Ninth European Expert Meeting on Self-Help Support

THINKING OUTSIDE THE BOX
EXPANDING THE BOUNDARIES OF SELF-HELP SUPPORT IN A CHANGING SOCIETY
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1 INTRODUCTION

The Ninth European Expert Meeting on Self-Help Support was organised in Leuven by Trefpunt Zelfhulp vzw. Because a change of scenery often helps to gain new insights, the venue of the meeting wasn’t Bruges as in 1997 at the occasion of the Fourth Meeting, but Leuven, the home basis of Trefpunt. Trefpunt welcomed 23 participants from 12 different countries to the Irish College in Leuven. The meeting brought together this selected number of self-help supporters to map the evolution in their countries and to exchange new knowledge and practical experiences on working with and developing self-help groups and support centres in the years to come.

The overall focus of the meeting was on support for self-help groups. Its particular theme was ‘Thinking outside the box: expanding the boundaries of self-help support in a changing society’. The meeting aimed at gaining insight into the consequences of various social developments and trends for self-help groups. Social developments may be beneficial or detrimental to the functioning of such groups. The various changes may be of demographic, scientific, technological, cultural or socio-economic nature or relate to the supply and the demand of care, morbidity, lifestyles or relationships.

We set the meeting about to establish how these external changes are bound to influence self-help groups in the 10 years to come and how self-help supporters can support groups in facing up impediments and in making the most of opportunities.

The meeting has surely lived up to these expectations. Participants were enthusiastic and eager to exchange ideas. And once again exchanging ideas with peers, with ‘hands-on’ experts, turned out to be very fruitful in learning more about self-help support. In this report we have tried to give an account of the meeting in a surveyable way. We hope you will enjoy reading it. While doing so keep in mind that for this collective result your contribution was indispensable. Thank you.

Trefpunt Zelfhulp team
Anne-Marie, Annemie, Jozefien, Peter, Koen
2 ACADEMIC OPENING SESSION

2.1 Welcoming

Prof. Dr. Koen Matthijs
Chairman of Trefpunt Zelfhulp vzw
(Verbatim text)

Good afternoon ladies and gentlemen

I have the honour and it is my pleasure to welcome you all to the ninth ‘European Expert Meeting on Self-Help Support’ here in the Irish College. Trefpunt Zelfhulp is particularly pleased to host the expert meeting this year, because it celebrates its jubilee.

After 25 years of self-help support in Flanders, we, at Trefpunt Zelfhulp, are still convinced of the great value of self-help and of the necessity of support for the many existing initiatives. We are, however, also aware of the challenges that face self-help and self-help support. The theme of this meeting ‘Thinking outside the box: expanding the boundaries of self-help support in a changing society’ reflects the pro-active stance that Trefpunt is eager to take, by looking beyond obvious boundaries and into the future. The numerous contributions to the expert meeting that we received indicate that this ambition exists in support centres all over Europe.

Thinking from the outside-in begins with pondering external changes with regard to demography, technology, politics, economics, and so on. Those developments might, over time, profoundly affect your work as self-help supporters. The disentanglement of this complex relation is the central goal of our meeting. What challenges, threats and opportunities, do clearinghouses on self-help groups face today? How should we be looking ahead?

The meeting brings together a selected number of self-help supporters who do similar jobs in different countries. In the days to come you will assess developments in various countries, exchange new information and practical experiences on working with and developing self-help groups and support centres.

To cross boundaries one has to be aware of its surroundings. In this respect I am very pleased to welcome Dr. John Martin, the Director of the WHO-office at the European Union, prof. em. Yvo Nuyens, a co-founder of Trefpunt Zelfhulp and prof. Dr. Emmanuel Gerard, the Dean of the Faculty of Social Sciences. They will kick off the meeting by giving their vision on the diverse contexts that are relevant to self-help support, namely the international policy level, the national policy level and the academic world.

Before I give the floor to the first speaker, I wish you all good luck in the coming days. No doubt, the presentations you prepared will trigger challenging discussions and provide new insights on self-help support.
2.2 Self-help support and the academic world

Prof. Dr. Emmanuel Gerard
Dean of the Faculty of Social Sciences
(Verbatim text)

In Flanders the social relevance of self-help is acknowledged not only by the government but by the academia as well. This recognition goes far beyond lip service.

