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INTERNATIONAL SELF-HELP SUPPORT EXPERTS

*Fourth
European Expert
Meeting on Self-
Help Groups*
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Self-Help Support and Ethics

Information Desk/Inquiry Counter

Self-help groups in Sweden — a status report

There is virtually no Swedish literature about self-help groups and no research on the situation in Sweden. A group of researchers at the Sköndal Institute outside Stockholm has started a research project to study self-help groups in Sweden. This report is based on the first sub-report which was published in May 1997. In recent years in Sweden, discussions on the topic of self-help groups have begun in Sweden at county councils, the social services and voluntary organisations, for example. The professionals (doctors, therapists, psychologists and so on) have two basic attitudes towards self-help groups.

Firstly, they regard it as a resource which complements the assistance the professionals offer. Secondly self-help groups are perceived as being directly harmful to the participants and as lacking the appropriate assistance. In some cases, they can also be seen as an immediate threat to the professionals' own operations. The voluntary organisations also look upon self-help groups as a resource, but sometimes claim that the increased interest on the part of the public sector may have nothing but financial motives. What they mean is that self-help groups are a way of handing over responsibility and exploiting the voluntary sector.

There are different reasons to explain the increase in self-help groups. As already explained, the deterioration in the country's finances could be one of them. As a result of this deterioration, the government, county councils and local authorities are looking for alternative and more cost-effective forms of support and assistance. Next to that, the relatively high level of education in Sweden probably contributes to the development of self-help groups. Another fact is that the public service systems are not able to create close relationships between care-

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givers and care-takers via the support that is offered. Self-help groups are then regarded as a complement to professional assistance. Also the dissolution and the declining importance of the nuclear family has led to a reduction in traditional social support. People are now seeking this social support in self-help groups, for example. People's growing lack of confidence in experts and the fact that they wish to take control of their own lives on an increasing scale could also be a reason for interest in self-help groups to increase.

(Swedish) definitions

Self-help — help which is designed to solve clearly expressed problems and which is non-professional.

Self-help group — a small, participant-controlled group of people who meet regularly to analyse joint problems by providing mutual support and help.

Self-help organisation — an association to which the self-help groups are linked and whose principal task is to support the work done by self-help groups.

The relationship between self-help groups and the professionals

There are two main reasons which are usually given when attempts are made to understand why self-help groups are initiated in a problem area.

1. self-help groups can complement the health care system.
2. self-help groups as a reaction against the

functioning of the professional systems.

There is some tension in the relationship between the professionals and self-help groups. People's confidence in the established society has declined and more and more, personal control of the offered care, is wanted. The professionals have some scepticism towards self-help groups. Professional groups within the social and medical fields are in a powerful position when it comes to the right to formulate the way problems should be understood and solved. Tension is created when someone outside the professional sphere claims that the problems can be solved without the aid of professional groups.

The members of self-help groups attempt to make their own diagnoses, draw conclusions and treat their problems. The role of the professionals can become supervisor and provider of knowledge. They should play the role of consultants not leaders.

Self-help groups should not be regarded as a method to be used by the professionals. The principal reason for this is that the jointly perceived problem is a very important factor in a self-help group. The fact that all the members of the group have experienced similar problems increases the likelihood that they will understand one another. One important reason for the current tension between the professionals and self-help groups could be the lack of knowledge among some professionals of what a self-help group actually is.

Questionnaire study of self-help groups

To obtain empirical material about self-help groups in Sweden, the Sköndal Institute is planning to conduct a number of studies. The first empirical data have been obtained from a questionnaire study conducted in 10 Swedish municipalities. The results are as follows:

The problem categories which occur most frequently and which attract most groups are traditional problems such as alcohol problems and illness/disability. They are followed by groups aimed at people in the same situation, such as parents and the bereaved.

Self-help groups are not simply a metropolitan phenomenon but are as common in smaller areas. The preliminary results reveal that self-help groups could be as extensive in Sweden as they are in the neighbouring countries of Denmark and Norway. One of the reasons could be that there are a large number of groups working in the same way as self-help groups without using the term "self-help group".

Germany (NAKOS)

The development and promotion of self-help groups in Germany

In many respects, what is commonly referred to today as Germany's "self-help movement" is the outcome of social and political upheaval in the former West Germany during the late 1960s. Back then, the counter-culture

generation rejected the idea of the state controlling many aspects of their lives and, of particular interest to those of us working in the self-help sector today, they called into question the authority of professionals in the field. These forerunners of the self-help movement struggled to take more control over their own lives and to take on the challenge of working with others to create a new society. In the early 1970s, women were among the first to found self-help groups, although many did not refer to themselves as "self-help" groups. Many also focused on organising forums for self-discovery. And finally, starting in the mid-1970s, a large variety of different groups were formed in the health field, most of them stressing the psychological aspects of the issues involved. Since the mid-1970s, the number of self-help groups has grown exponentially, and this trend has continued uninterrupted throughout the 1980s and 1990s. Current calculations show that there are approximately 70,000 self-help groups in Germany today. Starting in the mid-1970s, *clearinghouses* were set up to support self-help groups. This new approach grew out of the experience that most self-help groups do not come into existence on their own and that the majority of those concerned need support and encouragement to join an already existing group or to form their own group. These observations have been confirmed by a number of research projects. Over the years, clearinghouses have evolved into institutions that provide easy access to the

general public, approach issues comprehensively, and offer a wide range of counselling to help people help themselves. The extent and type of services which they provide are unique. Clearinghouses:

- pave the way for those seeking access to groups,
- help new groups get started,
- aid self-help groups in attaining their own goals,
- stabilise groups during development crises,
- establish contacts between experts and self-help groups,
- and contribute to a climate in our society which is conducive to the establishment and development of self-help groups.

A dense network of local clearinghouses has developed in Germany over the past few years. Currently (November, 1997) the National Clearinghouse for the Establishment and Support of Self-Help Groups in Berlin (NAKOS) lists roughly 280 institutions providing support for self-help groups on a local basis. Not all these groups are clearinghouses in the narrow definition of the term, i.e. working as an independent entity with a permanent staff, with their own offices and materials, and offering field-related counselling. Some clearinghouses are associated with institutional departments, e.g. health authorities, welfare associations or even health insurance companies. Although the target groups and the range of support provided may vary, all of these clearinghouses have a comprehensive approach; they provide information on self-

help groups in the region and establish contacts *free of cost*.

Two pilot projects funded by the German government have made an important contribution towards the creation and development of the country's clearinghouses. The promotion of self-help groups through clearinghouses has become an issue, particularly thanks to these two federal government pilot projects, which can no longer be ignored by Germany's 16 states and numerous local authorities (municipal governments and administrative districts). This explains why an increasing number of states promote the development and work of clearinghouses, and why more and more administrative districts supplement this funding. In 1997, for example, Germany's 16 states provided some 14 million dollars for the promotion of the self-help sector, and roughly five million dollars of this sum was earmarked for clearinghouses. In addition to funding from the states and municipal governments, in recent years insurance companies have also provided funds in accordance with legislation (Article 20, Section 3, SGB V) which calls on them to support the self-help field. In 1996, their funding for self-help groups amounted to approximately 6 million dollars. However, in the same year clearinghouses received only \$200,000 in funding from insurance companies.

Self-help and self-help support in Nordrhein-Westfalen

Nordrhein-Westfalen (NRW) is a state of the Federal

Republic of Germany with approximately 17 mill. inhabitants. Estimations say, that in this part nearly 12.000 self-help-groups exist, working with all sorts of themes and problems one can think of.

Regional self-help support is mainly done by the 19 "Selbsthilfe-Kontaktstellen" which are situated in different towns. These Kontaktstellen work with payed professionals. They support persons who are interested in self-help as well as self-help groups in accordance to the fundamental concept of the "Deutsche Arbeitsgemeinschaft Selbsthilfegruppen" (DAG SHG). Most of the Kontaktstellen are financed by their community. The professionals of the Kontaktstellen in NRW meet regularly every two months in order to discuss professional questions and to develop their discipline.

16 of the 19 Kontaktstellen get an additional financing from a state department of NRW. In the last three years this state department has also organized "Self-help-days" where self-help groups of the whole land could present their work to people who don't know self-help groups. They also could get into contact with other groups.

The government of Nordrhein-Westfalen also finances KOSKON (Koordination für Selbsthilfe-Kontaktstellen in NRW). KOSKON coordinates the self-help support in NRW. This institution gives consultation to people who want to support self-help groups, organizes training courses for self-help

professionals, makes publicity for the basic principles of self-help groups, cooperates with land wide working institutions and supports the 19 Kontaktstellen and their meetings. KOSKON is an information and service center for everybody in NRW who wants to support self-help groups. KOSKON is the "sister" of NAKOS in NRW, both are "children" of the DAG SHG.

Finland

In Finland, no national or local self-help centres exist. There are however a variety of self-help groups all over the country. A national Living Conditions Survey from 1994 indicated that 6.6% of the population participated in self-help groups during the previous 12 months. This shows that self-help isn't a marginal phenomenon in Finland. In November 1997 a report 'Self-Help Groups in the Intermediate Area of Voluntarism and Public. A National Mapping of Self-Help Groups in 1994-1996 in Finland' written by Marianne Nylund appeared. This mapping illustrates how various self-help groups operate in Finland. Most of the groups were established during the years 1990-1994.

The relationship between self-help groups and professionals is constantly discussed. Some see self-help as a treat to professional care. Nevertheless, self-help groups have a positive attitude towards collaboration with professionals and the public sector.

An informal network of researchers and self-help

supporters (10 to 12 members) was established in 1995. Once or twice a year, meetings are organised. The last meeting, six new members joined the network, which indicates the growing interest of researchers, students and teachers at Polytechnics, in the self-help phenomenon. During a previous meeting, the possibility of having a list of people who are willing to lecture about self-help, was discussed. There is a continuous and increasing demand for it. In the next meetings, brochures for a national conference in Social and Health Care in May 1998 will be made. The idea is to make the concept and ideology of self-help groups visible for the public and the social and health professionals. A next step will be, planning a seminar on and creating a poster about self-help groups. Because there is no national self-help centre, Finland has to start on an informal basis, with a loose network. Presently, the arrangement of these meetings are performed by a Social Enterprise Workshop (kind of co-operative) in collaboration with the Polytechnic of Helsinki, the Citizen Forum, and a researcher from the University of Helsinki.

Belgium

Belgium is a federalised country, which means that former national policy powers were transferred to the Communities and the Regions. Therefore, a national support policy for self-help and mutual aid groups doesn't exist. Still, there is self-help support in the three Communities: the

German, French and Dutch speaking Communities.

Dutch speaking Community

Trefpunt Zelfhulpgroepen vzw, a largely government sponsored service-center dedicated to self-help and lay health care, occupies a particular place in the Flemish self-help scene. Originating from empirical research into lay initiatives in health and social care at the beginning of the eighties, the Center expresses the government's commitment to support the functioning and activities of the numerous Flemish self-help and mutual aid groups. The Center serves as a reference point for self-help to existing groups, professionals in health and social care, authorities, people searching for self-help and mutual aid groups, and society at large. It offers, among many other things, practical support, guidance, education and training for groups, it conducts research into the nature, extent and mechanisms of self-help, it publicizes, etc. The Center's aim is to ameliorate the functioning of existing groups, stimulate the creation of new ones and, in general, create a favorable climate to lay people's involvement in care delivery as a whole.

