds to our representativeness as the only non-governmental organisation with official consulting status in mental health to the United Nations and its specialised agencies.

This seminar was a first step in our consideration of these essential matters. Its report focuses mainly on the working relationships of voluntary and statutory mental health services in Europe, within the broader context provided by the Northern Atlantic Basin countries of the United States and Canada. The theme has many variations in other parts of the world, and analogies even in countries without voluntary associations. We expect to explore these further. In every instance the Federation is concerned with recognising private needs when public health policy is formed, and with maintaining individual dignity and wellbeing when the health of populations is being considered. Citizen participation in the development of mental health policy is an aid to such recognition. Even more importantly, it can be a source of new ideas and creative energy.

THE SEMINAR

Pat Gordon

Countries differ widely in the extent to which they permit or encourage citizen participation in mental health services. Where such participation is well established, it is valued as an indispensible part of the pattern of care. But it is not universal. In many situations professionals and volunteers view each other with mistrust and misunderstanding. The aim of the seminar, therefore, was to identify the "hot spots", the contentious issues and sources of friction which impede cooperation between volunteers and professionals.

Forty seven people from Europe and North America were invited to take part. To focus the meeting, three subjects were selected - advocacy, service provision and self help groups - and participants were asked to join a discussion group on one of these subjects. Three members were asked to write background papers describing their own national experience and at the same time laying the foundation for three days of international discussion. Simon Hebditch described advocacy in Britain, Raili Rinne described the services provided by volunteers in Finland and Christiane Deneke described self help groups in West Germany. During the meeting two of the groups decided to sub-divide so that, in all, five discussion groups met simultaneously throughout the seminar. Each had a reporter who made copious notes and these form the basis of this report.

In addition, there were three plenary sessions. Edith Morgan and Gary Vanden Bos set the scene with papers based on British and American experience. Joseph Casey, Judi Chamberlin, Melvin Sabshin, Inge Schöck and D van Beek were asked to address themselves briefly to the question "What are the main impediments to volunteer/professional cooperation?" Chris Heginbotham had the unenviable task of summing-up.

My job as seminar reporter has been to draw together all these contributions, the arguments and discussions that took place around them, and edit them into a final report. In doing so, several things become clear. First of all, the seminar was biased in favour of voluntary groups, striving to improve their performance. Only occasionally does the voice of the professional come through with any force and this is reflected in the report. One of the drawbacks in a report such as this is that all professionals are made to sound alike, with common values and opinions, when clearly this is not so. Since we hope that this is only the first of a series of monographs addressing a complex subject from different perspectives and different countries, this may shortly be rectified.

One of the powerful currents running through the meeting was the plea, made eloquently and often by Judi Chamberlin, that the voice of the patient should be heard and respected alongside that of the psychiatrist and the volunteer. Her paper is appended. I have not repeated her arguments in the text but the questions she raised are fundamental to any future discussion.

Our meeting took place in London in 1982 during a period of economic recession which is leading to cuts in public welfare budgets throughout the western world. This influenced all our thinking. Finally, we were an international group from different cultural, political and economic backgrounds and different health care systems. The impact of this diversity is implicit throughout the report.

ADVOCACY

Since the 1960s, the growing effectiveness of the consumer lobby has led mental health associations into the field of advocacy in an increasingly active way. From the traditional service-providing role they have moved towards a campaigning position: arousing public opinion, taking up unpopular causes, representing those who cannot represent themselves and seeking to influence policy makers at every level. It is hardly surprising that this has at times led to conflict with the mental health professions.

On page 16 Simon Hebditch describes the development of the advocacy role of MIND in the UK and Gary Vanden Bos gives examples of the achievements of American campaigners on page 39.

Those who elected to join the discussion group on advocacy began by trying to define what it means in the context of mental health. We were able to agree that advocacy means:-

- to stand for a person's or a group's perceived need
- to stand for a person's or a group's expressed wish
- to campaign for better services and greater public understanding
- to represent a cause as, for example, MIND has done in Britain in recent years on the issue of consent to treatment
- to promote or change legislation as, for example, MIND's campaign for a change in the law has culminated in the Mental Health (Amendment) Bill currently going through Parliament
- to initiate litigation as, for example, the Mental Health Law Project in the USA has done in test cases which have resulted in landmark decisions supporting the rights of patients
- to represent in a legal or quasi-legal setting as, for example, the Mental Patients' Advocacy Project in the USA has done in providing representation at commitment hearings.

When we tried to go further and define legitimate goals of mental health advocacy, we agreed on four categories:-

Anti-discrimination: Issues of basic civil rights including voting, housing, access to employment and employment protection, education, social security, insurance and medical coverage. In the housing field an example was given from the USA where residential restrictions define particular areas as suitable for particular types of buildings. Planning authorities disallowed the setting up of a group home for ex-patients on the grounds that the area was not zoned for that purpose. Intervention - and explanation - by the volunteer group persuaded the authorities to reverse the decision. In this case, the mental health association and the medical profession combined against the city authorities.

Treatment and the process surrounding its delivery: We were concerned here with the patient as a person with autonomous powers over his/her body rather than as the passive recipient of treatment. Advocacy here would deal with the right to comprehensive, accessible and appropriate treatment; the right to refuse treatment; the right of access to medical and other records; the right to privacy and confidentiality. An example was given from West Germany where former hospital residents asked the local mental health association to intervene to stop their medical records being released to the local authority which was housing and supporting them. The mental health group found this practice conflicted with current federal laws on data protection and their pressure resulted in an acceptable code of guidance on the handling of confidential personal data in the area.

Research: We did not mean pressure by laymen for more money for clinical research. While there is still much ignorance about the cause of ill health and the efficacy of treatments, there is also a strong medical research lobby which can fight this battle for itself, and not always to the satisfaction of the ultimate beneficiaries. Our concern was with the need for more socio-environmental data collection and analysis, more evaluation by consumers themselves, and most importantly, external voices to help identify priority areas for research funding. Voluntary groups equipped with knowledge about the needs of their clients should feel able to participate in determining research programmes. We felt that voluntary pressure to maintain research was also vital in a period of recession because of the vulnerability of research programmes to economic cutback. One member, however, asked to have dissent recorded, believing that the medical model would always dominate research programmes.

The promotion of mental health: This is the most overtly political activity, involving direct lobbying and confrontation with politicians and policy makers at all levels. It includes the demand for a fair share of resources in order to provide adequate services.

Advocacy in the above categories can be undertaken at international, national and local levels. Some issues are quite specific to an individual at a given time. Others are universally true. Strategies vary and deciding which strategy to use in a given set of circumstances requires skills born out of experience and a good working knowledge of "the system". It is likely that a national organisation with paid staff, access to the media and a visible membership will feel relatively confident about its role as an advocate with central government; fear of a weakening relationship in an already unequal partnership may be a deterrent to small community-based groups. Western democratic governments may feel that the nuisance value of a vociferous pressure group is outweighed by its role as a provider of information and services, and by the fact that it has a defined constituency. Nevertheless, the advocacy role is the one which most often seems to threaten the expectation of harmonious partnership between professional and volunteer.

As well as questions of style - whether to go in gently, or to wage war - there is also the need to assess whether in some circumstances a successful outcome can be reached by combining forces. The Flemish Association for Mental Health, for example, is now combining with civil rights workers to achieve mental health law reform. Even temporary coalitions of this sort, however, may blur the image an organisation has tried to build up and therefore reduce its credibility. On balance, we felt that groups gained more from speaking independently on subjects they know about, while drawing upon the resources and skills of the widest variety of individuals and agencies, when required.

A related argument is that of setting limits on the areas of advocacy an organisation can or should tackle. The concept of 'mental health' is relevant to most social issues. There is obvious mental health relevance, for example, in family planning, unemployment, political abuse of psychiatry. We felt that decisions about the selection of particular advocacy issues should be a matter for democratic discussion among the membership of an organisation. Flexibility and breadth of vision should be weighed against the risk of loss of credibility and dissipating energy and resources in an over-extension of interests.

Credibility is a prerequisite to successfully carrying out the advocacy role. It takes time to achieve and depends upon a number of factors:- the attainment of a clear identity of purpose; the identification of a clear, and possibly limited focus of activity; the ability to sustain a cause over time in spite of indifference and rebuffs; the possession of a body of knowledge appropriate to the purpose; the support of opinion leaders and "friends at court", and other organisations; a visible membership; a good track record in other spheres of work e.g. service provision, so that knowledge can be assumed.

Partners or rivals?

On the face of it, the partnership between professionals and volunteers in the field of advocacy should wither under the heat of adversarial confrontation. The volunteer may be perceived as more truly a partner of the person on whose behalf he is acting. But this is clearly not the whole picture. There are "hidden" partnerships where a professional chooses to promote a cause by joining a voluntary agency or where an agency is quietly approached by a professional and urged to pursue a particular line of attack. Many of the complaints received in the legal department at MIND, for example, come not from patients or their relatives, but from professional members of staff who clearly have little confidence in their own complaints procedures. We are aware of the risks of collusion here, and agreed that the autonomy of the voluntary agency to accept or reject these overtures must be acknowledged without sanction. We also agreed that a partnership, whether open or hidden, does not preclude rivalry or formalised confrontation which in the UK is exemplified in representation at Mental Health Review Tribunals.

We listed the following as being controversial issues likely to lead to conflict between professionals and voluntary bodies in the coming decade:-

- the fundamental question, what is mental illness?
- a growing sense of the inappropriateness of the medical model; the gradual removal of the care of mentally ill people from the exclusively medical/psychiatric arena; the extension of preventive mental health work
- the issue of freedom and rights versus treatment and care
- "whistle-blowing" i.e. alerting the public and the authorities to particular instances of assault, malpractice or exploitation by professional workers
- other areas of controversy, for example, conscientious objections by professionals to particular treatments, shortages of public money and the resultant rationing of services.

Two examples were given as illustration. A student psychiatric nurse in the UK approached MIND to support his conscientious objection to participating in the administration of electro-convulsive therapy as part of his training. The Royal College of Nursing and the General Nursing Council confirmed that such a refusal would jeopardise his nursing qualification. The case was raised in the House of Commons in Committee on the Mental Health (Amendment) Bill. MIND offered legal advice and possible representation but made no open statement and offered no direct conflict with the whole field of nurse training, at this stage.

In the second example, an English health authority refused to admit a severely ill 86 year old woman referred by her family doctor. Her 80 year old husband was forced to send her to a private nursing home, exhausting all his savings in the process. The health authority's reason for refusing to admit the patient was that shortage of money forced them to close a new psychogeriatric ward. MIND and the psychiatrists combined to draw attention to the economic constraints upon the hospital. MIND also tried to get the health authority to reimburse the husband for the cost of the nursing home fees as her care was their proper responsibility.

Issues such as these will take up an increasing proportion of the work of both professional and voluntary agencies. We felt therefore that two matters in particular should be given urgent consideration:-

- the need for some mechanism for resolving ethical dilemmas and other controversial matters, to be built into the respective professional and voluntary structures. In other words, an ad hoc debate on each issue is too time-consuming and unsatisfactory.
- the need for recruitment, specifically for the advocacy role, because we believe all mental health organisations can be more successful in attaining their goals when advocacy is an integral part of their work.

PROVIDING SERVICES

The traditional role for volunteers and voluntary organisations has been to provide a service for mentally ill people and their families, and this tradition continues today. Here are to be found examples of the closest cooperation and the most bitter conflicts between volunteers and professionals; cooperation often on broad, general aims, conflict more likely on specific issues. On page 44 Gary Vanden Bos describes it thus: "The basic issue in the conflict revolves around who has the knowledge, power, right and responsibility for determining and directing care. The decisions regarding how service delivery is organised, what services are provided .... who will provide the service .... and the evaluation of the quality and effectiveness of the care are at the heart of the issue."

Because of the complexity of a subject ranging from the characteristics of a volunteer to the decline in social policy budgets, the participants who chose to take part in this discussion divided into two groups to focus on (a) the relationship between individual volunteers and professionals and (b) the relationship between voluntary oganisations and government agencies trying to provide a service particularly in a time of economic recession.

Providing services - as an individual

Our concern here was with three groups of people and the interactions between them, namely, professionals, clients (patients and their families) and volunteers. We were clear that there could be no firm dividing line between them and that one person could be professional, volunteer and patient within a short space of time; helpers and helped changing places at different times in their lives. We agreed that the primary level of care is the community of family, friends and neighbours and that, only when this proves insufficient, is professional or voluntary support called for.

Most of our discussion took place from the point of view of the volunteer. We spent some time on definitions. On pages 31 and 32 Edith Morgan offers two classifications of voluntary activity. Philip Schraemeijer suggested another by distinguishing between volunteers and voluntary organisations which emerge as a reaction to existing services (e.g. would-be professionals and ex-patient support groups) and those which emerge more or less independently (e.g. women's groups and some self help groups). He linked this to the view that western society is in a process of democratisation whereby income, power and knowledge become more equally distributed. In this typology, would-be professionals are seen to compete with paid professionals for income, ex-patient groups to compete for power and self help groups for knowledge.

There was some sympathy with the view that a volunteer is simply someone who declares himself to be so. But Inge Schöck described what she felt to be the distinguishing characteristics of a volunteer:-

- he relates to the mentally ill person as a friend and fellow-citizen. They do not meet as part of the treatment process
- the voluntary helper does not give instructions. His position is rather that of a partner on the same level as the patient
- the relationship is not one-way
- reliability and commitment are necessary
- unlike the professional, the voluntary helper need not keep a therapeutic distance from the patient. This is an advantage although he must be aware of having limits to the relationship

- unlike the professional, the voluntary helper may disengage if the work becomes too much of a burden.