From its inception, 25 years ago, Trefpunt Zelfhulp vzw (TZ), the clearinghouse on self-help, has been subsidized by the Flemish government. But K.U.Leuven and Trefpunt share a long history as well. The centre was officially established in 1982, following a government ordered research to map the field of self-help groups. At that time, this study was carried out at the Sociological Research Institute of the K.U.Leuven. A descriptive research grew into an action research with many respondents pointing out their support needs with regard to information, group dynamics, legal, organisational, socio-emotional matters and so on.

For 25 years now, Trefpunt has played a key role in supporting self-help groups in Flanders by combining practical support and advice for established and new groups, promotion for self-help, policy development and research into self-help, networking and education/training. Ever since Trefpunt Zelfhulp has had its home basis at the Faculty of Social Sciences of the K.U.Leuven.

Such an alliance between a Clearinghouse on self-help and a university, between self-help supporters and academics, may seem rather artificial. To put it bluntly: self-help supporters are ‘doers’, whereas academics are ‘thinkers’. The former deal with the practical matters of self-help and draw from their working knowledge which is mostly tacit. The latter, and social scientists in particular, examine the social fabric thus acquiring ‘evidence based’ knowledge. And yet, a clearinghouse on self-help (such as Trefpunt Zelfhulp) and a university (such as K.U.Leuven) can be hand in glove.

For Trefpunt Zelfhulp, being embedded in an academic setting provides the preconditions for its functioning - apart from having competent researchers in its immediate surroundings. The K.U.Leuven has engaged itself to support the centre with offices for its staff members at the Faculty of Social Sciences, telephone and internet connections, administration in staff matters and so on.

In the 25 years to come K.U.Leuven and Trefpunt Zelfhulp can take up the challenge to set up research on self-help. As the German history on self-help and self-help support indicates ‘Knowledge is Power’. When universities and researchers draw attention to self-help, this is very likely to have positive effects for the landscape of self-help groups and self-help supporters. The support - with regard to research know-how and infrastructure - offered by K.U.Leuven is also noticeable in the title the university bestowed upon Trefpunt, namely that of ‘partner’.

For K.U.Leuven, ‘hosting’ Trefpunt Zelfhulp offers an opening to fulfill important tasks of service to society besides education and research. The clearinghouse on self-help serves as an example of a modern form of social service going from university. The academic authority deems self-help and self-help support to be of great social relevance for a number of reasons.

First of all, self-help groups are precursors when it comes to empowering individuals. Uniting people who share a common problem and looking for solutions in a constructive way, paves the way for a broader grassroots movement in society. Empowerment may be best defined as the strengthening of the resilience of vulnerable people in society, regardless of the problem they have.
Secondly, apart from anteceding the use of health and social care services, – and thus fulfilling a preventive role – self-help groups are complementary to these services. They guide people through the jumble of services, thus enhancing the efficiency in use. The time that self-help groups were anti-professional is long gone.

The K.U.Leuven’s concern for self-help is also realized in the university hospitals that host several groups. To give you some examples: self-help groups on transplantation, on neurofibromatosis (an autosomal dominant genetic disorder) or sarcoidosis (an immune system disorder).

The partnership between K.U.Leuven and Trefpunt Zelfhulp is still going strong after 25 years. With the structural support of the university and the continuation of the staff members’ effort, all that comes to mind is a promising perspective.

Future challenges for self-help support should of course be borne in mind, but as the overall theme of this expert meeting – ‘Thinking outside the box: expanding the boundaries of self-help support in a changing society’ – indicates you will be anticipating them in the days to come and thereafter, without doubt. I wish you all an inspiring expert meeting!

2.3 Self-help support and the national policy level

Prof. Em. Yvo Nuyens
Co-founder of Trefpunt Zelfhulp vzw

(Summary)

Prof. em. Yvo Nuyens gave the audience a bird’s-eye view of self-help and self-help support in Europe. Drawing on the Flemish experience, he formulated the main challenges for the lay and professional input to the health and social welfare system.

Getting a clear picture of the European clearinghouses for self-help is quite a challenge, Yvo Nuyens stated. This is because of the tremendous variety in their focus, scope, host organisation, function (e.g. information, advice, coaching, networking, research), structure and funding. There is no common “corporate” identity or voice on the European level at present.