Facilitation and outreach:

Under this heading the Center's function starts from a positive evaluation of self-help. It includes encouraging, supporting and conducting training activities for specific self-help and mutual aid groups and their organizations; enabling collaboration with professionals and providing expertise to professionals about self-help, ways to deal with active patients/clients and how to work with their groups.

It also includes policy-preparation for specific self-help organizations or, in a more general way, for self-help as a whole; the addressing and influencing of professional and public policy audiences as to the activities of self-help and mutual aid groups, their relationships with professionals and their relevance to public policy issues; and the influencing of public opinion in favour of active involvement of patients in their own care and in favour of self-help and mutual aid groups.

Information and

documentation: this includes collating addresses of self-help and mutual aid groups and organizations; maintaining an up-to-date databank, since information might become obsolete; and providing information or referral to those who call upon the Center. Documentation comprises the gathering of all kinds of materials pertaining to the groups, as well as to the problems they deal with. Furthermore, the popularization of scientific research data and the facilitation of research and actual research into self-help are functions of the clearing-house. The publication of regular newsletters, books, papers and reports help to realize these functions.

Provision of material

resources: within strict budgetary boundaries the Center avails material resources such as rooms and printing, reproduction and general resources, and instructions in the use of such resources.

Although *Trefpunt Zelfhulpgroepen* vzw has an independent status, it benefits substantially from and heavily

relies on the expertise, guidance and support offered by the KULeuven and its Department of Sociology. The offices and numerous facilities are offered by the Department and therefore paid for by the University, personnel and other administrations, accountancy, specific facilities and other resources are at university expense. The larger part from *Trefpunt's* financial resources stems from government funding. A small part comes from private sponsoring, educational activities and book sales.

French speaking Community

Although Self-help and mutual aid groups seemed to be restricted at first to the Dutch speaking Community, today, the French speaking part of Belgium pursues a, though coloured, policy towards self-help. This policy is implemented as an allocation of functions between the Christian and Socialistic sickfunds, with respectively health promotion and self-help support as principle tasks. The Socialistic sickfund established a support centre as a part of their health educational activities. This organisation of support has some disadvantages towards the self-help groups. Because of the coloured, this is Socialistic, support centre, information and support isn't accessible for everybody, but mostly for the members of the sickfund. Secondly, it isn't unthinkable that the centre will support those initiatives that are associated with their own activities. It is more likely that groups about physical problems will be stimulated more. The advantages are the

availability of more financial means for the self-help groups and the increase of the credibility of these mutual aid groups, by being embedded into an institutionalised organisation. The question is of course to what extent do these groups maintain their own responsibility.

German speaking part of Belgium

Patienten Rat & Treff is a clearinghouse for self-help in the German speaking part of Belgium, which has a population of about 67 000 persons. The organisation has a person for all the work that has to be done for the diabetes group and for organising meetings with experts, a secretary, two teachers for individual education and a team leader. The team leader (Annie) helps new and existing groups, AIDS commission activities, health education projects, a health telephone service.... The main problem is to find people that want to take any responsibilities in their group. Some of the members come to the meetings once or twice and lose their interest. Others have high expectations and are looking for a real solution to their problem. They go around asking for information in the group, contacting doctors and psychologists in order to get free advice.

Because of the small population and the language problem (the German speaking part officially is a part of the French district; German speaking patients have to go to French speaking hospitals to have their diagnoses or treatment), another problem is

finding enough members for a group.

A positive development is the growing interest in self-help. A growing number of people call for information or visit the Patienten Rat & Treff. For the next months, a few more groups are planned. Twice a year, a conference for group leaders is organised. In the future, the same will be done for volunteers.

Next to all this, the organisation became an active partner in health prevention.

Israel

In a survey, conducted in 1982, about 30 self-help groups were counted in Jerusalem: to-date, over a hundred groups operate there, 25% of them in East Jerusalem. Currently 413 groups and organisations are listed in the ISHC data base; 27 are groups in formation stage and 300 callers are registered as interested in forming groups in 113 new topics.

It's hard to gauge the meaning of these figures: Israel has a population of about five million; ISHC gets about 100 new calls per month and has no data on the number of individuals that join groups and organisations directly. Hereunder are a few telling facts:

- a steady rise in numbers of groups and people involved in self-help;
- new initiatives by Arabs and new immigrants, until recently oblivious to self-help;
- rising interest of policy makers and politicians;
- increase in referrals by professionals
- increased media attention

In spite of the very small sum invested in infrastructure to promote self-help, or in direct financing of groups and organisations, more and more Israelis get organised around a wide variety of issues. Similar tendencies are reported in other countries in which health, education and welfare became privatised. As governments take less responsibility for providing services, citizens seem to realise that they have to join forces and create their own new powers and recourses to solve their problems.

Research is needed to know more about self-help initiators, active and passive members, reasons for people to join often stigmatic groups: a personal need for support, political consciousness to fight stigma, or a combination of both? Comparative data from different countries could throw light on the above and many other interesting issues concerning the growing tendency to join often stigmatic and marginal collectives which seem to be in contradiction with the high value placed on individualism. Understanding these and other dilemmas arising from self-help could help predict its' future role and direction in rapidly changing societies.

The Israel Self-Help Centre:

Budget - \$220,000

Staff - 4 positions, 5 volunteers

Information

1145 callers were serviced;
494 groups and organisations listed in computerised database

17 groups are in various stages of getting organised; 287 service organisations assisting self-helpers are listed; 98 topics await self-help initiation; 259 callers registered on waiting list of a/m topics; 280 literature items from other countries; 214 books; 290 journals; 53 films. 35 articles were translated by 20 volunteers

Training:

190 professionals and self-helpers attended ISHC courses; 863 people heard about self-help at various conferences.

Consultation:

209 self-helpers and professionals received consultation.

Supervision:

1 Hebrew Univ. student did field work in an Arab School

1 Tel-Aviv Univ. student worked among illegal African workers

Hothouse Services:

15 support groups met at the centre; 8 groups operated hotlines; 10 held meetings and workshops; 5 groups received services in WLI-Haifa; 9 groups received technical assistance.

Special projects:

with the Jewish Agency: SH as a tool to promote democracy; with ESHEL: SH among caregivers of elderly; with Galilee Society: SH among Arab population.

Publications:

3 articles written by ISHC director were published: - in Hebrew, J. of Society and Welfare; - in English, in SIGIES, Wiena; in

Hungarian, Tarsadalom Kutato Csoport, Budapest.

ISHC Director participated at International Forum of Social Sciences in Health, Istanbul, Turkey.

ISHC is about to publish a Directory in 1997.

Switzerland

There are about 2 200 -2 500 self-help groups in the whole country and 16 regional clearing-houses in the German part. What we call "clearinghouse" - "Kontaktstelle für Selbsthilfegruppen" - actually means quite a lot of different things:

- professional, independent centres, specialised on shg-support (4 centres are already existing, 2 are on the way to be created)
- working-groups of professionals (sometimes with some shg-members) who also have another job (2)
- any kind of a social office where shg are a more or less an important part of the work (6)
- voluntary, not professional work (2)

The trend goes to professional and independent centres.

Nearly all of the regional centres have real financial problems. Of course there are several reasons for that, but one of them must be seen within the global health-care system in which the promotion of self-help groups hasn't found a place yet.

KOSCH is an association of 13 of the 16 clearinghouses, which aims at a national

clearinghouse. We received a credit of a national health-promotion-organisation (Schweizerische Stiftung für Gesundheitsförderung) for the planning-period with a extern expert. This work is going on just now and turns out to be very interesting and helpful. The main question will be:

- Whether we want to have an informal promotion-office, and whether the financial problems of the regional centres will be positively influenced "along the way".
- Whether it should be an formal institution, which turns out to be the only way to provide money of the state-department to the regional centres. A national centre in this sense would have to guarantee a certain standard of work and a permanent control.

You can imagine, that there are many questions to be discussed and answered. At the end of that process, the regional centres will decide, which way it shall be.

The health-promotion-organisation, I mentioned, will take on a part of the costs of a national centre in future. It is quite interesting to know, that this organisation is domiciled in the French part of Switzerland.

We are now in discussion with a state department for the rest and for all the conditions of their "New Public Management- Visions".

Irma works in local clearinghouse called Teamselfhilfe Thurgau (founded 1985) in the Eastern part of Switzerland, a region

without big towns, but a lot of nice villages.

The local clearinghouse in which Vreni works is Selbsthilfezentrum Hinterhuus (founded 1981), Basle, a town right on the border to Germany and France (about 200 000 inhabitants).

Thursday, June 5

Welcoming

Peter Gielen, Trefpunt Zelfhulpgroepen vzw
Bie Callens, Responsible for Hof van Watervliet / Hof Lanchals

Prof. Dr. Koen Matthijs,
Chairman of Trefpunt Zelfhulpgroepen vzw

Good afternoon ladies and gentlemen.

I have the honour and it is my pleasure to welcome you all to the fourth 'Expert Meeting on Self-help Groups', in this most beautiful setting. I am quite sure that Hof Lanchals and certainly Bruges will appeal to your imagination. To be honest, we were somewhat afraid that Brugge is too magnificent a place and that its setting would overshadow the meeting, but now, thanks to the contributions and suggestions of many of you - and of course the creative and positive intervention of the Flemish self-help crew - I am convinced that the programme of this meeting is captivating enough to keep you all in here. Normally it is my task, some say it is my duty to represent the Flemish Trefpunt Zelfhulpgroepen on official and less official occasions, and to draw attention on the necessity of self-help support in Flanders, to balance the financial books and to care for a good-running organisation. For evident reasons, I am sure that you are all convinced of the great value of self-help and of the necessity of support for

the many existing initiatives. Self-help groups serve as a useful antidote to the still growing medicalization of social problems, in which professionals widen their domain to include areas where they have little special knowledge or competence. The growing medicalization is as much a product of the breakdown of social supports in social life as of professional imperialism, but strong self-help movements serve as a useful check on what could be a dangerous trend. Many self-help groups reject professional hegemony and share the ideology that only those affected by a problem can really understand it. Although the self-help movement has many constructive aspects, it is frequently subject to fads and exploitation that can damage vulnerable persons seeking help or meaning. I have the impression, and it's no more than an impression, that the most successful self-help groups are those that provide tangible as well as group support, that are organised to resist bureaucratic organisation and individual profiteering, and that are operated exclusively by their own members.

In order to understand our ambitions, it is important, not only as a ritual, to go back to the roots of self-help expertise in Flanders and, within that story to give credit and place to the different supporting partners that made self-help support possible. This year we celebrate our fifteenth anniversary, as Trefpunt Zelfhulp came into existence in the beginning of the eighties as a result of research, commissioned by the Minister of Well-being and Family at

the time, and carried out by the department of sociology (division medical sociology) at the Catholic University of Leuven. After some years, the Minister decided on the financial support of the centre, while the University agreed on housing the centre and the provision of practical support. The initiating of a centre such as Trefpunt is meant as general support for self-help in Flanders, as only few of the groups can receive direct financial means from the Flemish government.