In her background paper Edith Morgan poses many questions relating to successful collaboration. We had time to concentrate on only a few:-

Lack of communication: D van Beek described "the most important impediment to collaboration" as the professional's lack of understanding about what volunteers do. The most easily recognised role may be that of patient-aide but there are many others: the board member, the client who "stays on" to help others, the professional who works as a volunteer in his own time, the fund-raiser. Better communication is needed as well as a recognition on both sides of the special competence of the other.

Stereotyping: Melvin Sabshin made a plea for an end to stereotyping and gave examples of ideological slogans which only hinder cooperation e.g. 'all pharmacotherapy is bad'; 'de-institutionalisation is inherently superior'; 'professionals are only interested in guild issues'; 'volunteers are do-gooders who muck up the system'; 'volunteers should do what we think they should do'; 'rehabilitation, re-socialisation and preventive services are ancillary and subservient to the real medical treatment'. He argued that rivalry was not necessarily a bad thing; that differences of opinion and attitude were to be expected but that the crucial factor was for both sides to behave with dignity and make efforts at understanding the other's position.

Fear of the mini-professional: Many professionals fear the volunteer who over-reaches himself and dabbles in matters beyond his competence. But conflict may also arise from a misplaced fear of rivalry. D van Beek sees the personal contact that takes place between patient and volunteer as being the most important aspect of the relationship. For the professional, however, the most important thing is the quality and effectiveness of the assistance he is able to offer. Personal contact is of secondary importance, in van Beek's experience, and may be avoided if it is thought to interfere with treatment. These are complementary but different functions which can lead to friction, particularly if treatment is not going according to plan and the professional feels vulnerable.

Confidentiality: Anxiety over confidentiality is often given as a reason against using volunteers. Joseph Casey pinpointed this as one of the impediments to cooperation particularly in a rural district where everyone knows everyone else. Raili Rinne also discusses this in her paper on page 21. We saw potential conflict here when the professional's ethical standpoint precludes him from passing to the volunteer confidential information which could be regarded as essential to his relationship with the client. Similarly, conflict is inherent in a situation where the volunteer receives confidential information which is unknown to the professional.

Unacceptable practices: One of the strengths of the outsider, coming in with fresh eyes, is to be able to see things in a new light. This can lead to problems, however, when the newcomer perceives practices which he finds unacceptable. The only way to avoid conflict here is to have an effective complaints procedure capable of resolving the issue speedily at the lowest possible level within the service.

Three major values of cooperation between professionals and volunteers are bridging the gap between potentially isolated professionals and society at large; acquainting the public with the problems of psychiatric institutions, their users, and their staff; stimulating public interest and concern which influence policy makers and therefore the level of services provided.

In order to facilitate cooperation, the following issues require careful attention:-

- recruitment and training of volunteers
- resistance to using volunteers in what would otherwise be paid positions
- open and effective channels of communication
- mutual discussion of roles
- willingness to acknowledge the others' special competence.

Providing services - as an organisation

This discussion group concentrated on what they saw as the critical issues in the 1980s in the relationship between the voluntary sector, professional bodies and government agencies.

Participation in the planning of statutory services: We recognised the enormous differences in planning systems in different countries and in the structure and financing of statutory services, but agreed that in each country it was essential to develop mechanisms for effective participation by voluntary organisations. We recognised, too, how easy it is to talk of 'community involvement' without defining what we mean or devising methods for making it work. We tried, therefore, to formulate conditions for effective participation by voluntary organisations:-

- an interested membership, prepared to invest time and energy
- an information/secretariat service to provide back-up
- travelling expenses and income support to allow all those interested to play a part (otherwise those who can afford to do this work, financially and in terms of time, tend to be other professionals)
- training in planning and information systems
- the right to vote on planning committees
- a planning timetable which allows reasonable time for consultation
- effective consultation within the membership of the voluntary organisation itself
- some form of neighbourhood or patch consultation to enable as many local groups as possible to take part
- willingness by officers of health and social services to accept non-professional involvement
- willingness by officers and board members to accept the testimony of ex-patients
- greater understanding by bureaucrats of the dialectic of voluntary organisations e.g. working towards a goal via the planning system and simultaneously campaigning politically for the same ends.

The development of comprehensive local services both statutory and voluntary: We identified three significant functions of voluntary service-providing organisations: (a) to provide experimental services which, if successful, will be taken over by the state; (b) to provide alternative services to those provided by the state; (c) to provide a service where none exists. Only with a comprehensive service is it possible to offer the choice which is necessary to meet the needs of patients and their families. To achieve this we strongly recommend the formation of local forums to bring together all service-providing agencies in a neighbourhood to plan an integrated service.

The emphasis on community care: The phrase "community care" is used to mean a shift in the balance of resources from institutions to community-based services - fewer hospital beds and more local homes; fewer hospital nurses and more community nurses, home helps, geriatric visitors; fewer people removed from their neighbourhood to receive treatment and more health workers able to provide a local service. Community care is not intended as a cheap option to hospital care but as a more "human" form of care. The phrase is also used in another sense, however. In the current political and economic climate in Britain, for example, 'community care' is used as an ideological slogan by the political forces determined to undermine state-financed services. Public services are being cut back and this results in increasing reliance on so-called community care which is, in fact, unpaid care by the family, particuarly by women, or indeed public neglect of those in need. Service-providing voluntary organisations face considerable challenges in this situation.

Declining public budgets: Cuts in welfare budgets may also lead to inertia in changing the patterns of service. This in turn may mean that new needs, for example those of the elderly mentally infirm, are met increasingly by 'low-cost' solutions. This is another challenge for voluntary organisations.

Growing unemployment: Rapidly rising unemployment in western societies is likely to alter the attitudes of paid staff to voluntary work. At the same time, it is likely to lead to a growing number of volunteers for whom volunteering may have a new meaning i.e. as a route to job-related experience.

These are the types of challenges voluntary organisations face in the 1980s. We have suggested a number of responses which might be helpful at local level. Some mentioned earlier are stressed here:-

- the creation of local forums where there can be a dialogue between statutory and non-statutory services
- careful analysis by voluntary organisations of their members' views in order to participate authoritatively in statutory planning processes
- drawing on the experience of users and former users of services in order to shape the future pattern of care
- developing greater sensitivity to staff organisations, particularly where there are cuts in services
- developing demonstration projects or good practices which make better use of existing resources
- using the experience of providing services to 'signal back' to the community at local and national level, the consequences of public policies.

SELF HELP GROUPS

Self help groups are a growing phenomenon in Western societies. Our medical and social service systems have to take account of that growth. Christiane Deneke's background paper on page 25 describes the development of self help groups in West Germany and in Hamburg in particular where the WHO research project on 'self help groups in health' is based. A European clearing house has been set up and is similar to the National Self Help Clearing House based at City University of New York and described in Dr Vanden Bos's paper on page 42.

Participants in this discussion group decided to split up for part of the seminar to look more closely at internal relationships within self help groups and external relationships between self help groups and other welfare organisations. Before reaching this point, however, some time was spent on definitions. The most useful definition of self help groups was found to be "those groups which are centred around a specific illness and condition in which people with the problem or closely affected by it help each other by providing mutual aid, understanding, information, technical assistance and emotional and social support."*

There are, however, many kinds of self help groups with a wide variety of purpose and organisation. Some groups are closely related to professional services e.g. CARE, the Cancer Aftercare and Rehabilitation Society in Britain which tries to provide the "human care" so often found to be lacking in medical services. Some are formed to offer alternative services to the medical model, as for example, some women's health groups. Some seek only to treat themselves as they were once treated by professionals. Some groups are formed by professionals who then withdraw. Some are formed by ex-patients and then manipulated by professionals. Some avoid all contact with professionals.

Judi Chamberlin suggested three models of self help groups. The partnership model where professionals and non-professionals work together to provide a service. Those who receive the service are also partners but, she suggested, in name only. There remains a clear distinction between those who give and those who receive help. Most half-way houses are an example of this model. The supportive model allows membership to everyone who wants to use the service, all members are equals since all have problems at some time and all are capable of helping one another. Professionals are only "bought in" when their expertise is needed for a particular purpose. They are not allowed as members because they draw a distinction between those who give and receive help. In the separatist model, membership is open only to "sufferers" or "ex-sufferers". Professionals and volunteers are excluded.

There is, then, a wide variety of self-help groups and the nature of their relationship with professionals varies from group to group. We tried to pinpoint some of the controversial aspects of that relationship which need to be studied in greater depth. The question of membership is one such issue. Membership is the prerogative of the "sufferers". The primary focus of the group will be the mutual support to be gained by the members themselves. Both professionals and volunteers will be, to a greater or lesser extent, outside the membership yet their role may be crucial to the way a group develops.

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* definition proposed by David Robinson to WHO Working Group on "WHO, Self Help and Health" held in Leuven, Belgium. Nov.1981.

The very process of gathering together as a group to support each other will lead members to discuss and assess their own needs. This in turn may lead to a re-definition of needs and so to a demand for different services. Traditionally, it is the trained professional who defines needs. Many professional workers react with dismay and alarm at the prospect of their medical or social diagnoses being challenged. The more rights patients have, the more impact they make on professionals. If the aim of the self help group does not coincide with the aim of the professional, the chances of conflict are increased.

Self help groups also assess their own values and goals and there is no doubt that many of them will look outside their own environment to make assessments of the society in which they live and the extent, if any, to which that society is responsible for creating the conditions which led to the emergence of the group itself. To a certain extent, therefore, the political system in which we live is an issue and many self help groups will include a campaigning role in their work. The Mental Patient's Liberation Front, Boston is an example of such a group and is described by Judi Chamberlin on page 47. They are a group of ex-inmates of psychiatric hospitals who "question whether we were ever 'ill' (although many of us were indeed troubled). We see the medical model as masking the true nature of our experience .... We see many people whose overriding problem is poverty and this, too, gets re-defined as 'illness' requiring 'treatment' .... Ex-inmate groups have lobbied state legislatures, testified before numerous boards and committees, appeared on local radio and television shows, picketed and leafleted and tried in every way to be included when decisions are made which affect our lives most of all".

Self help groups tend to work in gaps left by the professional providers. They are often seen by professionals as another institution to whom patients can be referred. Moreover, they are frequently seen as 'catch-all' groups who never turn people away and are therefore a means of getting rid of problem patients. The danger of self help groups becoming institutionalised and used by professionals is another contentious area worth examining further. It is precisely their growth and development which causes the problems. The build up in membership, increase in demands, external activities and need for more funds can all compromise the group's original goals.

Another source of conflict is likely to be the growing demand for increased resources which will lead self help groups into competition with the statutory services. Is the self help group to be funded as an alternative to traditional forms of service? We agreed that the crucial issue for the 1980s will be the level of provision of services as a whole and not just the way in which they are divided. In other words, one big question is likely to be the size of the cake itself and not just that of the slices.

We were strongly in favour of encouraging self help initiatives. We were convinced that where there is a strong community network and services are organised on a neighbourhood or patch model, self help groups can thrive. We identified the single most useful type of practical support to be the setting up of local resource centres. These would offer not only equipment such as typewriters and printing presses, but also information about services, funding, legislation and so on. Social resource centres in Norway are an example of this kind of development.

Efforts to simplify the legal machinery involved in establishing self help groups should be encouraged. Current legal restrictions in some countries may inhibit the formation of groups or oblige them to dissipate energy on unwelcome administration. All measures which help to relieve the pressure to "grow or die" are to be welcomed.

Knowledge and access to information is of the utmost importance to self help groups. This report referred earlier to the role of the professional as consultant. Volunteers are also in groups as helpers and professionals and volunteers may have a joint role here 'to work the system' so that appropriate assistance is made available to self help groups. Some Community Health Councils in the UK see themselves as part of a local resource network able to 'work the system' in this way and so help those trying to find their way around the National Health Service.

On an international level, we endorsed the WHO/UNICEF Declaration of Alma Ata, particularly its emphasis on a community-based approach to mental health care. We welcomed the initiative of WHO's special focus on self help and health and urged that it be sustained, with due importance given to mental health. One means of achieving this would be for the World Federation for Mental Health to pursue its interest in the subject and follow up the work of this meeting in more detail and greater depth.

WHAT NEXT?

Key points for action

We met for three days to exchange ideas on what turned out to be an extremely complex subject. Inevitably perhaps, a great deal of time was spent on definitions and the discussions tended to be extensive rather than intensive. We saw ourselves at the beginning rather than the end of a debate; one which will continue in other places and from other perspectives. We did reach some conclusions. We also identified several issues to be taken further and studied in greater depth at both local and national level in our various countries, and at an international level by WHO, WFMH and the IHF.

Above all, we want a comprehensive mental health service. To achieve this we need better planning. If volunteers are to work constructively with professionals for a better mental health service, then they must be party to the planning of that service. We believe that statutory planning processes can be enriched by "outside" contributions, but voluntary organisations must do their homework. How can they best make their contribution? What are the most effective local forums for planning comprehensive services, voluntary and statutory? How can the neighbourhood or patch model of service provision be put into operation? How can voluntary organisations best represent the views of their members? How do we define 'the community'? Is it perhaps very much smaller than is usually allowed, say the 3,000 people of a neighbourhood in London rather than the 150,000 of a London Health District?