Therefore Trefpunt Zelfhulp has to be the driving force and the advocate of the self-help movement in Flanders. In many ways and by different channels, it tries to create a favourable atmosphere in which self-help groups can develop and find support and recognition. Trefpunt Zelfhulp also tries, with varying degrees of success, to promote research on self-help and support systems. This attitude puts the social scientist in the position of promoting self-help groups, as opposed to his usual role of simply investigating social phenomena and communicating the result of his research to others. In any case, combining the ideas of understanding and fostering seems to imply that there is a communality of goals in the scientific study of self-help and social policy attitudes towards it.

Another important fact in the growth of the Trefpunt is the temporary presence of an International Information centre on Self-Help (IIS), which came from Hamburg in 1984 and remained in Leuven until 1990. The IIS organised four international meetings: one on support systems and

self-help, self-help and chronic disease, self-help and aids, self-help support systems and HIV/aids self-help groups. We lost that centre for mostly financial reasons, but didn't lose the expertise. Yet, I find it most regrettable that we were not able to continue this important initiative. There is indeed on different levels a tendency to the internationalisation of self-help. You might interpret this as a request to all the self-help supporters to recharge the batteries, to reconsider the realisation of an international self-help support network and to work on it. I sincerely hope this meeting to contribute to that network, with information exchange, co-operation and regular contacts.

Self-help groups at the individual level and collective mobilisation at the social level are expressions of people's capacity to (re)construct society in terms of their own images and needs. These movements are based on the premise that people have a great capacity to control their own fate. Both movements depict people as active agents in their own environments, with the ability to meet their problems by collective action rather than by continued passivity and dependence on the health-care bureaucracies and professionalisation. Although the long-range potential of these movements in modern industrial societies remains unclear, they offer an optimistic and spirited reaction to the growing specialisation, segmentation, and depersonalisation of modern life.

The effectiveness of self-help groups or groups of common interest - either as social

supports or enhancing coping capacities - is dependent on a variety of factors, many of which still remain uncertain. But it is clearly prudent for the health practitioner interested in dealing with risk factors associated with crisis, to recognise clients' needs for social support and to use the means available in the community for providing it. With initiative, health personnel may even contribute to the development of such groups or serve as a professional resource for them. We should at the same time be giving greater effort to understanding more precisely the nature of these risk factors, the way they can be more effectively conceptualised, and the most effective possible interventions. It is my hope that this meeting will contribute something to each of these goals.

As to the inside of the Flemish Trefpunt Zelfhulp, I want to stress that it is a great pleasure for me to support and to stimulate, to receive and to give feed-back to the initiatives of the staff-members. Not only for big initiatives such as the organisation of a European Expert Meeting, but certainly also for all those that comprise the daily activities. The annual report shows indeed a growing appeal to the centre, in the sense that there is an expanding demand for legal advice, training, information, conflict mediation a.s.o.

During the fifteen years of organised and global self-help support in Flanders, many altruistic donations and restricted subsidy of different authorities have made the running of Trefpunt more

comfortable. I explicitly want to thank for all that support.

The succeeding of this meeting does not only depend on all the careful preparations and the participants. The setting too plays an important part.

Therefor we are very obliged to the board of Hof Lanchals and Hof van Watervliet for giving us the opportunity to use this most beautiful and impressing house (mansion) for the fourth Expert Meeting on Self-help Support. I wish you all good luck for the coming days. And remember, the meeting is not all about work, but it is also an occasion to meet with others in a relaxed atmosphere, an opportunity to renew friendships and to start new ones.

Last but not least I want to thank (in alphabetical order) Anne-Marie, Annemie, Hilde, Kristel en Peter for their continuous efforts tot promote the Flemish self-help landscape. And of course I want to thank them cordially for their tremendous investment in the organisation of this meeting. They indeed did all the possible to make a success of it.

Have another drink, enjoy your stay and have fruitful discussions.

Practical announcements and overview of the programme

Introductory lecture: “Different ways of supporting self-help:

implications and effects”

(Peter Gielen, Belgium)

Introduction

Ladies and gentlemen, dear colleagues. A few days ago, I gave a training course on how to conduct meetings and gatherings for the Flemish Society of Shy People, timid people. That is one of those rare and seldom occasions, maybe even the only occasion, where the audience is much more nervous than the speaker. Today is quite the opposite. Although some of you might not yet feel a hundred percent at ease in this new environment, I can assure you that I am quite nervous. But at the same time I am very pleased that there is a fourth European Expert Meeting on Self-Help and I do hope that a fifth, sixth and many more will follow, since these meetings provide us with an excellent occasion to do things, to discuss issues, that are mostly left untouched because of the workload imposed by the daily routine. We are enthusiastic and often do a very good job but sometimes still have questions, worries and doubts regarding our approach with self-help initiatives - some of them you'll find in what follows - and we are very happy that we now have the opportunity as an entire team, to discuss these questions and worries with experts from abroad.

Now, what about this introductory lecture or rather “talk”. The purpose of it is certainly not to present a complete and detailed overview of possible ways to support self-help initiatives and then scientifically and meticulously analyse impacts and effects. That would be boring I guess, and also maybe even important: I couldn't do it, I am not smart enough for that. The only, the sole purpose of this talk is simply to sketch what this meeting could be about, what questions and topics could arise when we look at self-help support from an ethical point of view. I'll only ask questions, describe some effects and impacts of self-help support, simply as food for thought. Some examples in this walk through self-help support and its impact and effects, are real, some circumstances are hypothetical, others pure invention and imagination. You don't have to agree or disagree, just hold the thoughts that pop up in your mind and talk about it in the small groups later on or at any other appropriate occasion during this meeting.

Even before we leave for our “walk”, we encounter some barriers. They already exist for some time but during other meetings in other places it became clear that these hindrances can easily be overcome. Even more, they often stimulate discussion and allow us to discover new ways of approaching or looking at things.

- The first barrier, or better challenge, is the different understanding of the concept of self-help. For some, self-help is practically the same as every “citizen’s initiative”, every voluntary action. Others use a more limited description and exclude for instance self-help initiatives that particularly envisage structural problems such as housing or environmental issues. Still others focus on self-help groups as therapeutic groups or also include self-care, and so on. It is clear and obvious that the interpretation and connotation that is given to self-help and self-help groups heavily depends on the historical, cultural and socio-political setting in which the actual self-help practise takes place. Again, this is more a challenge and an advantage that render our discussions exciting and interesting, than a barrier or an obstacle
- In the same sense, we all have our own idea of self-help support. Based again on the historical, cultural and socio-political circumstances I just mentioned, and of course within a specific organisational and financial framework, we all do many things that look and often are alike - these things bring us here together. But again, there are meaningful differences in our actual work with groups, in our

support. In sum, with the words “self-help support” we all use, we not always mean the same. We all use our own method, or rather approach, since during earlier meetings it became obvious that there is no approved recipe or magic formula for self-help support. There is no universal method but we all more or less use a set of tools that among other things contains the non-directiveness approach, decision-making through consultation, reactivity, stimulation, collaboration a.s.o..

- The last barrier or rather challenge on this walk through the different ways to support self-help and possible effects and impact, is again about understanding. The overall theme of this meeting is self-help support and ethics. But what’s “ethics”? Webster’s Dictionary says that ethics is a “*discipline dealing with what is good and bad and dealing with moral duty and obligation; it is a set of moral principles or values*” For the helping professions, the human services, this set of moral principles are the foundations of responsible and appropriate behaviour with regard to the person receiving help and the larger context in which the support or assistance takes place. Professional ethics, the ethics of doctors, lawyers, nurses, self-help

supporters and so on, are naturally heavily coloured and influenced by personal ethics - your own set of moral principles or values which is the result of your upbringing, education and all kinds of societal, cultural, religious and other influences. Sometimes, professional and personal ethics are in conflict: in jails you’ll probably find quite a number of lawyers who in stead of following the professional ethics of behaving according to the boundaries of the law, preferred their personal ethics that allow, ripping of people, stealing, murdering and so on.

Now during this meeting we’re not going to be the judges of what’s good and bad. What we want to do is to explore what appropriate behaviour regarding self-help groups is in the given context of individual, organisational and societal circumstances.

Ways of supporting; implications and effects

So far for the introduction, the possible barriers that in all look more as challenges. Now something, again not everything, about ways of supporting self-help groups and possible implications and effects. The approach I used for this part of my talk is, that I first give a short description of a possible way of support for self-help groups followed by possible implications and effects. I am talking about all

kinds of support here: direct support such as the provision of finances and practical resources, but also about general facilitation support. The ethical implications and effects are each time considered from the point of view of the supporter as from the point of view of the supported, the self-help groups and sometimes the self-help support centres.

The first possible way to support self-help groups then. And this is, in the light of my passions, my personal favourite.

1. No support

A description of this kind of support is easy. It's simply the absence of any of the kinds of direct or general support I'll be talking about later.

Implications and effects of this kind of support: I believe that when circumstances, that is when the economic, political, cultural and social climate allow it, there will probably always be people who are looking for fellow-sufferers and together start some self-help initiative without any support. Also, in most countries groups precede support. Belgium could serve as an illustration here. Until recently, we always presumed that in the French speaking part, the Walloons, there were practically no self-help initiatives as we define them. But then our colleagues from Brussels, who unfortunately could not make it to this meeting, in only a year's time came up with a list of 150

initiatives that answered to the self-help label. Where they thought they first had to introduce the self-help concept in order to stimulate initiatives, they already found 150 groups to work with, to support.

Conclusion: in countries where support is absent, groups do exist but they are simply not visualised and probably also work more isolated. Maybe these groups that start even without any support, are much stronger because they had to invent everything for themselves, had to struggle for their place? Aren't these groups the ultimate example of real self-help? These could be a few hypothetical, and in a policy context perhaps dangerous, remarks that could be made when we're talking about this first way to support self-help groups.

2. ideological support

A second way to support self-help groups is ideological support. With this I mean lots of words but no action. Verbal appraisal and recognition of the tremendous value and indispensable contribution of self-help groups by government officials, policy responsables of all sorts, professionals and their organisations, all without actual help. The official excuses not to give any help you'll all probably know are: respect for the autonomy and creativity of groups, no intrusion in the group processes, careful without spontaneity and voluntarism in groups and so on. Unofficial reasons for doing nothing often

are no means, money or time, doubts about the effectiveness and reliability of citizens' initiatives, doubts about experiential knowledge, politically not interesting and so on.

Impacts and effects of ideological support: It's nice to hear once in a while that what you do is valuable. It's also good for the credibility and image of a group to have some label of seriousness and respect, but in all it's just a Band-Aid on a wooden leg. It's value is purely symbolic and probably ideological support will neither slow down nor stimulate the growth and expansion of groups. In the long run, continued verbal appraisal without any real contribution is embarrassing and maybe even raises aversion and aggression. In combination with other kinds of support verbal recognition and appraisal can of course play an important role.