We need demonstration projects to show how to get the best out of the service. In a period of recession when funds are scarce there is more need than ever to identify good practices and to disseminate the information. How can this best be done? How can we develop evaluation criteria for mental health services, comparable to the normalisation concept in mental handicap services? This could be a prime target for WFMH in the 1980s.

We need to think of the future role of volunteers. Who are the volunteers of the 1980s? Is volunteering becoming a means to job-related experience for unemployed would-be professionals? How can professionals and volunteers learn to recognise each other's special competence? Who should train whom?

Self help is one type of service. Relatively little is known yet about the impact of self help on more traditional services. There are many question marks and many pitfalls for the vulnerable mental health professional. We need a proper discussion of the problems and potential of self help. Can practical support be offered without inhibiting conditions? Should self help initiatives be funded as an alternative to state services? Is self help a result of the failure of present services or the outcome of a re-definition of needs by consumers themselves?

We want consumers to have a greater influence in shaping mental health services. We want the voice of the consumer of mental health services to be taken seriously, along with that of the provider of services. How do we achieve it?

What part does advocacy play in realising these aims? Mental health associations seem to be more successful in reaching their goals if campaigning is an integral part of their work. How can they best do it? How should they recruit effective lobbyists and train them? Should they set up permanent ethical committees to consider controversial matters? Must advocacy always be political? Does it inevitably lead to confrontation?

Partners or rivals? or partners and rivals? We found no easy answer. We saw plenty of opportunity for rivalry in the coming years but evidence, too, of successful and productive partnerships. We left with an awareness of how much we can do now to promote understanding but aware, too, of the need to continue the debate about how we can do it better.

ADVOCACY IN BRITAIN: The work of the National Association for Mental Health (MIND)

Simon Hebditch

My purpose in this paper is to give a sketch of the work of the National Association for Mental Health (MIND) and outline where that organisation stands in relation to the areas of service provision, advocacy and self help.

MIND is the largest and most active voluntary organisation in Britain on mental illness matters. MIND also works on mental handicap but to a much lesser extent at the moment. The National Association for Mental Health was originally formed in the early 1940s and was largely involved in providing direct services - the development of group homes, other forms of housing and accommodation, social clubs and various forms of psychiatric day care. The subject of this seminar is so important not just because each of the areas can be seen separately but because they represent, historically, particular fashions of interest. As I have already mentioned, the basic purpose of the National Association for Mental Health in its early years was the direct provision of services at a local level. It was really only in the late 1960s that many charities and voluntary organisations started to balance the service work they did with a more campaigning and 'political' approach. This shift of emphasis was mainly brought about by the example of Shelter, a British housing charity which decided it had to focus public opinion on the appalling housing conditions in which some families are expected to live and to arouse public opinion by an unashamed use of the press and the media.

It is important to realise that other charities and voluntary organisations owe a considerable debt to Shelter for breaking the traditions of the past and striking out in new directions. Of course, many difficulties are still presented by this more "activist" approach to voluntary activity. In Britain there is a Charity Commission which regulates the rules by which charities are allowed to operate. Such rules ban political activity for charities and there are constant arguments about campaigning and its justification. I will come back to that issue in relation to MIND's work a little later.

Some people seem to assume that a choice has to be made between direct service provision and a campaigning approach. There is no reason to believe that these aspects are in opposition. Any voluntary organisation that fails to provide direct services should not be listened to when it comes to advocacy. Equally, any organisation that is frantically running services but failing to draw any conclusions from this work is also failing to act in the best interests of its clients.

The Provision of Services

There are 170 local MIND associations providing a wide variety of services. We have six regional offices offering information, advice and practical assistance both to these associations and also the state sector. It is always important to remember that local voluntary assocations can vary enormously in size and effectiveness. In one town there will be a fairly large and thriving MIND association offering many schemes and in the next town along the road there might well be two people and a dog! Even more importantly, in many areas of the country there will be large gaps with no local resources at all. For that reason if no other, there is no doubt in my mind that the state sector is of greater importance than the voluntary movement. To use a clear illustration, I believe that the role of the voluntary movement is to provide the icing on the cake but not the basic ingredients of the cake itself! The voluntary movement exists to add to and improve upon state services rather than replace them.

What sort of services are offered by the 170 MIND associations? Local associations have been traditionally associated with various housing schemes and group home arrangements. This sort of work has continued and at the beginning of this year there were nearly 350 housing projects in operation and another 45 planned.

In 'core and cluster' schemes the core acts as a centre in which certain support services are available (or can be called upon) and the clusters simply represent ordinary living accommodation situated relatively near the core. The important element is to ensure that ordinary housing stock is used for housing people rather than building new blocks which can be recognised, and therefore, categorised by the rest of the population. More and more core and cluster schemes are being started. This is an area where the voluntary movement has been able to show the way and give examples of 'good practice' for the state services to follow.

In addition, nearly 200 social clubs are now being run by MIND associations as well as approximately 70 day centres. Activities within such clubs and centres will of course be various. Many such clubs are now including befriending schemes and counselling arrangements within them for those who wish to take advantage of them. Calderdale, Scarborough and Barnet are examples of groups organising befriending schemes. There are also an increasingly large number of MIND associations running advice and information services for both mentally ill and mentally handicapped people. Despite the fact that we are regarded as an organisation only interested in mental illness there are over 40 schemes for mentally handicapped people being organised by MIND groups.

Nationally, MIND distributes funds to groups - whether members of MIND or not - for starting up various projects. Evidence shows that the majority of MIND local association projects relate to the more traditional areas of residential accommodation and day centre provision whereas the majority of counselling schemes are being organised by non-MIND organisations.

There is no doubt that MIND associations do provide a large number of valuable services around the country and that such provision is valued by the state sector both at local and national level. The question marks for the future relate to the nature of services offered, the development of self help and prevention and the ability of the voluntary movement to expand at a time of economic recession and theoretical change. One of the much praised virtues of voluntary organisations is their greater flexibility and lack of top heavy administration. Such beliefs will certainly be put to the test in the coming years. One of the issues now facing the voluntary movement is the ever increasing number of national schemes, devised by government to provide voluntary organisations with funds to set up projects in which the unemployed can be directly involved. It is clear that unemployment will continue to have a major impact on social policy for some time to come. The problem for voluntary organisations is to resolve the dilemma between taking advantage of the proposed schemes while not wholly altering their priorities.

Voluntary Organisations as Advocates

One of the functions of voluntary organisations should be to speak out on behalf of their client groups and, where appropriate, represent them before statutory bodies with which they might be in conflict. Since the end of the 1960s the voluntary sector has been more active in this area of work. The success of Shelter, the housing charity, and the development of the National Council of Civil Liberties encouraged other bodies to take up issues that were appropriate to their expertise. The trouble is that people tend to interpret the word 'political' wrongly. The political process is the pursuit of change or the maintenance of existing conditions through public argument and democratic choice. Such activity has nothing whatsoever to do with party political allegiances. It is surely right that if a voluntary organisation comes across abuses, whether these be personal or institutional, that it should attempt to remedy such abuses. To obtain a remedy means that you campaign. You might write to the appropriate Minister or local government councillor and the abuse may be immediately remedied. That is a campaign. You might provide evidence for members of the Government about their policy plans - and government will constantly ask you for such views - and the process of forwarding such views is a campaigning one. Social progress is not brought about simply as a result of individual or collective virtue but as a consequence of public campaigning. There is no reason at all why voluntary organisations should not play a full role in this area. The only restriction should be to ensure that such organisations do not become party political and, therefore, partisan rather than rational.

In 1974/75 MIND's Council of Management decided that the organisation should become more involved in the issues surrounding the rights of patients and so Tony Smythe, who had been General Secretary of the National Council of Civil Liberties, was appointed as MIND's Director and subsequently Larry Gostin was taken on as Legal and Welfare Rights Officer. Over the last seven years MIND has developed a considerable reputation as a body willing to take up unpopular causes and represent those who found it difficult to pursue their own cases. Much work has been done on the 1959 Mental Health Act and campaigning for changes in the law has culminated in the present Mental Health (Amendment) Bill at present completing its progress through the House of Commons. MIND has concentrated a great deal of attention on psychiatric hospitals and on the issue of consent to treatment. An individual's right to participate in decision making, if he is competent to do so, has been the basic belief which has governed our responses to all issues.

Such a role has inevitably led us into conflicts from time to time with the psychiatric profession. That is inevitable and nothing to be overly worried about. If we concentrated attention on the quality and quantity of services provided by local authorities we would no doubt come into conflict with local authority leaders. But not all the advocacy with which we have been involved has been controversial. MIND has taken the lead in launching and supporting an Advocacy Alliance which will help to provide individual advocates for patients in hospitals. This is currently being done in some hospitals with the full agreement and cooperation of the hospital authorities. One of the aspects which we need to consider in the hospital sector is that a vast amount of the complaints we receive in our Legal Department about treatment or ill-treatment within hospitals comes not from the patients themselves but from members of staff who clearly have no great confidence in their own complaints procedures.

It will be necessary for MIND to keep an interest in hospital care but the increasing importance of care in the community means that we will be inevitably shifting our emphasis once again towards the services being provided by the National Health Service at primary care level, by local authorities and by voluntary organisations themselves. This does not mean an end to the role of advocacy. There is much wrong both with the quality and the nature of local authority services and there will be plenty to keep campaigners busy.

Self Help Movement

One of the developments of the 1970s has been the movement towards self help. For quite some time this has existed at community level on housing and general environmental matters but it is clear that more and more community groups are taking on health issues and emphasising the need for prevention work. In terms of mental health there has been a growth in groups for anorexics, agoraphobics and even those suffering from depresion - although the latter produces great difficulties in organisation and progress.

One of the arguments in favour of directing voluntary efforts towards self help is the lack of financial resources for the provision of adequate state services. The advocates of self help not only believe in it in theory but also say it is inevitable given the acute lack of resources in the social policy field and the fact that we cannot go on expecting public expenditure to rise to meet needs in the traditional way. For MIND such an argument produces a problem of strategy in relation to our campaigning role for greater social services. There are also implications for our MIND local associations which are, in the majority, based on traditional service provision and methods of organisation. However, it is true that our concern with the psychiatric hospital population, and especially those who are compulsorily detained, has meant that we make no impact on the majority of people suffering from some form of mental or emotional distress. Those organisations applying to the MIND Projects Fund which were not MIND local associations were precisely those providing the more modern counselling schemes and other initiatives. There is no doubt that MIND has to urgently consider its strategy in this regard. At present, the organisation is really doing very little to provoke or support self help projects. Of course, MIND's national impact can only be really in the provision of information and advice services or the danger would be that local self help initiatives will get swallowed up in national bureaucracies - and voluntary organisations have those just as much as state services.

What Strategies?

National voluntary organisations must continue to provide direct services although it may now be time for each to examine critically those that are being offered. The voluntary movement must also continue to fulfil a campaigning function. Can this be done locally without incurring financial penalties? Can it be done nationally without the same penalties or falling foul of the charity commissioners?

With the best will in the world there is no way in which the state services can cope with the demand for assistance and so a partnership is vital between the state and voluntary sectors. Having said that, it is equally important to state that the role of the voluntary movement should be to add to the provision of state services. In that sense we should be increasing our role in the self help field as well as campaigning on issues relevant to the provision of effective community-based care. In collaboration with professionals of all descriptions we should be devising practical ways in which a comprehensive psychiatric service can be organised. We must also listen to the voice of the consumer far more and reflect her/his needs and desires.

For what seems decades now people have been endlessly debating the theories of community-based care. Many can be forgiven for feeling that they have heard it all before. The play never changes - only the actors are new. It is now time, and past time, to discuss the mechanics of providing such care, the technicalities of moving people out of inappropriate settings into the right environment. We must beware that word 'strategy' for often it is a code word for endless talk rather than actual work. Stated briefly, we should all be aiming and working for the following principles and the methods used by both the state and the voluntary sector must be judged solely on the criterion of whether they advance us towards these objectives or not:-

1. The creation of a series of comprehensive services within localities providing such a choice as will allow the right person to be in the right environment at the right time.
2. To ensure that practical check lists of such services are widely available so that the quality and required quantity can be verified. The lack of adequate provision is justification enough for a campaigning approach, regardless of who is upset in the process.
3. Voluntary organisations, whether national, regional or local, should be consciously balancing their work to ensure that they are contributing to the provision of basic services, taking up issues and speaking out publicly to protect the rights of individuals and improve collective services and encouraging and sustaining self help initiatives especially in relation to prevention projects.
4. Voluntary organisations should set themselves similar checklists and standards for their own work and ensure that these are publicly available. Collaboration and partnership with the state services is obviously to be encouraged but not at the expense of the independence of the voluntary sector. New ideas and schemes can be pioneered by the voluntary movement and the state should be prepared to fund such developments regardless of the other functions of the voluntary movement.

Once we have agreed a rough list of principles and objectives such as the above, surely we simply have to get on with it.

VOLUNTEER ACTIVITY AND ITS DEVELOPMENT IN FINLAND

Raili Rinne

Voluntary activity got an exceptionally favourable start in 1978 following the report of a committee set up by the Ministry of Social Affairs and Health. Its terms of reference were:-

- to assess the potential of voluntary work with regard to existing social and health care systems.
- to make proposals for suitable forms of cooperation at local level.
- to give information about the administrative issues related to volunteer work and make proposals for potential changes in legislation.
- to assess financial need and make a proposal for a financing system.

The Committee established that volunteer workers could either act independently or support professionals in the field of social welfare. Volunteer activity is today very considerable in such fields as crisis intervention, intoxication care, children's day care, support person activity, family and youth counselling, aid of the elderly, support of lonely people, serving people with sensory defects, care of the disabled.