3. support by professionals and their formal health and welfare organisations

Another way how self-help groups are supported has been the subject of practically all international meetings I thusfar attended. It is support from professionals of any kind of discipline and their organisations. This support can range from promotion for groups and the provision of practical resources such as rooms, telephone and other facilities, to starting and running self-help groups, as well as general support of the

kind offered by clearinghouses.

One can see interests to support self-help groups emerging from all kinds of professional areas and for all kinds of reasons. Sick funds and hospitals, large voluntary organisations or trusts, in sum various professional groups, are starting to support self-help groups. Sometimes they even are the initiators of full self-help clearinghouses. This is of course a development to be happy about. But, one might also wonder whether the kind of support offered to groups is in this case free of obligations. Although it heavily depends upon the personality, engagement and idealism of the person actually working with the groups, the question could be asked whether the traditional way of service delivery is still not, even subconsciously, maintained. Whether the support is not coloured by the ideological base of the "mother-organisation" or in what way supporting self-help groups will become a way of customer relations and canvassing or image building?. You could for instance wonder in how far a clearinghouse within the bosom of a Christian sickfund is prepared to start and facilitate a self-help group for women who have had an abortion.

In all, support for self-help has become fashionable for professional institutions and human service agencies. Various professional organisations are including the initiation and facilitation of

self-help groups in their service packages, sometimes simply for reasons of image building and customer relations.

Possible impact and effects on groups in this context could be in a few words, dependency, lack of autonomy, lack of interest and initiative. Much more could be said about the relationship between self-help groups and professionals, and about support for groups by professionals and their organisations. But in the interest of brevity I refer you to Judy Wilson's book on this subject, it's called "Two Worlds" which very clearly sums up the dangers but certainly also the possibilities and advantages of self-help groups and professionals working together.

4. Support from government or other official agencies

Next then: support from government or other official agencies. I already mentioned the ideological support earlier, I'll here only focus very shortly on financial support. Most groups need money or want money at least for personal expenses in the beginning and later maybe for larger projects such as books and brochures, symposia and so on. Money indeed makes some things easier and also, if it comes from government it gives you the aura of importance and credibility. Sometimes however, groups bend over backwards to meet funding criteria. They develop activities, change goals,

structures and purposes simply to get hold of cash. Other consequences of official funding are accountability, control and bureaucratisation. Sometimes self-help support centres are dragged into the money game. Funding agencies ask advice whether this or that self-help group is "serious", sometimes they ask to help set up criteria for a funding strategy. The demand to help attain government funding sometimes also comes from groups. They heard from a certain funding scheme and ask the clearinghouse for help in writing applications, formulating requests for money and so on.

Suzanne Biewinga will elaborate further on financial support tomorrow. I therefore leave this topic but not without mentioning that governments can also financially support self-help indirectly by giving their money to intermediate agencies such as self-help support centres.

5. Support by professional self-help supporters in self-help support centres

The support-activities of these centres could briefly be summarised as collection and dissemination of all kinds of information, provision of practical and logistical support, facilitation of the start of new self-help groups and assistance of longer existing ones in moments of crisis or transition. Support centres also offer training and organise consultation, collaborate with human services professionals, the media, authorities and

finally, promote the idea of self-help.

Impact/effect: For a respected number of people in Europe, including Israel, supporting self-help groups has become their job. They make a living on self-help, pursue their personal ambitions and want to be recognised as professionals and, as such try to occupy a respected position in the service delivery system. Alongside these ambitions, tendencies that are at a first glance opposed to the values and philosophy of self-help and self-help support, are perhaps slowly slipping into the job. These tendencies are characteristic for the institutionalisation or professionalisation process. Structures are elaborated, procedures described to work more efficiently, and successes are hunted to secure funding and future. It is also felt that is necessary to justify the work they are performing towards groups of other professionals. For these reasons and also to solicit and establish co-operation and to make referrals possible, self-help support schemes evaluate, analyse and systematise. It is also becoming increasingly difficult not to act as spokesperson of the self-help groups, not to act in their place and take over and defend their interests. A self-help supporter is after all a professional worker and the general pattern of expectation that professionals do something for their clients, is gradually introduced by the so-called self-help consumers: people who see self-help

groups as one possibility besides others to overcome their problems or difficulties. Also, the problem of the "new" self-help supporter emerges, the one who does not take on the job out of pure idealism and engagement like the by now notorious pioneers, but who enters the job of self-help support as any other job in service delivery. Are they still allowed to learn by trial and error? Isn't it easier, faster and more effective for the organisation to work with directives or orders, to apply a certain model or technique? Is there room to combine their personal ethics with the existing professional set of values. Personally I feel that when self-help support schemes come to the conclusion to apply a support method or technique, it might well be that the self-help supporter will become or be considered as an expert like many others, an expert who, often unconsciously, is using his knowledge as power and places clients in a position of dependency.

- Some other issues concerning support through self-help support centres, but only briefly: Routine: don't people who are already some years in the job become impatient when yet another similar initiative is presented. "I've seen it all, done it with the Alzheimer's Club, this would also work for your group" In stead of offering people the opportunity to learn and discover things for themselves, the

experience build up during the years is maybe sometimes bursting to get out.

- Another issue, still briefly, is training. Apart from the consequences in the long run, for instance the power of knowledge, who decides about methods and approaches, what about the danger of manipulation, is the self-help supporter because she or he "knows the needs and subtleties of groups best" the one to give training are just some of the questions that we at our centre see ourselves sometimes confronted with.
- Referral is still another issue that we could talk about. Don't we all make maybe even subconsciously, some kind of appraisal, judgement of groups. And doesn't this influence our referral and also our contacts, our willingness to work with groups?
- And finally for this short list of tangible questions: in how far do our personal principles and values help or hinder us to stimulate or discourage certain initiatives. Some years ago we were asked to help with the initiation of a self-help group for child abusers. Another example is a request we once had for assisting an initiative for people engaged in sado-masochism. Our personal ethics did not allow us to go ahead with these groups. Our professional ethics

could not convince us to still do it.

Dear colleagues, there are still other ways to support self-help. Mixed forms of the once I mentioned, research, support from private companies and so on. It was not my intention with this talk to sum it all up. Just to set the tone and point at certain directions or possibilities. Other speakers during this meeting will elaborate further and much better on specific issues. Thank you and I do hope you all have a great meeting

Friday, June 6

Level and boundaries of professional involvement in self-help activities

(Martha Ramon - Ruth Belkin, Israel)

Introduction

There are some basic assumptions and dilemmas to be discussed:

1. Self-help is a grass-root social movement occurring with or without professional intervention. Whose problem is it about?, humility vs. professional authority
2. Professionals involved in self-help come from different disciplines and belong to various institutional frameworks. Professional integrity

(skills, qualifications, limitations), tension between loyalty to the client, to the employer.

3. Professional help and co-operation can facilitate the self-help process. Negotiating and distributing responsibilities; who decides on suitability to join a group; initiating, leading and letting go of groups; setting goals.

Code of Ethics for Self-Help Professionals

Definitions:

Self-Help Professional (hereunder SHP): any person gainfully employed to promote, encourage and facilitate the self-help approach.

Client: any person or number of people looking for existing groups or endeavouring to establish new ones.

Service: information, referral, organisational consultation, training, supervision, a.s.o..

- The SHP will help the client find or found the group which is the focus of the clients' interest while respecting the clients' right to privacy.
- The role of the SHP is a social, not a psychological one - he is a facilitator and not a personal helper or therapist - hence he cannot enter therapeutic relationships with clients.
- The SHP will respect the clients' problem and not argue or discuss it - as long as the problem does not counter the laws of the country. (Discussion and comparison of controversial

issues in different countries: the right to die with dignity, business debtors in Gaza, terror victims, homosexual youth)

- Most referrals of the SHP are to the public non-profit sector; when making referrals to the private market - i.e. groups run by individuals or institutions on an fee-for-service basis, the SHP will endeavour to have a list of options and prices.
- The SHP will at no time offer services on a fee-for-service basis as therapist, lecturer or consultant on self-help issues to clients who approached him through his official paid position.
- The SHP will refrain from accepting money, gifts or other benefits offered to him beyond his salary.

Cases

An ethical dilemma is an inner condition in which the professional is confronted with a conflict of two sets of values and belief. It can not be resolved. The self-help professional has to find a way to live and work with them. In the following cases, such ethical dilemma's arise.

Case 1

A new self-help group for women affected with breast cancer was formed. The initiator/leader (Lea) was assisted in the process by the self-help support team. She asked for a training course to prepare the group members who volunteered to operate a hot line. Lea and another group member (a psychologist) met

with the volunteers to screen the participants. The self-help support team members were not asked to evaluate the participants' ability to operate the hot line. Lea participated in the course. During the sessions she was active more than the other participants and took time for organisational matters. The team members, who assisted her in the past and also ran the course, wanted to allow her this time for the growth process of the organisation. It also became clear that some of the volunteers were less suitable than the others to man the hot line and that it might be advisable to offer them other tasks in the organisation.

Case 2

A new group of people who suffer from Chronic Fatigue Syndrome starts to form. Its members are in various stages of the active illness and have difficulty in devoting consistent and defined portions of time to the groups' activity. A company which imports and sells nutritional products and herbals medicine assisted the group with typing, stamps, a place for lectures, a.s.o.. The group started to operate a hot line from the Israel Self-help Centre (ISHC) but members found it difficult to come at the scheduled time because of their illness. The company offered to operate a hot line from its office and its secretary to answer the phone and to give information. This offer caused a heated debate in the group. One of the group members started to work in the company and accepted the above offers. The others tried to continue and to operate the hot line from their homes, and severed contacts with the

company. When a patient calls the company he/she is offered written information about the illness and the company's products. He/she is not offered to meet or talk with others in his/her condition. Questions are referred to the company dietician who gives consultation about the products to be used to better cope with the illness. The ISHC consultant explained to the group the ethical dilemma: a commercial company that promotes its products takes advantage of the situation and curtails the patients' freedom of choice when offering only one alternative. The group decided not to 'waste' their meagre energy on confronting the company's manager. Because of their inability to provide services, they preferred to have at least this channel of information for patients. The company continues to advertise this 'service' in the newspaper.

Case 3

A group of parents for hyperactive children was formed. The initiators - the mothers - developed the range of services the group provided. They translated and printed a guidebook for parents into Hebrew; organised workshops run by professionals for parents to acquire skills of handling children; arranged summer camps; did lobbying at the Ministries of Health and Welfare; gathered information; a.s.o.. The organisation's leading committee (parents) decided to charge a yearly fee of \$60; the leader required expenses for her travelling to other cities and lecturing to new parents' groups. She claimed that this is at least some income in view of the

substantial time she devotes to the organisation. When new parents were referred to the organisation, they were required first to pay the annual fee. If not, they were not provided with any information of services. Often, new parents received private consultation at the leading mother's home, for a fee to herself.

Case 4

Results of the workshops

Self-help differs from country to country. Some self-help supporters use a broad description of it, others define it very narrow. The same can be said about self-help support. The limits and boundaries of the professional self-help support are at discussion here. One thing is sure, it's about groups, not individuals and professionals shouldn't set the boundaries for those groups but must consider their role as supporter in finding a balance between listening, acting and recognising mutual support.