The Committee recommended that cooperation be encouraged by establishing permanent local negotiating delegations.

The Support Project

The Finnish Association for Mental Health is the oldest organisation in the world in the field of mental health. Voluntary mental health work has been undertaken since 1897 and has included humanizing the care conditions of mentally ill people, experimenting with new methods in caring work, preventive mental health work, psychiatric rehabilitation and family counselling.

In 1980 a major new project was started in 15 areas in the country, with the aim of seeking out and supporting people in mental crisis. The widening of voluntary activity in this project has its roots in the successful crisis intervention work of the Suicide Prevention Center of the Association (the SOS-Service) in the last ten years. The 15 experimental areas were chosen in conjunction with the regional mental welfare offices of the public health care system. Regional trainers were appointed to lead the voluntary activity in addition to their daily work. They received additional payment. The local trainers were mainly social workers, specialised nurses and one of them is a psychologist. Their training was started in 1980 in Helsinki with the goal of getting the project started simultaneously in all experimental regions. The selection and training of the support persons was then started in 1981 and was similar in every region. Selection was based on such factors as how established the candidate's own life situation was, what were her motives in volunteering, and what was her ability to feel and show empathy. Students or professionals were not chosen very willingly. The size of the support-person groups varied between 10 and 30 people. In all, there are 250 support persons in 15 regions.

The voluntary work began at the beginning of 1982 and can be divided into two areas:

- On duty crisis telephone service was started in six areas, mainly in cities, and accommodated in their mental health offices or health clinics. Other support activity was started in 9 regions, for example, conversation groups for people experiencing a loss, another for young adults. Every support person has one to four individual support relationships.
- Support activity in the work place produced interest in several areas. One to six supporters were trained for a large enterprise in Helsinki. The employer's attitude towards the project was very positive. The support persons are permitted to work during working hours in nearly every enterprise and the interest in this form of activity seems to be growing. Two big industrialised cities have expressed their willingness to participate. Tampere, the second biggest city in Finland, has sought help from the support group and has offered to spread information with the help of 3,000 people working in hotels and restaurants.

One interesting experiment was initiated by the Finnish emigrants in Sweden. A survey by the Finnish Association for Mental Health revealed that emigrants are helped only in the late stages of their mental problems and that language problems hamper proper help. Jønkøping was interested in starting support activity among emigrants, and crisis telephones and conversation groups for young alcoholic men and unemployed people have now been started. Many Finns, who had not previously taken an interest in Finnish affairs, volunteered. Thus many emigrants were reached all of whom seemed to have serious adaptation/language/mental problems.

The project will be analysed in 1983. In addition to general information about the support activity, there will be more specific reporting on:

- the potential use of supporters in mental health work.
- whether certain basic information was of value in predicting the success of the person as a supporter (eagerness, skills, capacity). This will be used in the future selection of support persons.
- the direction training should take to meet the objectives more efficiently.

A series of 8 questionnaires has been developed to monitor the support activity. These include self-esteem questions at the beginning of training, measurements of the success of training, descriptions of crisis telephone calls and so on. The purpose of the questionnaires is not only to serve as a basis for directing the work and to preserve the collected information, but to assist the support persons themselves to follow their personal development as well as the general development of the support relationship. Each support person is enjoined to secrecy after the training and before they start the actual work. The promise of silence forbids the support person to spread any knowledge of the people in need of help to outsiders.

Other developments in voluntary work since 1981

Two of the biggest mental hospitals in Helsinki proposed cooperation with the Finnish Association for Mental Health. These hospitals had used the Red Cross' Friend Service before. The Finnish Red Cross is experienced in working with the elderly, with prisoners and with chronically ill people but they more or less avoided psychiatric patients and had difficulties with crisis and dependency situations. The Red Cross confessed that they were lacking resources to undertake that kind of work.

The Association first suggested to the acute psychiatric hospital setting up a social club based on team work and led by the support volunteers. Very much to my surprise, the attitude of the hospital was somewhat negative. They seemed to prefer more concrete action. Perhaps they felt their own therapy group work was threatened. The chronic hospital, on the other hand, was more interested in our idea. It is situated outside Helsinki and many patients suffer from feelings of loneliness after getting back to Helsinki, so our suggestion of cooperation was received with gratitude. In the autumn of 1982 we plan to start conversation groups in the acute hospital for divorced patients, single parents, and for relatives of psychiatric patients. In the chronic hospital we plan social club activities, emphasising adaptation training.

I find it is most important in this form of activity that the action model is formed outside the hospital and that the work guidance responsibility belongs solely to the Finnish Association for Mental Health. But generally the responsibility is assigned to the nurse or person responsible for the caring of the patients in hospital.

The autumn of 1982 will also bring cooperation with the psychiatric patients' organisation who wish to train a support group from among themselves. We agreed that the best solution would be to train supporters from people who have been patients in mental hospitals, but now live an established life. It emerged that the patient organisations felt averse to the strict selection procedure for support persons, described earlier. We agreed finally that the support group from the patient organisations would act more on the basis of self help. I can also predict that patient organisations are finally daring to criticise the doctor-centred activity of the Finnish Association for Mental Health. The professors of psychiatry have given support to the patient organisations' activities with the Association. The chief physician of the biggest acute hospital in Helsinki was then invited by the patient organisations to give a public speech on his ideas. He has criticised the establishing of huge psychiatric hospitals and their institutionalisation and has recommended instead the Fountain House type of institution originating in the USA. These institutions work more democratically and so encourage patients to act for themselves. One centre of this kind has been established in Tampere and has proved very successful. A similar centre is planned in Helsinki.

Many professionals believe that patient organisations should be led by professionals and need continuous professional support. It seems at the moment that the Finnish Association has the necessary skills to succeed in cooperating with patient organisations and is accepted in doing so. The patient organisations themselves want the Association's support in making their problems public, supporting their activities and giving necessary work supervision. Patients' problems now receive much attention in the media.

Cooperation with state services

My personal view, as the leader of the support activity project, is that there should be close cooperation with state services. However, there seem to be more opportunities for independent work than cooperation and this leads to increasing responsibility for volunteers. This causes problems when, for example, our trainees found work unexpectedly difficult and demanding. The danger then is that the support group delegates responsibility to the professionals. Preserving interest and enthusiasm and keeping trainees active seem to be the main problems during the project.

Professionals are well disposed to cooperation but practical situations have brought difficulties. There have been arguments about the accommodation used in the project. Support persons have been accused of breaking their promise of silence and of being unable to estimate situations correctly. There have been several discussions on whether professionals should take responsibility for the mistakes of the volunteer workers, and if so, to what extent. Special doubt has been directed to the volunteer workers' skills in leading groups. Expressions like "they may act as long as they don't interfere with our work" have been hanging in the air.

Psychiatric thinking is still very disease-centred and institution-centred in Finland, even if there has been a move towards open care in the last ten years. Support training is trying to get rid of disease-centred thinking and the results seem to be good. Unfortunately, this way of thinking is not always seen positively by professionals.

The rights of the patient

The Finnish Association for Mental Health has supported patient organisations and individual patients in difficult situations, such as involuntary care and the position of minority groups. I personally think that this kind of activity should be strongly promoted. Patient organisations are increasinly in need of support and they lack attorneys for the efficient running of their business.

Self help movements

With self help groups I mean primarily groups that come together with common physical and mental difficulties. They keep together and try to widen their contacts to people in the same position. They try to support each other in difficulties. This kind of activity demands courage to enter into the public arena. It is important that they gather of their own will, independently, under their own conditions and in their own accommodation. These kind of organisations in Finland are AA-Association (Anonyme Alcoholists), sexually abnormal people, union for divorced people, but this form of activity is still very new in Finland. I see a very positive future for self help in the field of mental health, and I hope that self help activities will extend to chronic schizophrenic patients, relatives of mental inpatients, divorced people and lonely people. The Finnish Association for Mental Health is taking its first steps in this field, with the support activity for self help groups in the autumn of 1982.

I am a bit afraid of the direction things seem to be going in Finland at the moment. The financial support of the Ministry of Social Affairs and Health has made it possible to start many kinds of new volunteer activities, but, as usual, bureaucracy brings dependence with it - not to speak of the competition for money. There is strong support from official organisations but they may kill spontaneous and creative activity especially in self help groups.

SELF HELP GROUPS IN HEALTH

Christiane Deneke

This paper is based on research findings from a project on 'self help groups in health' at the University of Hamburg. It is funded by the Federal Ministry for Research and Technology and is part of a wider research programme on "lay participation, patient activation and self help in health".

The project is concerned with self help groups in three ways. It is a research project on the origins, development, performance and effectiveness of self help groups in health, including the relation of self help groups and the professional system. It has a small local clearing house for self help groups in Hamburg. It started a European Information Centre on Research into Self Help and Health in collaboration with the WHO-Regional Office for Europe.

We have used a broad definition of self help associations in the project and have divided the health relevant associations into five categories:

- associations concerning specific diseases (for coping with a medically classified chronic disease or impairment)
- associations concerning life problems (social and psychological) e.g. women's and men's groups, groups for the lonely, associations of social security recipients
- associations concerning public health or social services e.g. community action groups for the maintenance or installation of health institutions, patients' rights associations
- environmental associations e.g. fighting chemical pollution of the environment
- alternative culture associations e.g. communal living, collective working where healthier living is an expressed aim.

We have defined the criteria for a self help association in health as:

- being affected by a shared problem
- little or no involvement by professional helpers
- no profit orientation
- shared aims (personal and/or social change)
- procedure emphasising cooperation based on equality and mutuality of aid.

Associations comprise small groups and organisations, but we have limited the empirical research to those organisations where at least a subgroup meets regularly at least monthly. Large associations, even though they might call themselves self help organisations are often not included, because the criteria of "self help" are not met.

The incidence and development of self help groups

Looking into German history, self help roots can be traced in the unions, the now compulsory health insurance system and many welfare organisations. In the health - or rather ill-health field - groups exist for many chronic diseases, handicaps and addictions. And there are lots of other groups which have some direct or indirect impact on the people's health status - women's groups, groups for single parents, sexual minorities, or the elderly.

But looking at the whole of the population, only 32% have ever participated in self help group activities or consulted a self help group for advice. Nevertheless, about one third of the population feels, that a self help group could be of some help to them in case of need (Grunow 1981). This figure cannot be interpreted as meaning potential members for self help groups but rather as an indicator of a positive attitude towards the groups.

The only comprehensive figures available are for the urban area of Hamburg. Hamburg is a city-state, the biggest city of the Federal Republic of Germany with 1.7 million inhabitants. Economically, Hamburg is one of the wealthiest areas of Germany with the largest port and much international commerce.

We know of about 570 groups, out of which 400 are directly disease-oriented and 170 deal with social and psychological problems. Because of the less formal organisation of many groups concerned with social and especially psychological problems, 170 is an underestimate of their number. To give some idea of the distribution of groups, the table below shows the figures for different categories.

Category	**Number**	**Percentage**
Alcohol, incl. groups for partners	235	59
Other psychiatric	9	2
Internal medicine*	35	9
Physically handicapped	68	17
Surgery, incl. cancer	12	3
Other diseases	16	4
Groups of relatives	29	7
Total	404	

* These include 29 groups for people overweight, which have been organised by the clearing house in Hamburg.

This distribution shows the very strong bias towards alcoholism. There are networks of groups for cancer patients (especially women), but for the vast majority of health problems, only very few groups exist. Even though there are few figures about the growth of self help groups in West Germany, the experiences of local, regional and national clearing-houses show a growing interest in groups, supported by intensive mass media coverage. New groups are emerging all the time. The increase in Hamburg has been about 33%, in 20 months (May 1980 to January 1982). This figure does not include those groups directly concerned with alcoholism.

Links with the professional system

Our findings about membership, motivation and success agree with findings in other countries (Deneke, Kegler, Slotty 1981). Our findings on links with the professional system show contact with state agencies in 90% of the somatic disease groups and groups for relatives and 25% of the addiction groups and groups for other psychiatric problems. Contact with professionals is again most frequent in somatic disease groups. Professionals are at least sporadically involved in 64% of all health groups. For many groups, professionals were (or still are) important, because they helped with the founding of the group, or stimulated its foundation. Disease groups get quite a few of their members through professional referrals but this does not happen in groups concerned with social and psychological problems, or groups for relatives. Even though the deficiencies of the professional system are one of the main reasons for joining a group, there is little anti-professional attitude within the groups. Most members want to cooperate - but they want professionals to accept their aims and their approach.

The professional's view of self help groups

We undertook a survey of the professional's view of self help groups with the aim of (a) gathering information on knowledge about, attitude to, and cooperation with self help groups by physicians, psychologists and social workers in the health field, (b) identifying those professionals interested in further information about self help and those interested in more cooperation.

The following statements are based on this survey of 600 Hamburg health professionals (doctors, psychologists, social workers):

- whilst all professionals had heard of self help groups before, 50% (doctors) and 64% (social workers) knew more about at least one of them than their mere existence.
- lack of information is often mentioned. Information about the phenomenon in general and groups in particular is widely asked for.
- knowledge about groups is strongly biased towards groups for alcoholics.
- self help is seen as suitable for a variety of problems - but addiction is again predominant.
- prerequisites for group referral seem to be oriented towards professional control. This is so especially with doctors, less with psychologists, least, but still noticeable with social workers.
- prerequisites on the client's side are not strongly self help specific.
- the place of self help groups is seen to be in after-care, as a complement to the professional system.
- self help groups are seen to have a function, even when the professional delivery system is sufficient.
- the general attitude of health professionals towards self help groups is positive.
- professionals are able to accept personal goals in a self help group more easily than social goals, such as lobbying or trying to influence the social roots of the problem. This is especially true of physicians.
- the achievements of the groups are in areas outside professional concerns.
- self help groups are generally seen as successful.
- the single achievement of self help groups mentioned most often by professionals was the lessening of personal isolation of members.