Code of ethics

While discussing the code of ethics, questions about the terminology arose. Some participants suggested adjustments. Because of the often difficult, even problematic relationship between self-help groups and their members on the one hand and professional care-givers on the other, 'Expert' probably is a better word than 'professional'. In the same sense, 'consumer' might be better than 'client'. Another remark is that the problems groups are set up

about, should not conflict with the organisations' values instead of 'the laws of the country'.

The self-help expert should rather be helping to define the problem than counselling.

While doing that, he has to show respect for the problems of the client. The self-help expert should not argue, although he can question motives a.s.o..

It's not necessary to exclude the private market in the referrals, but it is important to offer all possibilities and to give advice in order to protect the client. The self-help supporter as a person can not accept money or payment from the group, but in certain situations, the support centre can (e.g. when the service was received by a well sponsored, rich organisation or group). Small presents like a bottle of wine, flowers, chocolate and so on, the self-help supporter is free to accept.

Cases: Ethical dilemma's

Case 3 is an example of an ethical dilemma between on the one hand 'the good practice for a self-help supporter not to intervene' and on the other 'promoting good practice in the group'. The self-help supporter should refer people to the group, after informing them about how the groups is being run.

(Financial) support of self-help groups: a goal or a trap

(Suzanne Biewinga, The Netherlands)

Results of the workshops

There is an increasing pressure on the groups to find means. They need them in order to buy stamps, to make copies, to create their own brochure and/or newspaper, to rent a meeting place, to buy a little gift for a speaker and so on. There are many ways to support groups and inventive groups can find a lot of ways to be supported. Funds or means can come from local, regional or federal authorities, the lottery, sponsors, the E.U. or members. A mixture of these financial sources probably is the best. The support can be direct (supporting a group or a project of a group) or indirect, for example through funding a support centre or a clearinghouse. It can be either logistical or financial. (Financial) support as a result of meeting criteria is OK if these criteria don't interfere with the contents of the group. The use of professional criteria is dangerous because it denies the characteristic traits of self-help and mutual aid. Groups have to decide for themselves if they want to be financed on this basis, but should be made aware of the consequences, because financiers in most cases don't seem to have an ethical code. It might be better if it were the groups that decide on the basis of financing.

Pharmaceutical industries - a new partner for the self-help movement?

(Jürgen Matzat, Germany)

Pharmaceutical industries try to become a 'new partner' of self-help groups. What this partnership consists of and how they try to realise such partnership consists of, can be derived from the following examples.

First example on a European level

After a preparatory meeting, on which some self-help supporters were invited, a conference on 'Patient Empowerment: New partnership in Europe' was held in November 1995 in Brussels. Around 29 patient's representatives from Austria, Belgium, Denmark, Germany, France, Italy, Netherlands, Portugal, Sweden, United Kingdom, USA (e.g. Alzheimer, Asthma, Allergy, Cancer, Myopathy, Mucoviscidose, Parkinson, Eczema) plus a similar number of pharmaceutical industries' managers were invited. The conference was organised by the European Federation of Pharmaceutical Industries (EFPIA, Brussels) and the Pharmaceutical Partners for Better Health Care (PPBH, Basle). One month later, the EFPIA announced the newsletter 'The Patient's Voice', a video tape on the conference and the conference proceedings. March 1997, the 'Second Conference for Patients in Europe: Partners in the Health Care Journey' was held in Paris, with over 120 participants.

The target groups of these conferences are opinion

leaders, representatives of patients' (self-help) organisations, preferably of long term / chronic conditions / diseases with high demand for pharmaceutical products and research (including genetic technology).

Second example: Through the doctor's practice

A drug manufacturing company planned a comprehensive PR strategy to place the self-help topic in (private) doctor's practices. The elements of the strategy were:

- a booklet on self-help groups ('Wegweiser') containing general information and addresses of relevant umbrella organisations and of 'Kontaktstellen' (clearinghouses, information and support centres)
- a poster for the waiting room's wall as an eye-catcher, referring to the booklet in design and content
- a display for exposing leaflets and folders of local self-help groups
- a 'waiting room newsletter' on self-help
- a certificate (later: declaration) of the doctor's commitment to self-help

This illustrates the use of the doctor's practice as a gateway to the patients (the consumers), putting to (good) use the partly still solid doctor-patient relation, the traditional connection between pharmaceutical industry and (private) doctors and the personal contact through a

nation-wide network of sales representatives.

Third example: seminars for self-help groups

The 'Bundesverband der Pharmazeutischen Industrie' (BPI) and the 'Verband der Forschenden Arzneimittelhersteller (VFA, association of researching drug manufacturers) offered seminars in major cities to all self-help groups in the area, on:

- methods of public relations,
- dealing successfully with journalists,
- finding sponsors and financial support from the commercial sector as well as from foundations,
- recruiting new members,
- editing and financing a newsletter,
- leading group meetings.

The lectures were held by members of a special advisory committee, other self-help experts and local journalists.

Results of the workshops

Jürgen asked if we had similar activities going on in our country and if we had been confronted to some ourselves. If not, could we imagine similar activities to come and if so how might these look like? Who would be the actor and who the target group? What pros and cons could we personally see in our work situation to collaborate with the pharmaceutical industry and how would we advise self-help groups and patients' organisations concerning their relationship to this industry ?

In Sweden and England there were no such activities. Austria, Switzerland, Belgium and the United Kingdom have already been confronted with similar activities. It ranges from handing out information on drugs or other medical material, sponsoring a booklet or newspaper, financing the organisation to using the participants of groups as guinea pigs. Although some countries haven't heard about it before, they all expect it to increase because of the cuts in government funding and/or other funding. Conspicuous is the fact that these industries are more interested in working together with the groups than with the self-help centres. There are pros and cons to this development:

- + resources: money, information
- + pharmaceuticals do a lot of research which can be useful to groups
- groups selling out their souls in order to receive some money
- giving information to the industry poses problems of privacy
- abuse of individuals is possible in connection to treatments
- inequality between self-help groups and pharmaceutical companies (on the basis of their consuming)

Nevertheless, the self-help group has to take the initiative, should be the actor. The group can ask for promoting self-help in the workplace, inclusion of information in company literature, a.s.o. The advise supporters would give to groups is:

- ask questions about their motives
- remember the privacy of the members
- take the initiative yourself
- use them, don't let them use you

Privacy and self-help

(Paul van der Hijden, The Netherlands)

Ethics and specially privacy in ethics/morale questions, are hard to concretise. I want to fly some balloons in order to help you conclude this interesting congress day.

Privacy and self-help was the theme that I invented some months ago when the organisers asked me to prepare this meeting. Thinking about ethics, words which often are used in politics like morality and more heavier words like euthanasia, abortion, and the relation between these themes and our work, recurred.

Who are we, the supporters of self-help groups, to interfere in these so private subjects that partners in distress can struggle with? Perhaps you know in The Netherlands, a rather large liberal movement, that supports the freedom of people to decide about their own body or their unborn ones, is active. A small minority with feeling for publicity is against this personal freedom and by the grace of their religion they form some opposition.

To illustrate personal feelings about ethics and self-help support, I would like to start with a personal situation that is very actual at the moment:

A friend of mine is called Harry. Sixteen years ago he got ill, an illness that turned out to be unknown at that time. Glands were remote out of his body. They were tested in the United States. One month later the diagnosis was AIDS. He had only three months to live. He had the worst three months of his life. After that period he felt resistance against the treatment. He decided to diminish the checks in the hospital. He said to himself: 'Now I will show them what I can do myself'. The years that followed everything went okay. Then he had to face several hospital-admissions. Two years ago, he finally decided to end his 'isolation' and told his friends and relations about his terrible illness. It struck us enormously, as you can understand, but the fairness of his remark was good. Since the beginning of this year we often hear him say: 'I do hope that I can reach it.' He meant to be still alive on his fiftieth birthday, this very next Saturday. And he will reach it, as far as I knew yesterday. Is it an ethical question to ask me whether I can be present at this, perhaps his last birthday he so intensely looked forward to?

I already told you about the political ethics. The norms and values which in and out of season are used by politicians: euthanasia and abortion, interference in peoples lives. My next thought was how to make this relevant to self-help support? Should we, teased or nourished by morality, let ourselves be influenced while supporting groups involved in

these ethical questions? Or is our contribution always an encroachment to the privacy of people?

Between the moment I first heard about the conference and one month ago some time passed by.

Meanwhile I grew older and wiser I hope.

I let the words privacy, self-help and ethics spin around in my mind and I tried to put them at a distance. I looked at them from a bird-eye view, and saw myself and my colleagues already in discussion about these so popular subjects in my country. I don't know if this discussion is that interesting for you. Besides that, and up till now an ethic discussion on these subjects hardly ever occurred in our centre. Once I was confronted with a man who suffered a progressive muscle-disease. He sits in an electric wheelchair, he can hardly use his hands and lives with his wife in my town. When there was a lot of news around abortion in the newspapers he uttered: 'I am glad that I was not aborted in those days'. Another ethical question that happened with one of my colleagues was his contact with a women with cancer. She said that her cancer was caused by God and that it was the punishment for the bad life she had lead. Could my colleague help her to find other partners in distress? No, he could not. He could not reconcile her idea about getting ill with his own idea. So far one of my colleagues. Does this shock you? It is not my intention to shock anyone. Speaking about the definition of privacy, I could ask each of you about his personal opinions on private things.

Even this conference started with our passions. Thank heaven that we were not too personal on them.

Does the feeling of intimacy of our own privacy also exist in our contact with groups? Or do we ask them - in the name of our so called professionalism - the most private things about their illness, their handicaps, their social life, their physical behaviour before and after the accident or the awareness of their handicap?

Do we take care for their personal live? Remember the code of the professional versus the code of the group[, as Martha Ramon from Israel mentioned this morning.

And how do we behave at that moment to ourselves? Are we not holding a mirror before ourselves when we enter the private world of the ones we meet in the groups? I do hear you think: 'That is a part of my profession. I am controlled by my office or my colleagues in intervision or supervision.'. But, our board lets us work alone, some of us even are the boss themselves, the controller of morality within the organisation. We have to be careful in giving the asked support. As I understood Peter Gielen, he mentioned some wanted help can also damage a lot in the self consciousness of the so called client.

The role of the self-help supporter in my vision is not a role of a disc jockey: you ask your favourite songs and I play them. In my opinion it does not stop at the ideological do-nothing method. The self-help supporter is also a scrupulous watchman in the self-help castle. When he or she scents danger or does see a ghost, the lord of the castle should be warned at once and the lady of

the castle should be rescued courteously. The next step of the watchman will be to attack the evil.

The possibilities for the self-help supporter, as a surplus to do-nothing are numerous. When you support them in a general way to make them aware of their own possibilities. Don't interfere with their privacy, but help them to defend it.

It's obvious that a very client-friendly form of self-help support is to organise a course or training.

Themes can be assertiveness, reading papers of civil servants, successfully starting a new self-help group, gender specific self-help, coping with a chronically illness, a handicap or life event, a.s.o..

The main subject during these courses should be the partner in distress or partner in experience as Suzanne Biewinga from The Netherlands said. She or he arranges the programme. If the courses start with a session in which the clients make their wishes clear and explain their aims, it will be their help in self-help. With their experiences, new experiences and wanted behaviour can be trained.

The self-help supporter in general or the specific instructor has the function of translator of the knowledge.

Another form of self-help support that doesn't interfere with the ethics or values of self-help groups is the help to spread the ideas of the self-help groups.

The following example, that offered pride and publicity,

breaks down privacy but with a good purpose: Eight years ago our support centre decided to reserve money to distribute a free magazine every six or seven weeks, for all the self-help groups in our province. Thanks to the sponsoring of an insurance company, we can also send it for free to all the general practitioners and libraries in our province. We gave that magazine the defiant title 'Maatgevend', which is in English: Decisive. The magazine is written by the Limburger self-help group members and we, the professionals produce the magazine.

In a later stage of my thinking and talking about the theme of this conference I spoke to Miss Evelyne de Leeuw of the Maastricht University. She is a member of the Board of Health, the WHO collaborating centre for research on healthy cities. She informed me on the book by John Rawls, 'Justice as Fairness'.

Mr. Rawls does not speak about equality, he talks about justice when people are treated fair, by the government, their friends and by themselves.

Being aware of this theory some final ethical questions you can discuss during the workshop, occurred:

- Is privacy a theme in your support of self-help?
- Is it just when professionals in for instance hospitals send patients to self-help groups so that they do not have to give adequate information or do not have to listen to the questions and

the complaints of those patients?

- Is it just that self-help groups keep the people off the streets?
- Is self-help the XTC for the people?

Results of the workshops

The core of self-help is mutual support, which implies people continually taking alternating roles of helper and helped. This often means that everyone reveals very private aspects of his/her life. Participants become very vulnerable. They speak openly about their problems, often for the first time, without ever having told any close friends or family members. The demarcation of privacy depends upon culture and personal feelings. A clear evidence of protecting the individual against hostile society and himself are the anonymous groups like AA. But most groups don't have this build-in safeguarding. The practitioner's role is to protect every individual's privacy towards other members in the group and others outside the group. Too often, self-help groups members are exposed in the media against their will or intention. The self-help supporter should inform members of the consequences of giving up privacy. The professional ethical code of the self-help supporters should prevent them from abusing private information, sometimes even prevent group members or initiators of giving unnecessary information.

Saturday, June 7

Solidarity and self-help

*(Verena
Vogelsanger,
Switzerland)*

Introduction

I hate, to look up words in the dictionary, but I like painting. So I take all my energy and hope you will forgive me my mistakes.

As far as I see, there is a strong and good working solidarity in many self-help groups. Of course there are always some problems, and sometimes it isn't that easy to say "Yes she is one of us!" But after all it is working nicely. Solidarity seems to be one of the main attractions of SHG. For the members as well as for myself and maybe also for you. But what keeps me busy for quite a time is, that the same solidarity doesn't work as well among different SHG.

I will speak about:

1. some possible reasons for that fact
2. why nevertheless it should be an important goal for a clearinghouse, to support that solidarity
3. some examples of how we try to support solidarity at our place

Reasons

Without any support of a clearing-house, self-help groups seem not to bother to much about other groups. I often realise there is a low interest in the sorrows of

others. They rather mind their own business.

Sometimes they even fight other groups - in order to discuss, what kind of destiny or disease is harder than another.

*"They do everything for the blinds, and nothing for us!"
"If I wouldn't have other problems than yours, I would stay at home and be happy!"*

As I started to think about this fact, my special interest turned to questions about group-dynamics. I'm going to mention some reasons, and I'm sure, you know a lot of other reasons so I'm looking forward to the discussion.

1. A strong enemy makes a strong group. Sometimes the enemy is the whole social surrounding, and that could be one reason, why they are not that much interested in having new friends.
2. Some groups have a really good time. They seem to be somehow in love with each other. Theoretically, this state of development is sometimes called "honeymoon". This is of course not the best situation for being interested in others. And even if this time doesn't last forever, some groups seem to long so much and for a long time for this wonderful time, that they won't see other groups "getting older" and turning to an every day life.
3. Many of the new members have some problems to feel self-conscious. They need the support of the group to realise the meaning of their

special problem in their life. And it is very important, that the own problem becomes a part of the personal identity. I wonder, how much the refusal of other groups is connected to the danger of losing that - maybe still delicate - identity (as an individual and as a group-member).

Goal: Solidarity among different self-help groups

Even if the conditions don't seem to be that easy, it must be an important goal for a clearing-house, to get groups in touch with each other and to promote solidarity at any occasion.

I want to enumerate some of the reasons of importance:

1. Groups do need the exchange of experience and a mutual stimulation.
2. The consciousness, to be part of an important infrastructure and al larger movement, provides support.
3. Self-help groups won't be successful in reaching political goals, until they work together.
4. There is a number of self-help groups, that suffer on public discrimination. As a part of a community of groups, they feel less disregarded. And after all, words and arguments can never help as much as new experiences of working together and having a good time..... and that always has a positive effect on the public opinion.

5. Most of the groups do wish more interest an understanding from other people. But every member is such an "other people" for the next group. So why don't we use these relations to diffuse that knowledge about the intellectual and the emotional meaning of special situations for the concerned persons.
6. Some members still don't have to much company besides their own group. Specially for them it is important to use the potential of communication and friendship within a movement. In order to create occasions to get in touch with more other persons.

It still makes a difference if you run into one or ten familiar faces on a walk in town.

Examples how we try to support solidarity at my place

After all we see: Solidarity among different self-help groups will only take place through a long process of many little steps and slow growing traditions.

Examples

We organise permanent exchange-meetings and we specially try to reach all the members, not only their delegates. Depending on the subject, there is a changing interest. On the one hand, whole groups show up, on the other, regular visitors. Nevertheless, each

meeting we get to know some new faces.

In this context discrimination and rejection have been a matter of continual interest. Thus in 1995 the self-help groups of our region decided to organise a common information-market in the city. You may have experience with such events: I was rather sceptical. And I was right - at least as far as the public was concerned. Passers-by reacted very reserved (which is probably based upon the typical Swiss mentality, not to talk about problems in public). On the other hand, I completely underrated the gain of this event for the solidarity among self-help groups. There were quite a number of occasions to work together, to get to know each other - phone-calls had to be made, preparations had to be done, cakes had to be baked. It was also a real coming-out for certain groups, to present their problem in public for the first time, well protected by better known groups.

In the following year - our 15th anniversary - we searched an activity, which would at the same time avoid the mentioned inconveniences and guarantee the advantages in the above sense. The question was: How can we create an event, where as many members of self-help groups as possible can meet, united by a common task - even those, who don't like to talk much, or those, who need a lot of protection? How can we show, that our movement is a creative one - without having the members to expose their very personal problems in public?

The idea we had then, was to knit together a textile network, as huge as 30 square metres. A network that should be exhibited in a public place. During the two weeks of activity, we asked the regional self-help groups, to meet in our centre in order to take part. The idea was taken very well, even from members of self-help groups, who had never attended common activities before. Another success was to witness, that the self-help groups from the 'outside' and our own guided groups (which harbour farther disabled persons) got closer to each other. Beside those groups there were other persons who kept coming. They had an important function in instructing and helping the others.

When the impressive network was finished, we found a sponsor, who was willing to exhibit the work of art in a public place - during four months and for free. The opening night, with important members of the political scene taking part, was fruitful; the media did not fail to present the spectacular, colourful network. It also was a good opportunity to accent, that Basle does not only need 'Novartis' (our new chemistry elephant), but also 'Solidartis', as a member of Swiss Parliament put it.

The local government has understood this and is willing to buy the network. It will soon be exhibited at the main city-hospital. This would mean, that our activity was a total success - symbolical and financial at the same time.

Results of the workshops

A lot of self-help supporters are confronted with the problem of solidarity among self-help groups. Solidarity or co-operation is indeed problematic but logically emerges from the single-issue groups becoming even more specifically single-issued on the one hand, and the voluntary nature on the other. This means that competition (which situation is the worst), the condition and the workload of the members and the financial situation of the groups stand in the way of solidarity.

But solidarity seems to be possible in some situations:

- when specific goals are defined: common (political) goals
- when it's limited in time
- when it's about small groups with a similar style
- when they are motivated to learn from each other
- when it's about self-help or umbrella organisations with professionals, that can form alliances at a national or international level

Clearinghouses mostly have the means and the information to make groups work together. They should facilitate and offer logistical support, reduce the workload so groups only have to think about the content.

Voluntarism in the self-help movement in Hungary

(Zsuzsa Csato, Hungary)

Results of the workshops

Voluntarism and the importance that is attached to it differs among the participating countries. In Germany, new impetus has been given to this altruistic activity in society. Volunteer centres are being set up. In Italy, children are taught about the values of voluntarism. The UK 'encourages' unemployed to work in voluntary organisations, and there is a widespread and well organised system of volunteers. In Belgium voluntary work has a long history and specific institutions exist. Self-help groups are a special form of voluntary work and apply for the same funds. Clearinghouses in the UK and Israel have volunteers for administrative jobs. They have voluntary experts and trainers. In Denmark volunteers have to support self-help groups and the paid workers do administrative and co-ordinating jobs. When paid personnel and volunteers do the same job, conflicts can arise about payment, equality, valuability, a.s.o.. Next to that, the danger exists that governments, local or regional authorities don't give any financial means as long as voluntary workers are doing the job.

Voluntary work can be described as unpaid work, a job of honour.

Free podium:

Lobbying

(Zsuzsa Csato, Hungary)

Professional involvement in citizen - government dialogue

(Martha Ramon, Israel)

Self-help groups in a wired world

(Solbjørg Talseth, Norway)

Self-help is such a strong and enticing approach to human problems that people are defying the barriers of time and space in order to participate. Rural inhabitants, people with physical disabilities - and people like you and me - think that telecommunications provide new opportunities to get involved in the self-help movement.

In this talk I give some examples of "*Self-help groups in a wired world*". I myself am new to the idea, and my experiences are limited to working with a group of rural inhabitants using telephone conferencing. I will briefly tell about these experiences, as well as our future plans for Internet-based self-help groups in Norway.

May 1996, a woman in northern Norway, who had participated in one of my seminars, called and asked if I would be willing to supervise a

group of 4 persons by telephone. She had contacted Deede Gammon - at the Dept. of Tele-medicine, Univ. Hospital in Tromsø - who was willing to fund the group for a pilot trial. Sure, I was sceptical in the beginning, but the people starting the group, were determined to try. Instead of focusing upon the problems and limitations - which I'm sure many of you here would also be concerned with - I chose to focus upon their needs, and their own belief that they could make a telephone group work. The basic setting was that three participants sat together with a loud-speaking telephone, while the other participant and myself participated from our home phones.

Sometimes all participated from their own home, and sometimes all were gathered together - depending on weather conditions, travelling on the part of participants and other factors. A total of 15, 1 hour sessions were conducted until the group was dissolved when one key participant resigned from the group.