- negative consequences of group participation were mentioned by about half the respondents, such as overrating their capability and worsening relations with the professional system.
- cooperation with groups and stated willingness to cooperate was higher than expected:

	physicians	psychologists	social workers
Frequent cooperation	14%	7%	24%
Occasional cooperation	31%	38%	35%
Cooperation conceivable	45%	51%	40%
Cooperation out of question	11%	5%	1%

- the reasons given for lack of cooperation are lack of information, lack of time and self help being inappropriate for the clientele.
- forms of cooperation vary widely. Very few participate regularly. The majority of professionals gather information about groups through contacts with group leaders or members and/or recommend groups personally.
- over 80% of professionals are content with the level of cooperation. Almost half of them want to increase cooperation. Very few want to reduce it.
- self help group members are important to professionals as a source of information and to initiate cooperation.
- doctors who cooperate most frequently are likely to work in hospitals, in internal medicine or psychiatry, and they are more likely to be in a self help group themselves. They are less oriented towards professional control over groups and they accept the general social aims of the groups more often than the others.
- social workers who cooperate most frequently work with addicts, assume a much higher percentage of their clientele to be suitable for a group, and are less oriented towards professional control. The cooperators feel more often than the non-cooperators that the professional system should not only be improved but changed profoundly.

* Deneke, C.; Kegler, R.; Slotty, A.: Selbsthilfegruppen aus der Sicht der Betroffenen in: Kickbusch; Torjan: Gemeinsam sind wir starker - S.139

Grunow: Selbsthilfepotential der Bundesrepublik Deutschland: Einstellungen, Motivation und strukturelle Rahmenbedingungen: 2. Zwischenbericht. - Bielefeld, 1981. Projektgruppe Berwaltung und Publikum an der Universitat Bielefeld.

The development of the voluntary movement in the U.K. - questions for the future

Edith Morgan

In the UK, which has a comparatively long tradition of voluntary organisation and activity, the level of voluntary involvement in the mental health field has varied considerably over time, with changes in public attitudes and in government health and social policy. Apart from the large state mental hospitals, many of them built in the Victorian era and still in use, most of the present mental health services were started by voluntary organisations, almost always with the intention that they should be developed into national statutory services.

Many people expected the introduction of comprehensive health and social services after the Second World War to make voluntary organisations, and services provided by volunteers, redundant. And indeed, following the establishment of the National Health Service in 1948, official policy allowed little place for voluntary groups or individuals, except those elected or appointed to committees managing the services. This reflected a revulsion against the idea of people with illness or social problems having to depend on grudging charity for help. A similar feeling, that people in need should be provided with the best possible services as of right, underlies the continuing resistance in some countries to the idea of non-professional, non-statutory intervention in health and social care.

But not everyone in the UK was committed to the idea of a 'welfare state'. For example, Lord Beveridge, who played a leading role in the introduction of the postwar British system of health and social service provision, believed it to be one of the products of a democratic political system. He wrote, "Vigour and abundance of voluntary action ..... individually and in association with other citizens, for bettering one's own life and that of one's fellows, are the distinguishing marks of a free society".

This was, however, an exceptional view at that time, and there was a marked decline in voluntary activity for almost two decades after the end of the War. It took years for opinion to change, but by the 1970s there had been a major rethinking of the role of volunteers in Britain. Some of the influencing factors were:-

- the cost of the National Health Service had grown more steeply than anticipated, and limits were being placed increasingly on the expansion of the statutory services.
- the needs, especially in the field of mental health were becoming clearer and had proved greater than anyone had foreseen. Previously much of the distress and the consequences of mental illness had been hidden by poverty.

More important than either of these factors, however, were the changes and expansion within the voluntary movement itself. It was an expansion of many dimensions:-

- in the size and scope of the voluntary provision for people who could, it was seen, still slip all too easily through the state's welfare net.
- in organisational efficiency and skills.
- in increasingly vociferous and effective demands to be heard from people personally affected by different kinds of illness and social problems.
- and in the extension of the voluntary sector's role as 'society's conscience'.

New approaches in mental health care

The development of voluntary organisation as a whole was closely bound up with substantial sociological shifts during the same period; the problems of families and individuals had ceased to be seen as separate from those of the societies in which they lived. Voluntary bodies concerned with mental health were also operating in the context of fresh approaches to the understanding and treatment of mental illness. The 1959 Mental Health Act was an important watershed, formalising in legal terms the more liberal attitudes that had been emerging in relation to mental illness, and putting emphasis on community care as preferable, wherever possible, to the in-patient treatment that had hitherto been the routine method of dealing with psychiatric illness.

Unfortunately, warnings that the adoption of the slogan 'community care', without ensuring that such care was actually provided, would be misleading and dangerous, were not heeded by government bodies. Through lack of a direct financial link between community and social services and the health services, the rundown of hospital populations was not accompanied by an equivalent expansion of community facilities, and the hoped for improvements in psychiatric care were frustratingly slow in coming. But despite inevitable disappointment and disillusionment, a steady shift away from residential hospital care has taken place. Official bodies, under constant pressure from the voluntary sector, have for many years been committed to a policy of community care for the treatment, support and rehabilitation of mentally ill people. Implementation of the policy lags behind, but gradually community facilities have been and continue to be built up both by statutory and voluntary organisations. The lively interest we find in the UK in new ideas and experiments relating to community psychiatry is certainly not confined to this country. The outstanding success of the 1980 WFMH Workshop in Ghent, Belgium on 'Alternatives to Mental Hospitals', and the persisting interest in the report of that Workshop, is only one manifestation of what is probably a universal trend.

It was perhaps inevitable that a drift away from hospital care, and the sometimes extravagantly phrased (and unfulfilled) predictions foretelling the closure of all the old mental hospitals, should create a belief that mental hospitals are bad in themselves. This has, however, been modified. While the focus is still firmly on developing community care, hospitals are more and more regarded as a part of the communities they serve, and a valuable resource for some people at some stages of a mental illness.

The response to these developments, in terms of changing roles of the professionals - psychiatrists, nurses, psychologists, social workers and so on - has been uneven and, to an extent, slowed up by successive adminstrative reorganisations and financial crises. But these upheavals have also encouraged new thinking on other levels and given the voluntary sector additional opportunities to become involved. Certainly in the UK today the contribution of voluntary bodies and of volunteers, in both voluntary and professional services, is generally accepted as necessary and indispensible, if appropriate mental health care is to be available on the scale and in the forms that society can accept as tolerable.

But this development is not a swing-back to the pre-1948 tradition. In the past few years there have been significant changes and developments in the views of both volunteers and professionals about the place of voluntary work in society, and the nature of the contribution volunteers can make to health and social services.

Partners or rivals?

Acceptance of volunteers and voluntary organisations was not quickly nor easily achieved. Especially during the years when groups of mental health workers were struggling to establish their own professional codes and training, 'interference' in mental health work by individual volunteers, not responsible to any authority as paid employees, was often resented. More farsighted, and perhaps better qualified, staff members could even then see the potential for complementary forms of activity, and they helped to pave the way towards more constructive relationships.

It has to be acknowledged that there is still some residual resistance to volunteer involvement amongst professional workers. Lack of understanding of the role of volunteers is one factor in this. Other causes may be an unfortunate experience with volunteers, a fear that standards of work cannot be maintained without professional control and direction, or dislike of a diverse collection of voluntary schemes intruding into a more orderly and structured system of statutory care.

Unwillingness on the part of professionals to cooperate with volunteers takes many forms and is not always expressed openly. Now that voluntary participation has come to be accepted by the establishment, outright opposition is rare. But lip service paid to its value can hide a strong reluctance to make a personal commitment to it. "Not needed here" is a fairly common escape route.

Friction between professionals in the statutory services and professionally staffed voluntary bodies is on a different level. Those employed in the official services often, perhaps understandably, resent attacks on aspects of the services by outside groups who do not share their responsibility for them. This is especially true of hospital staff who may be working in very difficult circumstances, which they feel are not fully appreciated. It has to be said that voluntary bodies to not always show tact and understanding in their criticisms, nor are they invariably accurate in making them. But when they do take the trouble to be well informed, and act responsibly, they can help to put a situation into perspective. It is undeniable that many serious wrongs have been corrected as a result of voluntary organisations, frequently with the aid of professionals, drawing attention to them. However, there is still room for considerable movement on both sides before a partnership of 'creative tension' between professionals and volunteers, which many people see as the ideal, is reached.

The voluntary sector

In any discussion of the roles of volunteers and voluntary organisations, it is important to distinguish some of the elements that make up the voluntary sector. It contains a very mixed bag of organisations, services and people with amazingly varied forms of training, abilities, functions and responsibilities. Voluntary activity has been classified in a number of ways and it may be useful to refer to two of these - the first made by doctors and the second by social workers.

- a definition by doctors

In 1972 a Tripartite Committee, representing the British Medical Association, the Royal College of Psychiatrists and the Society of Medical Officers of Health (i.e. public health doctors) specialising in mental health, defined four functions for voluntary bodies. They were:-

1. To seek constantly to improve the state services by trying out new ideas, experiments and forms of care that might eventually lead to new state provision.
2. To assume the role of 'loyal opposition' to the established services, offering criticisms of proposals, and suggestions for improvements in plans and services. The authors of this report explicitly recognised that this might sometimes lead to 'downright opposition to official plans', and to 'taking a militant line about what the voluntary bodies believe to be wrong, even when this offends the establishment'.
3. To undertake an important educational role, in forming and changing public opinion about mental health issues.
4. To represent the consumers of the mental health services, and encourage groups of patients or ex-patients, and the families of disabled people, to join in mutual aid activities to improve their circumstances.

- **a definition by social workers**

In May 1982 the Report of a Committee set up in 1980 to study the role and tasks of social workers under the Chairmanship of Peter Barclay, was published.

It gives its definition of the voluntary sector as comprising four main systems which constitute a spectrum of care. They are, the Report says, making a large and often underestimated contribution to the welfare of individuals and families. The four suggestions are:-

1. Informal carers (without which, the Barclay Committee believes, the social services would barely be viable).
2. Mutual aid groups.
3. Volunteers.
4. Formal voluntary organisations with paid professional staff.

This neat labelling of voluntary and volunteer groups is attractive and indeed useful. It is also misleading. Within each of the four groups there is a considerable degree of diversity and untidiness, which has to be seen as a strength rather than a weakness in the context of the enormous variations that exist in human nature and human need.

Informal carers

'Informal carers' - the families, friends, neighbours, workmates, local shopkeepers, the people found in most communities to whom others instinctively turn when in trouble, or those who just 'give a hand' now and again - are to be found everywhere. In countries where close supporting relationships within extended families and community groups are still in the norm, it might seem strange to categorise such caring by giving it a special name. In industrialised countries, where we are concerned about the large numbers of people who live alone, often in conditions of extreme isolation, it is a salutary reminder that a sense of individual and community responsibility has not been lost. A very great deal of care is being provided by a great many people, without their having to be organised for the purpose.

But such help falls far short of meeting all the needs; partly because of the sheer volume of problems; because the potential carers are not always in the places where difficulties are concentrated; and because certain kinds of problems produce behaviour in people that alienates those who might help, (what one writer described as lacking the 'cues' that babies and some older people have to attract willing helpers).

There are fears too that some problems of illness and incapacity - those of elderly mentally confused people come to mind as an example - are of such proportions that without adequate support the carers themselves can suffer real damage.

Self help and mutual aid groups

The rapid growth in self help and mutual aid groups in recent years has been one of the most exciting developments of all. In Britain there are now several thousand such groups in the health and social services field, with widely ranging purposes, policies, and of every conceivable size. At one end of the scale there are tiny groups of fellow sufferers who derive comfort from their shared experience, and who look to the professionals for advice and guidance. At the other end are large organisations whose policy is to keep the professionals at a distance, and who find the strength and energy for their work programmes from their own knowledge and convictions, derived in the main from personal experience either as sufferers from mental illness or members of their families. Their suspicions that over-close relationships with professionals could weaken them were vividly expressed recently by the founder of the National Schizophrenia Fellowship, when he said:

> "We must keep our eyes on what we are really for. We are, and must stay, a relatives' organisation and not fall into the hands of 'experts'. We have special knowledge out of experience, which we must tell to the Government.
>
> We have a double function:
>
> a) to give comfort and help to individual sufferers and their families
> b) to get improvements in the support available from public provision."

Volunteers

The label 'volunteers' in the context of mental health is deceptive because it is a generic term embracing people of widely differing ages, social groupings, abilities and experience, who perform an infinite range of tasks, from small (though important) practical services to highly skilled work such as counselling.

The old stereotype of volunteers as middle-aged, middle class and usually of the female sex, still persists though it is dying away. Nowadays every section of society - from schoolchildren to elderly people, and from every social class - is represented, though not of course proportionately to the population. The image of the volunteer as a 'do-gooder' - a phrase sufficiently offensive for one person interviewed on television to retort indignantly that he was as much a 'do-badder' as anyone - is also disappearing. We are coming to understand more about the mutuality of helping relationships. At the same time as those with problems are being assisted, a need in human beings to be useful is being satisfied.

It goes without saying that distressed people must be protected from incompetent busybodies, but the old arguments about purity of motivation in volunteers (leaving aside the motivation of professionals) now look rather old fashioned. The point is that the benefits of volunteering are not in one direction only, and helpers and helped can change places at different times in their lives. One British psychiatrist wrote about 'the biological need to help', and said of volunteering, 'it is as blessed and satisfying to give as to receive and it is quite wrong to regard voluntary service as a difficult chore requiring special gifts of saintliness'.

Those giving voluntary help in the UK include many people who have become interested and involved through being directly affected by a particular problem. They also include a substantial number of paid professional workers in the statutory mental health services, who join in the activities of voluntary organisations in their spare time. They do so for many different reasons; because it gives them an opportunity to escape the bureaucratic constraints that hinder them in their daily work; because their commitment to improving the mental health services impels them to give more than the basic hours or work; because as members of a community they want to share in its mental health efforts; and sometimes perhaps because it improves their career prospects. The ways in which these professionally trained volunteers help also vary; often they work on an equal basis alongside other volunteers who have no special training, but sometimes their role is to guide and support them. Unquestionably, their involvement has a significant effect on the way voluntary work as a whole develops.

The settings in which volunteers choose to work also vary, from voluntary organisations where they probably have a voice in shaping their own work programmes, to statutory services like hospitals where their tasks have to be fitted into the requirements on an official body, and avoid conflicting with the interests of paid staff.

Voluntary organisations

Formal voluntary organisations with paid staff have become big business in the last twenty years. Their numbers, compared with the numbers of people employed in government health and social services, are relatively small, but are by no means insignificant. They have, moreover, come to wield an influence out of all proportion to their size either in manpower or in money. They tend to attract personnel who are strongly motivated towards a particular cause and who are often highly talented. Sometimes they are staffed by people already trained in mental health work, who have chosen to abandon what they see as the limitations of statutory 'bureaucracy' and prefer to put their energies into the voluntary sector, frequently for less material rewards.

Most national voluntary bodies have access to a force of voluntary helpers through their network of local groups. These local resources enable the national organisations to extend their operations, and also make them aware of how local communities - including the users of services - perceive their needs and what they think of the services they are offered.

The services provided by voluntary bodies at national and local levels are usually popular with the authorities responsible for statutory provision and, especially in times of financial stringency, they are encouraged to develop this side of their work. National voluntary organisations are generally on their guard against being 'used' to fill gaps, or to take over anything they consider is rightly a statutory responsibility. Their proper role, they insist, is to complement - not supplement - the work of the statutory sector. The most successful voluntary organisations seek to be as well informed as the official bodies, with whom they frequently have a curious love/hate relationship. Official approval for the servicing and educational roles of the voluntary bodies tends to be counterbalanced by dislike of some of their campaigning activities, as predicted by the 1972 Tripartite Committee.

In 1962 the Chairman of MIND (then known as the National Association for Mental Health) described in its Annual Report how he saw the purpose of voluntary bodies:-

> "We concentrate public attention on problems which seem to be underestimated or misunderstood; we support and supplement what is being done officially; we pioneer experiments on which we are prepared to stake both money and reputation; we focus public goodwill; we mobilise individual effort; always we live adventurously on the edge of new opinions, ready to accept challenges as they arise."

To what extent would national voluntary bodies find that description valid today?

Finance

The brevity of the note under this heading does no justice to its importance. Many of the problems and crises of voluntary organisations are centred around finance, and fundraising is a perpetual and uphill struggle for most of them. Many voluntary bodies receive state funding to varying extents; some would like bigger grants (or one of any size), while others fear that receiving government funding threatens their independence.

A need for more staff, which immediately increases running expenses, is the usual corollary of success. Economic inflation sends up the costs of all health and social services, but voluntary bodies are the hardest hit since members and donors looking for ways of making personal economies can simply stop subscribing.

But fundraising is not considered a tedious necessity by everyone. Some see it as an additional opportunity for publicity and education, and also as a way of involving people who want to help the cause of mental health but do not feel able to work directly with mentally ill people.

Benefits of the voluntary contribution

Some of the benefits attributed to volunteers and voluntary organisations are set out below, but the list is by no means complete. It is said that:-

- though difficult to define, one of the most valuable contributions of the voluntary sector is in improving the quality of life for underprivileged people;
- freedom from official constraints allows voluntary organisations flexibility to respond quickly to new policies, ideas, needs and opportunities - especially in developing innovative services and educational programmes. They are better placed to take risks than official bodies;
- since they can more easily try things out on a small scale they are specially capable of innovation and pioneering activity. Some mistakes are inevitable in the early stages of any experiment, and these can be corrected while the new model is being put into working order and made ready for replication;
- they do not have to reject a request for help because a person's problems do not fit their rules. They can cater for minority groups more easily than an organisation operating large scale services;

- they are prepared to go on providing basic support and friendly help for the most severely disabled people, who may have fallen out of the treatment system and for whom no-one may acknowledge responsibility;
- they can take a special interest in meeting one particular need and thus acquire valuable expertise in that area;
- because they are not part of the 'official' scene, their help and information are more acceptable to some people. They can at times provide a bridge to professional treatment;
- their closeness to local communities enables them to reflect more accurately individual and local needs and ways of meeting them, than larger and remoter structures;
- in their watchdog role they can monitor the work of the statutory services, and campaign for improvements, as well as bring to light things that need attention;
- since they can divert their energies into any direction they choose, they are able to devote themselves to campaigning systematically, and often successfully, on major policy issues, such as a need for legislative reform;
- since they represent, and in a sense are, the general public, they can be particularly effective in mental health education and in improving public attitudes to mental illness;
- they are said to be especially well placed to work in the field of prevention.

Some problems of voluntary participation

Complaints about the voluntary movement are not usually as drastic as those made by a London Director of Social Services a few years ago when, in an article published in The Times, he declared it healthier for major social problems "to be tackled through its properly designated institutions, rather than through ad hoc self-appointed organisations responsible to no-one but themselves". But there are criticisms and anxieties about certain aspects of their work that have to be taken seriously. Some of these are:-

- there is a genuine concern about problems of accountability;
- since voluntary bodies formulate their own policies and work programmes, they provide an uneven coverage of services. Some causes and some districts are well catered for while others are neglected. Statutory provision can assure more uniform care;
- voluntary helpers, who are not paid employees, may be unreliable;
- there is a danger of volunteers being used as 'cheap labour', to the detriment of paid staff and also of services to clients. The trades unions are very watchful on this point;
- volunteers may model themselves on professionals and attempt to work in ways for which they are not trained.

Some points for consideration

The issues arising from this paper could occupy a seminar lasting much longer than three days. Even so, it has not touched on some fundamental themes such as policy formation and management of voluntary organisations. The following list of questions, far from complete and in no order of priority, is offered only as a starting point for preliminary thinking.

Volunteers

- What kinds of work are appropriate for volunteers?
- What are the best methods of recruitment now that one traditional source, in women not employed outside the home, is drying up? Are there some important groups under-represented (e.g. 'working class' volunteers, young people)? How can their numbers be increased?
- Are clients, as the Barclay Committee suggests, potential volunteers?
- Should all volunteers be selected? What criteria should be applied to selection and how should possible rejection be dealt with?
- Should volunteers be trained, or does this destroy the spontaneity that is said to be one of their assets?
- If training is desirable, who should decide its content and organise it?
- How can voluntary help be best coordinated? And given continuing support?
- What are the proper roles for mental health professionals who offer voluntary help? Can they avoid dominating the groups they work with? Does it matter if they do?
- Should the initial training of mental health workers include some basic teaching on cooperating with volunteers and community groups?
- Is there a problem about confidentiality of information when volunteers are involved?
- Does the concept of volunteering rule out all thought of payment? What about travel and other expenses?
- Are there any major differences between the work of volunteers attached to a hospital or another statutory service, and those working in the setting of a voluntary body?

Voluntary organisations

- Can voluntary bodies successfully undertake work programmes that include all aspects of voluntary mental health activity - campaigning, advocacy, service provision, education and information? Or should they select and specialise in certain areas of work?
- People in the statutory sector are sometimes critical of the number of separate voluntary organisations concerned with mental health. They talk about possibilities of overlap, duplication and misuse of time and money. Are these dangers real? And can they be avoided? Should voluntary bodies with apparently similar aims be encouraged to unite?
- What are the most important areas for advocacy and welfare rights programmes? Does work in this area present any particularly thorny problems in relation to accountability?
- What can professionals in the mental health field offer to voluntary organisations?
- Funding seems to be a big problem to most voluntary organisations. Should they be funded by government? What are the implications of this?

- Are there problems when paid staff are employed a) by voluntary organisations, b) by statutory bodies, to recruit and work with unpaid volunteers?
- What kind of working arrangements with statutory bodies are most likely to facilitate a fruitful partnership?

Self help and mental help groups

- What are the most important roles and functions of such groups and what advice and assistance do they need?
- Is there a danger that the members of self help groups may become too preoccupied with their problems?
- The number of self help groups is growing fast. Many of them are concerned with very specific and narrowly defined problems and some have a very short life. Should (and could) anything be done to rationalise the self help movement?
- Do professionals have any role in relation to self help and mutual help groups, either in their initial setting up or in their running? If so, what is it?

Informal carers

- The Barclay Committee believes that without informal care the social services would barely be viable. Yet the burden that this care places upon relatives and friends who undertake it is just beginning to be recognised. What are the roles of professionals and volunteers in the development of support services for this area of care? Should the coordination of support for this resource be left to chance?

AN AMERICAN VIEW

Gary R Vanden Bos and Mary K Uyeda

Volunteers and voluntary organisations in mental health throughout the world typically perform one or more of three functions. One function is policy or legislative advocacy. This can mean attempting to influence the way in which existing programs are carried out, or conceptualising (and working to pass) legislation needed to achieve certain ends (i.e. seeing that particular groups are served or certain services are provided). A second function is legal advocacy. This may involve legal action on behalf of a given individual (either as an individual or as representative of a class of individuals), or it may involve legal/administrative aid to help persons in need of services to obtain them. The third function is service provision. This may take the form of alternative service provision (e.g. community based, paid or unpaid, non-professional care) or self help groups established by patients themselves or their families and other support groups members.

In some countries there is one major governmental department or national non-governmental organisation which carries out all of the above-mentioned activities. In other countries the functions may be broken into three separate governmental agencies or non-governmental organisations. In still others there may be combinations of national level and local level activities that overlap and to some extent duplicate each other.

The United States is an example of the latter type. There are some associations that have highly organised national offices with paid staff, whose organisational patterns (and type of activities) are then repeated on regional and state levels. In other non-government associations, the national level staff may be paid, but regional offices staffed by volunteers. There are others who have no national office and who form loose and unstructured coalitions of other like-minded groups on regional or national levels. In some cases, the functions carried on at the national level will be completely different than the activities done at the state or local level. For example, the national office may be primarily involved in policy and advocacy, while the local offices may be solely addressing service issues. Or, the national level office may be an information gathering, policy analysis, and knowledge dissemination operation, with the material that has been developed being used by regional or local offices for advocacy purposes. Sometimes, the functions described above are carried out by a government unit, such as consumer protection office. Examples of these various and varying models follow. It should be kept in mind that it is a rare group that sees itself as performing only one of the listed functions. For example, an organisation that sees its primary function as self help may also see advocacy as an important additional role. Generally, however, groups can be roughly categorised by their primary function (e.g. what the majority of their time or dollars goes towards).

This paper is primarily concerned with the goals and activities of voluntary organisations and groups through which citizens carry out voluntary activities. In addition to organised participation of this type, many highly important contributions are made on a voluntary basis as individuals. They may serve on a Board of Directors of a community mental health centre, a mental hospital or a sheltered workshop. In addition, many hospitals and community clinics/programs have formal programs for volunteer workers to assist in where professional skills are not seen as essential. Recreational programs, transportation assistance, basic clerical and custodial duties are examples of this type of volunteer activity.

Policy/Legislative Advocacy

One of the most broad reaching examples of a US voluntary mental health organisation is the National Mental Health Association. It is a nationwide group with dues-paying citizen members. Eight hundred local chapters and 44 state divisions are separately incorporated; they are linked by a Washington-based central office and information network which is directed by a representative system. Priorities for each biennium are established by representatives to a national meeting. The three main purposes of the NMHA are: to promote mental health, to prevent mental illness and to promote better care for the mentally ill. On the national level, a paid staff of forty supports activities in areas such as organisational development, training, resource development, planning and program development, public affairs and government affairs. State level offices perform the same functions but through voluntary committees instead of paid staff - working for reform within state legislatures and administrative improvements in state departments of mental health. At the local level, chapters operate through voluntary committees and work to influence city council and county commissioner decisions affecting mental health service delivery. The level of activity of local chapters varies greatly, as might be expected. At the local level also there are some examples of direct services provided by associations but these take the form of support activities rather than professional services. Social clubs or visiting programs address social needs not personal problems, and MHAs make it a point not to interfere with or assume any professional roles. There is no systematic interaction with self help groups, although the MHAs do promote working with such groups. All manner of persons belong to MHAs and the associations are an important link between the strictly professional provision of services and public awareness of mental health issues and concerns.