I could talk for hours about the experiences from this group and why it dissolved. What I will emphasise here is that all participants, including the person who withdrew, are positive to telephone-based groups and want to continue with new groups. They themselves believe that two alternative models appear best: Either the group should be exclusively telephone based (instead of some sitting face-to-face), or all participants should sit face-to-face with a loud-speaking telephone, while the supervisor participates by phone. Furthermore, they

found that friends should not participate in the same group, a view that I also share from previous experiences. We are now recruiting new members to a group exclusively telephone-based. Hopefully, the group will be operative by autumn this year, and I will be happy to report the experiences at our conference next year.

My collaboration with Deede Gammon (a research psychologist in tele-medicine) has given us both new insights, and lots of new questions. She started looking for literature about "distant self-help" and found some references to telephone conferencing self-help groups for HIV, domestic violence, leukaemia, and elderly. Even more exciting, she discovered a silent revolution taking place on the Internet - a myriad of self-help groups emerging world wide, although mostly dominated by Americans. Among new groups alone, she found 54 themes for self-help ranging from depression, anxiety, schizophrenia, manic depressive, to various physical disabilities. Thousands of people participate in these groups (which are open), as well as other types of groups which are closed to the general public.

During this process Deede asked me - as a European self-help veteran - to think about some difficult questions: "Solbjørg, why do you think that Internet-based self-help is growing so fast? Do you think that on-line self-help can have some of the same health promoting benefits as face-to-face self-help? Do you think that your experience and knowledge in self-help can help us design services

supporting Norwegian/Nordic Internet-groups?"

I would like to invite all of you here today to help me think about these questions. I'm not a person that says "no" to challenges and I will be working with Deede and the Norwegian Council for Mental Health in designing on-line self-help support services. I think it's important for us in the European self-help movement to become more active - not only in designing new services - but also in debating the potentials and pitfalls of new methods for self-help group participation.

The ethos of self-help and self-help supporters in the area of mental health

(Elzbieta Bobiatynska, Poland)

The relationship between researchers and self-help groups: exploring ethical aspects of participatory research

(Jane Bradburn, United Kingdom)

Introduction

This paper explores ethical aspects of the relationship between researcher and self-help groups. It considers research from the self-help supporter's point of view, looking at the advantages and disadvantages. It then shows how collaborative research approaches can address some of the ethical concerns which self-help supporters have about research and suggests ways in which they and the groups themselves might carry out their own research.

Working in the field of health, as a self-help development worker promoting links between self-help groups and professionals I found myself more and more drawn into doing research as a way of explaining the nature of self-help groups and especially the particular properties of groups, their knowledge, mutuality and autonomy. Working with cancer self-help groups, I found that research helped to explain members' view of the experience of having cancer and of being the partner of someone with the disease. So I am a self-help group supporter turned researcher or to put it another way a 'research-practitioner'. As such, I found myself considering how self-help group research can be conducted in an ethical way. In traditional research, the researcher decides on the topic

of study and how this is to be carried out and expects the subjects of that study to be the passive participants. My background in self-help group support meant that by preference I took a developmental and facilitating role. This does not fit well with the way in which research has traditionally been conducted. This difficulty is shared, I believe, with many working with self-help groups.

Concerns about research and self-help groups

First of all I am going to consider the disadvantages of research. Research may be perceived by self-help groups as an elitist activity, conducted by 'experts' using methods which may be a complete mystery to those taking part. Self-help groups can feel exploited when, having agreed to a researcher or 'outsider' conducting research on their group, they then hear nothing more. The findings may be explained in terms or numbers which have little relevance in meaning to the self-help group members. Research can be a very powerful tool, the findings of research can be used to influence policy and resource allocation but often, because the research is conducted for agencies or organizations other than the self-help groups, they cannot take advantage of this because they do not 'own' the research. I think that it is for many of these reasons that self-help supporters have been wary of research activities. In the past research has been conducted by people who have little idea of what the reality is for the subjects of their research or an understanding of the concept

of empowering self-help groups through collaboration. The focus of the research may not reflect the concerns of the supporters but just be something the researcher happens to be interested in. The research may not be fully understood by the supporter. Often self-help supporters have little or no training in research. The research methodology used may not be consistent with their values such as empowerment and the valuing of the individual's experience.

The advantages of research for self-help

The picture I have painted of research and self-help is rather bleak, so let me now turn to the advantages because I do in fact believe that research is very important in promoting and sustaining self-help. Having studied some the volumes of research about self-help produced in North America, I have been impressed by the way in which it is able to offer new ways of explaining self-help to the wider audience. For example one strand of research in the States conceptualizes self-help groups as communities of interest or belief and this has led to research which looks at how they create their own culture and transmit beliefs and knowledge, which are often at variance with professional ideas (1). There are many examples which demonstrate how research can be useful promoting a better understanding of self-help groups. For example research I carried out in 1992, which mapped the character and activities of local cancer self-help groups was very useful in

explaining the value of such groups to local health professionals and to a wider professional audience through publication in a national medical journal (2). Secondly, research can be used as a tool by self-help group supporters to improve their practice and who better to conduct the research than those who already have an understanding of the issues and a relationship with the groups themselves. So I want to encourage you all to consider undertaking your own research.

Thirdly, and I think most importantly, research can be a tool used by the self-help groups themselves for solving their problems. I am going to give you an example of this from my work with local cancer self-help groups. The research I referred to which was carried out 5 years ago; the mapping local cancer self-help groups, found 18 autonomous community-based groups. Having established contact with the groups they were keen to meet together and a network was formed. The groups met regularly to support each other, to exchange information and seek ways of improving links with health professionals. Soon they were recounting their experiences as cancer patients and raising concerns about the care provided. The main one was the way in which they were told they had cancer. Some had been told in a very unsympathetic way and offered no support or information. As a result of the groups voicing their concerns, a research project was set up to see how the practice in giving a diagnosis of cancer could be improved. Qualitative

research methods were used, including tape recording group discussions with the self-help groups and interviews with individual cancer patients about their experiences. Self-help groups are often accused of being excessively negative. An important finding was that the issues raised by the groups did not differ from those raised by individual patients. Cancer doctors who gave the cancer diagnosis were also interviewed about their experiences. All this information was put into a report for a joint working group of self-help group representatives and health professionals. They developed guidelines on how people should be told that they have cancer, together with a leaflet, to be filled in with the patient at the time of diagnosis, which gave details about the diagnosis and treatment plans and support contacts. This research was funded and published by the King's Fund, a national organization promoting good practice in health (3).

Collaborative research

This example shows how self-help groups can set the research target and work with the research practitioner to solve a problem the group itself identifies. This approach to research is known as participatory action research. Participants and researchers become actively engaged in finding the solutions to problems by looking at the problem, thinking about a solution and putting that solution into practice. I am currently working with a group of self-help group members who wish to take part

with health professionals in making local policy decisions about the way in which care is delivered. We are finding ways of doing this, how it can work and what the barriers there are (4). By working together in this way, the research practitioner addresses the lack of power experienced by self-help groups. This research approach, values self-help members own experiences and knowledge. Members are being asked about things which they know about and included in the decision-making process. Participatory action research emphasizes collaboration, the research seeks to empower the self-help group members through a process of discovery not only to find possible solutions to problems but to become more aware of their own 'expertness'.

Even with collaborative research approaches, there are ethical dilemmas. It is considered an ethical requirement in human research that the consent of the subject is obtained. But when there are many self-help members taking part, who is consenting? Is it enough to obtain the consent of the leader or of each member? Another question is 'what are they consenting to?' In participatory action research, the course of the research is largely unknown because it is developed by the researcher and participants as it progresses. Then there is the difficult question about the nature of the collaboration; who owns the research; who decides what goes into the research report and if, where and when it is published. It is important to reach agreement about these matters at the start.

The researcher may be undertaking the research as part of an academic qualification as I am, in which case, although he or she may share the aims of the group members, there will also be another aim, to meet academic requirements so that interests may conflict. Again these interests need to be quite clear from the start.

There are many ways of doing research. I have suggested one which appears to answer some the ethical requirements when working with self-help groups, but any approach requires careful planning and negotiation about the nature of the relationship between researcher and self-help groups because it is a power relationship. Kauffman, in her study of research involving mental health service users in the States, suggested the following degrees of participation in research (5). Self-help supporters are in a good position to conduct research themselves and so are self-help groups who are using it not only to solve but to highlight problems. For example, one local group conducted research to discover what information was available on self-help groups in local doctor's surgeries. The results were used to encourage more information to be displayed for patients about local self-help groups.

Conclusion

In conclusion, I would suggest that research has many benefits for self-help groups which may not have been maximized in the past because of the kind of

approaches taken.

Collaborative research which is done with or by self-help supporters appear to offer one way towards ethical and meaningful research in the future.

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I hope that this paper has inspired others to take an interest in research. If so I would like to suggest that we start a network of self-help researchers across Europe. In the UK, we have taken our first steps in this direction by holding our first meeting at Self-help Nottingham in October this year. We have established links with the Canadian Self-help Research Network who plan a international meeting next year. For further information please

contact: Jan Myers or Jane Bradburn

A paper which challenges the current lack of interest in self-help group research in the UK entitled 'Looking Again at Self-Help - the Building Blocks of Voluntary Action?' was presented by myself and Carol Munn-Giddings at the National Council for Voluntary Organizations Research Conference in London in September 1997.

Sunday, June 8

Closing lecture: Good practices in working with self-help groups: a partnership approach (Stephanie Varah, United Kingdom)

Introduction :

The aim of the lecture was twofold:

- to summarise and draw together key themes emerging from the Conference
- to present Nottinghamshire County Council Social Services Departmental User Involvement strategy as an example of a good practice model or ethical approach towards working in partnership with Self-help Groups

Key Themes :

THEME 1: Code of Practice / Ethics

From the Conference it was evident that self-help supporters were seeking a code of behaviour or ethical guidelines as professionals in working with Self-help Groups. Delegates were questioning how are workers to know whether their support is appropriate to Self-help Groups? whose agenda are we serving?

THEME 2: Self-help Ethos

Increasingly, external pressures upon self-help supporters detract from the 'user-led' perspective. A model needs to be developed

therefore which maintains the self-help ethos and encourages closer positive relationships with groups to inform our working practice.

THEME 3: Strength of Solidarity

The sharing of ideas and coming together as 'partners in experience' has provided a strong foundation upon which to build and develop a good practice approach. This shared solidarity needs to be harnessed to generate a common approach towards working with Self-help Groups, also to act as a catalyst towards legitimising and prioritising resources to effect the requisite 'culture change' amongst organisational personnel.

Nottinghamshire County Council Social Services Department User Involvement Strategy :

The main focus of the presentation, the 'User Involvement Strategy', offers a model which philosophically reflects and builds upon the aforementioned key themes.

The model represents an operational framework for working practice revolving around the concept of empowerment, to ensure support to groups does not merely remain an ideological or a symbolic activity.

USER INVOLVEMENT THE PROCESS OF EMPOWERMENT

Broad Objectives

- to recognise the value of self-help as complementary to statutory provision
- to promote self-help and community development
- to enable and facilitate self-help group participation in decision-making, planning and development processes which affect them
- to develop a positive working relationship with self-help groups and the voluntary sector
- to ensure adequate and appropriate support

WHY HAVE A STRATEGY ?

The strategy:

- demonstrates a formal high level commitment to the concept of empowerment, embodying an *'action not words'* approach to *'change good intentions into working practices.'*
- builds on strengths:
 - ◊ through existing work of staff
 - ◊ through wide range and strong networks of Self-help Groups in Nottinghamshire
- impact of Government legislation
 - ◊ has brought into sharp focus relationships between local authorities and the voluntary sector

HOW WAS THE STRATEGY DEVELOPED ?

The strategy was developed in collaboration with Self-help Groups over a period of two years and was therefore 'user-led' and reflects a self-help ethos.

- led by designated Partnerships Officer
- had political commitment - key elected member
- through consultation with local Self-help Groups
 - ◊ networking meetings
 - ◊ partnership conferences
- had staff input - existing good practice
- learned from national research on good practice
- identified targets and tasks for all social services activities
 - ◊ assessment of need
 - ◊ staff training
 - ◊ staff recruitment
 - ◊ advocacy
 - ◊ self-help support
 - ◊ planning, consultation and evaluation

COMMON OBJECTIVES FOR SELF-HELP SUPPORT

To build unity and solidarity of approach common tasks and target objectives have been identified, for example :

- To make the development and support of Self-help Groups and their networks a priority
 - Task: prioritise resources to aid self-help development, i.e. staff time, funding, training, transport costs, a.s.o.
- To support and encourage staff to enable the development of self-help activities
 - Task: create internal support, standards and communication required to promote mutual support and

awareness of self-help among staff

- To ensure the move towards a self-help focus is a sensitive process and addresses training and development needs of staff and users
 - Task: focus training on the development of appropriate skills for staff and users, e.g. listening skills / confidence building
- To work towards a 'culture' of user involvement in planning, consultation and evaluation
 - Task: explore ways of collecting and reviewing user views to use as training material for staff

ETHICAL ISSUES

To avoid the risk of the strategy being ineffective and offering only ideological support, the following ethical issues need to be understood and addressed:

- Relationships between Self-help Groups and the local authority.
 - ◊ lack of understanding / interaction
 - ◊ unrealistic expectations on both sides
- Pressures on staff time to implement strategy
 - ◊ requires 'culture change'
 - ◊ may be resisted due to pressure of work and become a token gesture
- Changing roles and assumptions from legislation

- ◇ confusion around how local authorities and Self-help Groups carry out new roles
- Danger for Self-help Groups of loss of focus on traditional aims
 - ◇ increased use of groups as service providers
 - ◇ pressure on local authority financial resources

There needs to be a recognition that Self-help Groups are a delicate balance of interests and motivations and any inappropriate outside intervention may disrupt this.

A GOOD PRACTICE MODEL

Key Characteristics :

The strategy demonstrates:

- Clear vision of the role / contribution and world of Self-help Groups
- Recognition that the self-help movement is valuable and should be nurtured and developed
- Commitment from professionals to an approach which cultivates and promotes self-help activity in all aspects of policy
- Long term commitment of resources and processes to change attitudes and develop an understanding of Self-help Groups
- A strategy or policy statement as a framework, supported by adequate resources for both professionals and self-helpers.

Conclusions - or a New Beginning ?

As professionals working with Self-help Groups we come from a range of backgrounds and experiences and are now facing many challenges from the external environment which face us in supporting Self-help Groups:

- Let us look for the opportunities and re-interpret them not focus on the threats.
- Let us consider new approaches to self-help support and be creative. Let us recognise that the structure of a group may take many forms and be affected by many influences, e.g. gender/culture etc. Therefore, the nature of the 'group' will be highly context specific and user-led. Thus the structure of the group should reflect this perspective, e.g. The 'Virtual Group' via the Internet, networks of contacts for people in rural areas etc.
- Let us recognise strength through solidarity and build upon our common strengths/ approaches to our work to further develop and promote good practice. Let us continue to exchange information and knowledge and initiate, develop and promote a code of ethics for self-help support.

As self-help supporters we enable groups to develop and flourish through facilitating empowerment. In ethical terms, in the 'garden' of self-help are we the 'compost' which cultivates empowerment ? or, are we as

professionals, the 'expert gardener' who decides what to plant and where ?

Let us harness our collective 'partnership in experience' towards supporting and empowering self-help in the future.

Summary, conclusions and evaluation of the fourth European Expert Meeting.

Prospects on how to network and/or collaborate more systematically among self-help supporters in Europe

Exploring the possibilities of a fifth European Expert Meeting

List of participants

Andrea Lins

Fonds Gesundes Österreich,
SIGIS
Laxenburger Strasse 36
1100 Wien
AUSTRIA
☎ 0043-1-71 172 43 67
Fax: 0043-1-71 172 43 98

Gerlinde Müller-Grohotolsky

Selbsthilfe Kärnten
Stauderplatz 5/3/308-
9010 Klagenfurt
AUSTRIA
☎ 0043-463-50 48 71
Fax: 0043-463-50 48 71 - 24

Hilde De Wilde

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-23 65 07
Fax: 0032-16-32 30 52
✉ hilde.dewilde@soc.kuleuven.ac.be

Annemarie Dinneweth

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-23 65 07
Fax: 0032-16-32 30 52
✉ anne-
marie.dinneweth@soc.kuleuven.ac.be

Annemie Vandermeulen

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-23 65 07
Fax: 0032-16-32 30 52
✉ annemie.vandermeulen@soc.kuleu-
ven.ac.be

Annie Cornelis

Patiënten Rat & Treff
Neustrasse 67
4700 Eupen
BELGIUM
☎ 0032-87-55 22 88
Fax: 0032-87-55 76 83

Bie Callens

Hof van Watervliet / Hof Lanchals
Oude Burg 27 - 23
8000 Brugge
BELGIUM
☎ 0032-50-44 03 70
Fax: 0032-50-44 03 90

Koen Matthijs

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-32 31 73
Fax: 0032-16-32 33 65
✉ koen.matthijs@soc.kuleuven.ac.be

Kristel Matthys

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-23 65 07
Fax: 0032-16-32 30 52
✉ kristel.matthys@soc.kuleuven.ac.be

Peter Gielen

Trefpunt Zelfhulpgroepen vzw
E. Van Evenstraat 2C
3000 Leuven
BELGIUM
☎ 0032-16-23 65 07
Fax: 0032-16-32 30 52
✉ peter.gielen@soc.kuleuven.ac.be

Helle Bertelsen

Selvhaelpsgrupper i Esbjerg
Gasvaerksgade 2
6700 Esbjerg
DENMARK
☎ 0045-75-45 70 85
Fax: 0045-75-45 70 84

Lone Moller

Kontakt mellem Mennesker
Toldbodvej 5
5700 Svendborg
DENMARK
☎ 0045-62-20 11 30
Fax: 0045-62-20 11 13

Marianne Nylund

University of Helsinki
Department of Social Policy
P.O.Box 18 (Snellmaninkatu 10)
00014 University of Helsinki
FINLAND
☎ 00358-9-19 17 766
Fax: 00358-9-19 17 764
✉ marianne.nylund@helsinki.fi

Balke Klaus

Nationale Kontakt und
Informationsstelle
Selbsthilfegruppen
Albrecht-Achilles-Strasse 65
10709 Berlin
GERMANY
☎ 0049-30-89 14 019
Fax: 0049-30-89 34 014

Jakubowski Anita

Koskon der DAG SHG e.V.
Friedhofstrasse 39
41236 Mönchen-Gladbach
GERMANY
☎ 0049-2166-24 85 67
Fax: 0049-2166-24 99 44

Jürgen Matzat

Deutsche Arbeitsgemeinschaft
Selbsthilfegruppen
c/o Friedrichstrasse 28
35392 Giessen
GERMANY
☎ 0049-641-99 45 612
Fax: 0049-641-99 45 609

Zsuzsa Csato

Self Help Information Centre
Kira'ly 72
1068 Budapest
HUNGARY
☎ 0036-1-14 10 675
Fax: 0036-1-13 16 112

Ruti Belkin

Israel Self-Help Center
37, King George Street
Tel Aviv 61231
ISRAEL
☎ 00972-3-62 00 259
Fax: 00972-3-52 54 486

Martha Ramon

Israel Self-Help Center
37, King George Street
Tel Aviv 61231
ISRAEL
☎ 00972-3-62 99 389
Fax: 00972-3-52 54 486

Kate Hoel

Frivillighetssentralen i
Frederikstad
Postboks 158
1601 Frederikstad
NORWAY
☎ 0047-69-31 68 70
Fax: 0047-69-31 68 74

Solbjorg Talseth

FRISAM / Angstringen
Duvresvingen 14c
1184 Oslo
NORWAY
☎ 0047-22-28 50 33
Fax: 0047-22-28 50 33

Elzbieta Bobiatynska

Coalition for Mental Health,
TOPOS
Długa 38/40
00238 Warsaw
POLAND
☎ 0048-22-831 22 12
Fax: 0048-22-831 47 12

Anneta Snarfelt

Dept. of Public Health
Box 11475
40430 Göteborg
SWEDEN
☎ 0046-31-61 28 96
Fax: 0046-31-701 08 13

Leif Torensreöm

Dept. of Public Health
Box 11475
40430 Göteborg
SWEDEN
☎ 0046-31-61 28 96
Fax: 0046-31-701 08 13

Verena Vogelsanger

KOSCH
c/o Selbsthilfezentrum Hinterhuus
Feldbergstrasse 55
4057 Basel
SWITZERLAND
☎ 0041-61-69 28 100
Fax: 0041-61-69 28 177

Irma Stämpfli**KOSCH**

c/o Beratungsstelle
Kurzfeldstrasse 11
8500 Frauenfeld
SWITZERLAND
☎ 0041-52-721 31 40

Suzanne Biewinga

Nederlandse Patiënten /
Consumentenfederatie
Van Dommelenhuis
P.O. Box 1539
3500 BM Utrecht
THE NETHERLANDS
☎ 0031-30-297 03 03
Fax: 0031-30-297 06 06

Paul van der Hijden

Stichting Symbiose
Unit Patiënten, consumenten,
gehandicapt
Postbus 1278
6040 KG Roermond
THE NETHERLANDS
☎ 0031-475-34 00 00
Fax: 0031-475-32 88 44
✉ paul.van.der.heyden@symbiose.nl

Jan Myers

The Self-Help Team
20 Pelham Road
Sherwood Rise, Nottingham NG5
1AP
UNITED KINGDOM
☎ 0044-115-969 15 14
Fax: 0044-115-960 20 49
✉ self.help@global.net.com.uk

Jane Bradburn

2, Cedar Way
Berkhamsted, Herts HP4 2LD
UNITED KINGDOM
☎ 0044- 1442 87 17 39
Fax: 0044- 1442 87 17 39
✉ ljmc.mvh@gpo.sonnet.co.uk or
mbradburn@aol.com

Stephanie Varah

NCC Social Services
Bassetlaw Community
Development Team
31, Shrewsbury Road
Manton, Worksop
Nottinghamshire S80 2PB
UNITED KINGDOM
☎ 0044-1909-47 61 11
Fax: 0044-1909-53 13 35