Other volunteer mental health organisations focus on specific sub-populations of those with mental difficulties or disorders. The Association for Retarded Citizens is a prime mover for coalitions and consortiums on the local level. It advocates a non-medical model that focuses on developmental aspects of behaviour. It is national in scope, claiming nearly 200,000 members. Nearly half the members are parents of retarded persons, while the rest are concerned private citizens - both professional and lay. The headquarters of the ARC is in Texas, but is has a policy/lobbying office in Washington. It has state affiliate groups in all but two states. Local chapter activities range from local policy/program advocacy to service delivery. Some local offices are staffed, and of these about half are involved in direct services such as community-based residence centres. The services provided are those generally not otherwise available such as sheltered workshops, day treatment, work activity centres and recreational/leisure activities. Other local chapters are engaged in advocacy activities such as legislation promotion, monitoring institutional operations, or assuring alternative services.

The National Alliance for the Mentally Ill is an alliance of local and state family support/advocacy/mutual self help groups or associations dedicated to work in the eradication of chronic mental illness. Founded in 1979, a Central

Office in Washington D.C. serves as a clearing house for over 200 local-based organisations. NAMI has affiliates on state and local levels. Each member pays a one-time initial fee and then each group pays an annual fee per member to the Washington office. A newsletter is published bi-monthly and sent to over 6,500 persons, the majority of whom are family members of mentally ill persons. The basic concern of NAMI is to advocate for the chronically mentally ill, primarily through promotion of alternative services for this population and support for research into the causes of mental illness. The group's primary function is to meet regularly and provide emotional/mutual support to families of mentally ill persons. NAMI views the role/activities of professionals in the treatment of mental disorders as essential; however, NAMI views the role of family members (of the mentally ill) as "working partners" of the professional caregivers (and as such NAMI does not see itself as an organisation of volunteers). Members insist on a partnership relation with professioanls. The NAMI views the etiology of mental illness as biochemical in nature, and it does not regard psychotherapy as a valuable intervention. It sees prevention in terms of research into biological causes, not early intervention/treatment or primary prevention of a psychosocial nature. This outlook helps explain why NAMI has a close working relationship with the American Psychiatric Association but has yet to establish a comparable relationship with the American Psychological Association.

Support, Inc. near Denver, Colorado is an example of a local group affiliated through the Alliance network. In existence for nearly four year, Support, Inc. has 30-35 members, all family of persons suffering from mental illness. They provide support for one another and advocacy for better services. Communication with the county mental health centre, state legislators and congressional representatives all focus on obtaining better services. Support, Inc. is one of 13 groups belonging to the Colorado Alliance for the Mentally Ill. The larger group stays in touch via a bi-monthly newsletter and has an annual conference.

Legal Advocacy/Representation

One of the leading law-reform advocacy groups in the United States is the Mental Health Law Project. MHLP's prime objective is the clarification and protection of the rights of persons who are mentally ill or disabled. The primary vehicle for this is test-case litigation which has resulted in numerous landmark decisions that support the rights of mental patients to suitable treatment in appropriate settings. The test-case approach is coupled with a coordinated program of legal and public advocacy as well as educational outreach and assistance to lawyers and concerned community groups. MHLP was founded in 1972 as a Washington D.C. based, non-profit organisation by lawyers involved in the famous Wyatt v Stickney case (which established a constitutional right to treatment for persons confined in mental institutions). With the passage of federal legislation, such as the Developmental Disability Act in the late 1970s, some monies were available to support advocacy activities but the project has primarily been funded by private donations and foundations.

The Office of the Public Advocate (formerly the state Public Defender) in New Jersey has an office that does on a public level what the Mental Health Law Project does privately. The Division of Mental Health Advocacy has several lawyers and field representatives who provide representation to persons at commitment hearings and pursue test-case litigation on behalf of mental patients. Three field offices are located in the most populous counties and the representative services offered cover at least half the counties in the state. Some test-case litigation is done by these offices, but most is done at the Class Action office in the Division. The preference is to settle issues through negotiation. Another New Jersey public office, the Community Mental Health Law Project, is funded through the state Department of Human Services and exists to assure ex-patients' rights and equity as community residents.

The Mental Patients Advocacy Project is a New Hampshire state organisation that developed from the interest of staff in a regional legal services office who worked with patients at North Hampton State Mental Hospital. NIMH provided funding for this project in 1976 and (independent of ABA and MHLP activities) it provided representation at commitment hearings and obtained statutory rights for patients already institutionalised. Once the project got underway, and with the increase in deinstitutionalisation, the focus gradually shifted from the rights and needs of inpatients to reform activities to ensure civil rights for former mental patients in the community. The Project interacted with legal services organisations as well as many groups in the "On Our Own" network, a name applied to a variety of groups of former mental patients discussed in a book by the same name.

Within the legal profession itself, the American Bar Association has sponsored the Commission on the Mentally Disabled since 1973. Now winding down its activities, it's remaining task is that of making recommendations for future ABA activities. The Commission has carried out research studies, sponsored legal advocacy projects on state and local levels, developed model legislation proposals and produced testimony and legal briefs relating to the mentally disabled population. The Mental Disability Law Reporter is an ABA publication that focuses on coverage of case litigation and the development of case law in this area.

Self Help Efforts

The National Self Help Clearing House, located in New York City on the campus of the City University of New York (CUNY), serves a kind of brokerage (or information and referral) function regarding a wide variety of self help groups. It is not a membership organisation but publishes a newsletter to a mailing list of 11,000 subscribers. The purpose of the clearing house is to link self help groups with formal care settings and providers. They provide training, technical assistance and other services for self help groups and professionals who work in related areas. With funding from the National Institute for Mental Health, the clearing house has developed a number of training modules on topics ranging from "how to organise a self help group" to "how to engage the professional system" in gaining greater sensitivity for the experience of receiving mental health treatment. The groups they serve address issues of weight control, alcoholism and numerous other subjects as well as mental illness.

There are a wide number of groups in the United States that fall under the rubric of "self help". They range from mutual support groups for the families of persons experiencing psychological distress and support networks for former mental hospital patients, to lobbying and educational groups whose goal is to ensure quality treatment or inform the public on the need and nature of mental health services. Some groups are limited in their membership; some are limited in the nature of their activities. They range in size from Reclamation, Inc. which is one group in San Antonio, Texas for former mental patients to the National Alliance for the Mentally Ill, with its state and local affiliates nationwide. The majority of these groups see their functions as combining mutual support with advocating for improvements in mental health services.

The membership of several groups and organisations is made up exclusively of persons who experience emotional difficulties or have received psychiatric/psychological treatment. The Conference on Human Rights and Psychiatric Oppression is an annual meeting of 50 such groups from across the country composed exclusively of former patients.

The Mental Patient's Liberation Front is one of the better known of these latter groups. Boston-based, it was started in 1971; the membership consists of around 150 persons who have experienced psychiatric treatment. The group is minimally funded, mostly from a local foundation called The Haymarket Peoples' Fund; there is no salaried staff. Regular meetings provide mutual help and support for ex-patients. Lobbying on a state level impacts and influences laws affecting mental patients and persons undergoing publicly funded mental health treatments. Representatives have testified on national issues in Congress. Speakers appear on public talk shows, before groups, in school classes, and so forth, and several publications have been produced. Professionals are not allowed as members, although there is a small spin-off group called Friends of Mental Health Liberation Front that is composed of supportive friends and professionals.

Recovery, Inc. is another group composed entirely of former mental patients. It was founded in 1937 by a psychiatrist, Abraham Low, and although initially it suffered professional mistrust and hostility, it is now generally accepted as a valuable, positive influence in assisting those suffering emotional disturbance to maintain functioning in the community. Over 1,000 groups nationwide meet weekly to practice the method developed by Low that consists of a rigorously structured four-point approach that accentuates the positive aspects of a person's ability to care for themselves. Coordinated from a national office in Chicago staffed by six persons, the organisation depends on volunteer lay group leaders and maintains itself through voluntary donations at the weekly meetings, membership dues (voluntary), and the sales of books and literature.

Communcation occurs through an annual meeting for all members, four or five regional meetings a year, and a Fall meeting for area leaders and the Board of Directors. Recovery, Inc. has been totally lay run since 1952 when Low turned over its operation to the members. Relations with professional groups have steadily improved since the group does not in any way compete with professionals and support members seeing them concurrently. It does not claim to diagnose emotional disturbance and does not attempt to handle psychotic episodes.

Yet another self help group is Emotions Anonymous, whose approach mirrors the 12 step procedure of Alcoholics Anonymous. Based in St. Paul since 1971, 300 groups around the country provide support for persons with emotional problems to enable them to function effectively in the community.

One of the few such groups to have money for paid staff and activities is Project Overcome in Minneapolis/St. Paul. Incorporated as a non-profit organisation, Project Overcome sees itself exclusively as a public education and referral resource. It does not offer direct services of any sort, but provides speakers on specific topics such as experience of mental patients and also does seminars on related topics for professional groups and the public. Funded by a small federal contract and private foundation support, a paid office staff of four persons coordinates a list of 17 on-call speakers who travel state-wide as well as out of state. The project estimates that in the past year, 20,000 persons have attended their seminars and talks.

Volunteers and Professionals: Agreements and Conflict

Many mental health professionals operate with and support/belong to volunteer mental health organisations and groups. These alternative activities are not seen as being in competition with but as a valuable supplement to professional care. Many of the volunteer groups make a point of articulating their expectations that professionals will in fact behave in a traditional care-giving manner.

At the national level, voluntary mental health organisations and professional mental health associations do not generally come into direct conflict. This is primarily because they are all working for a broad general goal - improvement in mental health care and meeting unmet mental health needs.

When the discussion between volunteers and professionals moves to specifics, conflict may begin. The basic issue in the conflict revolves around who has the knowledge, power, right and responsibility for determining or directing care. The decisions regarding how service delivery is organised, what services are provided (and which specific services are given to which patient and when), who will provide the service (and how it will be paid for), and the evaluation of the quality and effectiveness of the care are at the heart of the issue.

Legal advocates and mental health professionals are most likely to come into conflict over the decision-making authority (as well as process and documentation) of the professional. The role and rights of the patient (and, to a lesser extent, the patient's family) in the decision-making process is central. Issues such as the right to treatment, the right to refuse treatment, confidentiality, and responsibility for treatment are often sources of disagreement. These same issues are generally the basis for conflict between self help groups and mental health professionals. Self help groups may be established to provide an alternative to the perceived unresponsive and inappropriate control of professionals over the patients they serve.

Together, voluntary organisations and self help groups supplement and expand mental health services provided by professionals. Experiences provided by these individuals and groups encourage a greater sensitivity on the part of professionals to those receiving mental health care. Advocacy activities urge on-going attention to the needs of mentally distressed persons outside the purely professional sphere and thus help assure that such persons can continue to function in personally and socially rewarding ways. Nonetheless, we must consider mechanisms, guidelines and shared expectations about the interactions between mental health professionals and volunteers as it relates to the specifics of service delivery and mental health care.

A WHO Programme
for
Lay, Community and Alternative Health Care

Situation analysis

In the 1970s WHO began to turn its attention away from specialist medical care to primary health care, culminating in the Declaration of Alma-Ata, Report of the International Conference on Primary Health Care, 6-12 September 1978. The goal of Health for All by the Year 2000 has made it clear that WHO must now go one step further. Not only must medical care be reorganised, but there must also be a recognition of the importance of the health-related activities and health beliefs of the community itself, of the relevance of social support systems, and of the role of lifestyles and human ecology in the quality of life and maintenance of health.

A more critical approach to disease etiology has revealed the influence of social pressures on health, and has made it possible to understand the importance of a satisfactory social life for the maintenance of one's own personal level of wellbeing. Research into self care has revealed the range of health activities performed by non-professionals as part of their everyday life: self-treatment, self medication, family care, neighbourhood help, voluntary aid. It has made clear that self care is health work by responsible individuals.

The growth of mutual aid groups and health-related social movements, such as the women's health movement, has shown the creativity and seriousness with which people are able to solve many health problems without professional intervention. New ways of providing services have been developed pointing to a new relationship between lay and professional health resources, and which are beginning to revive traditional and alternative methods of treatment.

Women are the main providers of health care in the family and in the community. Discussions and programmes on self care and lay health care provision must be sure to take account of the division of labour between the sexes and to call for family and health policies that allow women to reduce their workload or at least to receive financial compensation. A better balance between lay and professional resources must be seen not only in terms of work and money, but also in terms of authority, responsibility and definition of roles.

As new models of health care develop, old ideas have to be revised as well. Social action in health implies conflict and many consumer movements are expressing protest, fighting to be heard and demanding their rights.

Contacting these groups, listening to them and taking them seriously is a learning process for professionals, bureaucrats and administrators. The developments in selfhelp and mutual aid are being documented in various forms in Member States: through national clearing houses, publications, and different forms of self help research.

WHO itself faces no less important issues if it is to collaborate with countries in the development of lay, community and alternative health care. WHO's concept of health will need to be constantly reviewed in the light of new developments, its structure and work will have to be adapted to deal with new approaches, and its expertise will have to be broadened to deal with new concepts.

WHO programme perspective

During the 1960s and 1970s various regional programmes touched on aspects of lay and community care, but it was only at the end of 1979, when preliminary discussions started on the regional strategy for Health for All by the Year 2000, that the issue of lay, community and alternative health care received more serious consideration. As a result, it was included in the health education programme for the latter part of the Sixth General Programme of Work (1980-83) under the title "Supportive health education". The extensive consultations that followed resulted in considerable emphasis being placed on this issue in the regional strategy for Health for All by the Year 2000, an emphasis which was strongly endorsed when the Regional Committee adopted the strategy in 1980.

Initially, attention focused on new forms of non-professional health care, such as that of mutual aid groups, and on the potential of self care. Subsequently, in 1980, the scope of the lay health care system was further discussed during consultations on the contribution of sociology to programme development and on self help and health. This provided important background for the development of a separate regional programme on lay, community and alternative health care for the Seventh General Programme of Work. Although the full programme will not be started until 1984, the Regional Office has already included some activities in its programme. During 1982-83 these will include a meeting on self help and health, and the establishment of a clearing house to monitor information on the lay care system.

The potentional of the family in caring is already being assessed in research projects in some Member States, and WHO will help assemble the range of already available knowledge, make it more widely accessible, and suggest policy guidelines to Member States. WHO will take a leading role in coordinating research on the social epidemiology of health problems so as to assess the range of lay health activities, to identify the problems that lay people have in coping with illnesses of all sorts, and to develop models that view professionals as resources for lay action in the community.

WHO sees as one of its main objectives the bringing together of different views on the future development of paid and unpaid services and of professional and lay care. This will involve training programmes to help health professionals to understand the role of social factors in health and the broad range of lay health activities, and information programmes to help the public understand the structure of the health care system. Models of interaction between 'new' professionals and 'new' consumers in the framework of community-based health projects will be developed, taking into account existing projects in Member States.

WHO's role lies mainly in promoting public awareness of lay, community and alternative health care in Member States, and in encouraging participation in health activities.

ON OUR OWN
A consumer view of cooperation with professionals

Judi Chamberlin

The topic of "successful collaboration" among the various actors in the mental health drama providers / recipients / volunteers / policy-makers / professional bodies raises questions of definition. How do we define "success", and what do we mean by "collaboration"? The form of the original question assumes something that is by no means the case - that the various actors have the same goals in mind, or even that they are "performing" in the same "play".

One set of actors - call them users of services, clients, consumers, patients, or psychiatric inmates (and the term you choose reveals much) - has been consistently left out of these discussions. I believe my participation here marks one of the rare occasions when a former psychiatric inmate (and this is the way I choose to identify myself) has been included in a seminar like this one. I represent the organised ex-inmates' (or "patients") movement, which has existed in the United States for more than ten years now, and which has links with similar groups in Canada, Europe and Australia.

Ex-inmate groups (and let me speak here particularly of the North American movement) have been outspoken in our opposition to the methods of the current psychiatric system, a system which is based on force and coercion backed by the full power of the state (as expressed in commitment laws and so forth). We do not see this system as a helping system; it is not based on our needs, and it is not meeting those needs. We see mental health rhetoric of care and concern from a unique vantage point - from behind locked doors.

Each of us has a different story to tell. Some of us have suffered enormously - our stories are often personal tragedies. Some of us sought out the help of the mental health system voluntarily (I was one); we were often surprised by what we found there. Others of us became "patients" against our will from the beginning - brought (often by force or trickery) to a place of confinement called a "hospital". All of us have felt diminished as individuals by the whole process of "care" and "treatment". We were people, and we were forceably transformed into "mental patients". Suddenly, our word had little value, our personal comfort perhaps even less. We were often required to bathe, dress and attend to bodily elimination under the surveillance of strangers.

Many of us went along with what was done to us - we had little choice. Freedom depends upon docility, on accepting (or appearing to accept) the values of those in power. Protest is of little value when it is quickly redefined as just another "symptom". But many of us remain seething with legitimate anger, and we have found that the only way we can express it safely is with the support of our brothers and sisters, other ex-inmates. We have come together in voluntary association with one another, to use our anger in constructive work for change - to fight the coercion of the psychiatric system, and to develop voluntary, user-controlled alternatives where we can help one another through the pain of living in an atmosphere of equality and self help.

We question whether we were ever "ill" (although many of us were, indeed, troubled). We see the medical model as masking the true nature of our experience, as systematically confusing nearly everyone (including many "patients") as to the distinctions between helping and confining, between benevolence and power. It is ironic that those of us who saw through this deception from the beginning, who called things by their true names, acquired just one more diagnostic label. As we say in the movement, "It's not paranoia if they're really out to get you".

Our organisations are active in many ways, in many places. In San Francisco, ex-inmates have been publishing Madness Network News for ten years now, providing a voice and forum for ex-inmates all over the United States. From Toronto, Phoenix Rising is the voice of the Canadian movement. These publications link us to groups around the world, as well. For the past ten years, the North American Conference on Human Rights and Psychiatric Oppression has brought together activists from around the U.S. and Canada. This year we met in Toronto, produced several position papers, and picketed the annual meeting of the American Psychiatric Association.

Ex-inmate groups have lobbied state legislatures, testified before numerous boards and committees, appeared on local radio and television shows, picketed and leafletted, and tried in every way to be included when decisions are made which affect our lives most of all. We have protested such institutional outrages as forced drugging and electroshock, as well as societal outrages, such as derogatory portrayals of "mental patients" in movies. We have also turned to positive action - ex-inmate groups run drop-in centres, thrift shops, residences, lecture and discussion programmes. We try to fill the many needs of our members - particularly for basic life supports such as food and shelter, in a society that puts wealth and power above the basic needs of human beings. We see many people whose overriding problem is poverty - and this, too, gets redefined as "illness" requiring "treatment".

Psychiatric "treatment", in both in-patient and out-patient settings, most usually means the administration of psychotropic drugs (a term I prefer to the euphemistic "medication"). As people who have suffered and who continue to suffer from the manifestations of these drugs (usually dismissed by the term "side effects", which include disfiguring and incurable tardive dyskinesia), a basic demand of the ex-inmates' movement is for control over our own bodies and minds, a demand we are expressing through legal action for the right to refuse "treatment" and the right to informed consent. We are also educating ourselves and other "mental patients" - many ex-inmate groups publish handbooks giving the effects of drugs in lay language, information which is usually unavailable to patients.

I now return to the original question. I cannot answer it because it seems we are operating under totally different definitions. I cannot see discussing "successful collaboration" - whatever that may be - before we address the questions I have so briefly been allowed to raise here.

PARTICIPANTS

Individuals & National Representatives

Ms Josee van Remoortel	Belgium	Director, Belgian (Flanders) Association for Mental Health
Dr Hubert de Craene Ronse	Belgium	Medical Director, Psychiatrische Kliniek, Bruges
M Jacques Nolet	Canada	Associate Director General, Douglas Hospital Centre, Montreal
Mrs Raili Rinne	Finland	Educational Secretary, Finnish Association for Mental Health
M Marcel Boss Colbert	France	Director, Union des Familles de Malades Mentaux (UNAFAM)
Dr Inge Schöck	W Germany	President, Dachverband Psychosozialer Hilfsvereinigungen, e.v Bonn
Ms Bettina Scholtz	W Germany	Psychologist, Psychiatrisches Krankenhaus Phillippshospital, Riedstadt
Mr Joseph A Casey	Ireland	Chairman, Mental Health Association of Ireland and Chief Nursing Officer St Senan's Hospital Enniscorthy
Miss Mary J O'Mahony	Ireland	Chief Executive Officer, Mental Health Association of Ireland
Ms Karolina M Bais	Netherlands	Information Officer, Dutch Organisation for Non-Residential Mental Health Care
Philip Schrameijer	Netherlands	National Centrum voor Geestelijke Volksgenonheid
Mr D van Beek	Netherlands	Ministry of Health, Netherlands
Mrs Rigmor Høyer Amundsen	Norway	Leading Medical Social Worker Diakonhjemmets Sykehus, Oslo
Ms Kerstin Nilsson	Sweden	Director, Fountain House, Stockholm
Ms Judi Chamberlin	USA	Patients advocate Mental Patients Liberation Front, Boston, Mass.
Dr Gerard Hunt	USA	Sociologist, Executive Secretary of Association for Behavioural Sciences & Medical Education USA
Mr Richard Hunter	USA	Deputy Director, National Mental Health Association USA

Dr Lucile Newman	USA	Associate Professor, Dept of Community Health and Anthropology, Brown University, Providence Rhode Island
Mrs Hilda H Robbins	USA	Volunteer/Consumer Advocate, National Mental Health Association, USA
Dr Melvin Sabshin	USA	Medical Director, American Psychiatric Association & WFMH Board Member
Dr Gary Vanden Bos	USA	Deputy Director, and Director for National Policy Studies, American Psychological Association
Lady Avebury	UK	Assistant Director, Local Associations MIND (National Association for Mental Health)
Mr William Bingley	UK	Legal Officer, MIND (National Association for Mental Health)
Mr Peter Clarke	UK (Scotland)	Director, Scottish Association for Mental Health
Dr Donald H Dick	UK	Director, NHS Health Advisory Service (England and Wales)
Mr Alan Ferguson	UK (N Ireland)	Director, Northern Ireland Mental Health Association
Dr Hugh Freeman	UK	Consultant Psychiatrist, Prestwich Hospital, Salford
Mr Chris Heginbotham	UK	National Director, MIND (National Association for Mental Health)
Mr Paul Hodson	UK	Researcher, Policy Analysis Unit, National Council of Voluntary Organisations
Mrs Inge Midforth	UK	Principal Social Work Service Officer, Mental Health Group, DHSS
Mr Foster Murphy	UK	Director, The Volunteer Centre (UK)
Mr J H L Richards	UK (Scotland)	Director, Glasgow Association for Mental Health
Mr John Tait	UK	Principal Nursing Officer, Mental Health Division, DHSS

International Organisations Represented

Dr John Henderson	Mental Health Adviser, World Health Organisation (European Region)
Professor Eugene B Brody	President, World Federation for Mental Health
Professor Stijn Jannes	European Vice President, World Federation for Mental Health, President Belgian (Flanders) Association for Mental Health
Mrs E N Balaszeskul	President, International Federation of Telephonic Emergency Services (IFOTES)
The Reverend John Eldrid	Vice President, International Federation of Telephonic Emergency Services (IFOTES)
Ms Christiane Deneke	Researcher, Information Centre on Research into Self Help and Health, Universitats-Krankenhaus, Hamburg

Seminar Planning Group

Lady Bingley	Chairman, MIND (National Association for Mental Health) & Senior Medical Social Worker, St Mark's Hospital, London
Mr Sandy Duncan	Training Officer, The Volunteer Centre, (UK)
Ms Pat Gordon	Project Officer, King's Fund Centre
Mr Miles Hardie	Director General, International Hospital Federation
Mr Simon Hebditch	Assistant Director, MIND
Mrs Edith Morgan	Director, Good Practices in Mental Health project and WFMH Board Member
Mr Kevin Richards	Information Officer, Good Practices in Mental Health project
Dr David Towell	Assistant Director, King's Fund Centre

SEMINAR PROGRAMME

Day 1 (Wednesday 21 July)

2.00-4.00pm Plenary Session I Chairman: MRS EDITH MORGAN

Opening Presentation: DR GARY VANDEN BOS, Deputy Director, American Psychological Association

Theme papers:

(i) service provision - MRS RAILI RINNE, Education Secretary, Finnish Association for Mental Health

(ii) advocacy - MR SIMON HEBDITCH, Assistant Director, MIND (National Association for Mental Health), UK

(iii) self help - MS CHRISTIANE DENEKE, Researcher, Information Centre on Research into Self Help and Health, West Germany

Questions and discussion

4.30-6.15pm Group Session I

The participants will divide into groups, each of which will focus on identifying aims in one of the following areas:-

(a) service provision
(b) advocacy
(c) self help

7.30-10.00pm Reception given by Islington Health Authority (Chairman: Mr Eric Moonman)

Day 2 (Thursday 22 July)

9.30-10.30pm Plenary Session II Chairman: PROFESSOR STIJN JANNES, WFMH, Vice-President for Europe

Five 5 minute talks, addressing the question "What are the main impediments to volunteer/professional cooperation?"

(i) service provider - MR JOSEPH CASEY, Chairman, Mental Health Association of Ireland and Chief Nursing Officer, St Senan's Hospital, Enniscorthy, Ireland

(ii) service user - MS JUDI CHAMBERLIN, Patients Advocate, Mental Patients Liberation Front, USA

(iii) volunteer - DR INGE SCHÖCK, President, Dachverband Psychosocialer Hilfsvereinigungen, West Germany

(iv) professional body - DR MELVIN SABSHIN, Medical Director, American Psychiatric Association and WFMH Board member, USA

(v) policy maker - MR D VAN BEEK, Head of the Primary Health Care Section, Ministry of Public Health, Netherlands.

Questions and brief comments

10.30-12.30pm <u>Group Session II</u>

To focus on strategies for achieving the service aims defined in group session I.

2.00-4.00pm <u>Plenary Session III</u> Chairman: MR FOSTER MURPHY, Director, The Volunteer Centre, UK

To receive brief preliminary progress reports from the groups and to discuss common aims, coordination of approach and overall strategy.

4.30-6.30pm <u>Group Session III</u>

Preparation of an initial statement of group aims and recommendations for the seminar report.

Day 3 (Friday 23 July)

9.30-10.30am <u>Plenary Session IV</u> Chairmen: M JACQUES NOLET, Associate Director General, Douglas Hospital Centre, Canada

Presentation of skeleton report and brief discussion of major points.

10.30-12.30 Group Session IV

Each group to discuss its own section of the final report, make final recommendations and identify principles.

2.00-4.00pm Plenary Session V Chairman: PROFESSOR EUGENE BRODY
President WFMH

Reports from groups, discussion of final recommendations and identification of main basic principles.

Summing up: MR CHRIS HEGINBOTHAM,
National Director, MIND, UK

7.30pm Dinner party at the House of Commons (preceded by guided tour of the Parliament buildings at 6.30pm).

£2.50