He went on to give an overview of the health status and preventive behaviour of the Flemish population, using examples such as rates of suicide, depression and cervical screening. He stressed the importance of the so-called “zero-line” or “hidden” health care system. Self-help is part of this system of informal support, which remains rather invisible in the health and welfare system as a whole. On the basis of health and welfare indicators, Prof Nuyens observed that most people perceive themselves as not being in full health. The professional health system can hardly cope with the demands posed by this predominance of poor health; thus, the professional and the lay coping systems need to cooperate.

In concluding, Prof Nuyens put six main challenges – which are at the same time dilemmas – to the fore that need to be faced by self-help groups: 1. centralisation versus decentralisation, 2. professionalisation versus deprofessionalisation, 3. medicalisation versus demedicalisation, 4. computerisation versus face-to-face contact, 5. institutionalisation versus de-institutionalisation, 6. interpersonal solidarity versus collective advocacy and action.
2.4 Self-help support and the international policy level

**Dr. John Martin**

**Director of the WHO-office at the European Union**

*(Summary)*

Dr. John Martin started his speech by remarking that the capacity to health is highly dependent on self-care and support networks, such as the family and self-help groups. He went on noting that health authorities, in spite of this, don’t seem to be very keen on self-help.

He described the WHO “Health for All” programme as highly ideological and aspirational and stressed the importance of primary health care and community participation. After all, the closer the action is, the more impact it has, he commented.

Dr. John Martin feared that primary health care is in danger of becoming appropriated by the state. In the US he observed a genuine ‘thirst’ at the grassroot level, below the federal level, for community involvement. But community empowerment and self-help too have become professional appropriations. They have become part of a technocratic approach that isn’t sufficiently based on health systems and communities.

According to Dr. John Martin the concept of primary health care is due for a re-evaluation. For, within Europe, an affluent region, health inequalities are far from eradicated. The WHO prepares a report on “The social determinants of ill-health” that will stress the importance of social and political action to tackle health inequalities.

Dr. John Martin concluded with the advice to the participants to the meeting to express themselves as self-help supporters and to make sure that in time self-help becomes a focal issue in health policy.
3 PLENARY SESSIONS

3.1 Self-help support in Europe

3.1.1 The expansion of self-help groups: initiatives in Greece, boundaries and perspectives

Alexandros Georgiou
Self-help Promoting Programme – Greece

(Summary)

Abstract

The growth in the number of Greek self-help groups and initiatives has been delayed in comparison with other European countries. However, in the last years the development rate of self-help groups and initiatives has increased. The course of the self-help movement in other countries can contribute to a thorough evaluation of the Greek situation. In this presentation I will discuss the perspectives and the boundaries of the expansion of self-help groups. The progress of the Greek self-help field issue is related to socio-economic and cultural factors, the status of the health system in Greece, the limited tradition in pure self-help groups, and the role of health professionals.

In Greece there exist different sources of social capital such as the extended family, the neighbourhood, the church or parish, the school as well as a variety of other collective and cultural activities and events. These components of the social capital offer a safe support to get over crises, to socialize, to communicate and to express feelings and thoughts.

The crisis of the welfare state and liberal policies have led to the mushroom growth of 12-step groups for addiction (NA, AA, FA) and to the creation of numerous self-help initiatives with regard to physical and mental health issues.

The Self-Help Promoting Programme, which is based at the Aristotle University of Thessaloniki, is an important actor in the Greek self-help scene. It supports drug addicts and refers the interested ones to 12-step groups. It also supports the creation of self-help groups for physical and mental health problems and those that prevent psychosocial problems. Furthermore it has developed a non-formal network of health professionals that are interested in self-help and offers them training in cooperation with the Ministry of Health. Finally it sets up field research at the regional level.

There are several factors that influence the self-help field in Greece: the way the state's central policies and interventions operate, the socio-economic situation, the limited tradition in pure self-help groups and the role of professionals.
The development of self-help groups is impeded on different levels. At the community level the self-help idea and practices aren't accepted fully yet. Health professionals interfere with self-help's growth in various ways: by showing lack of interest or consciously disregarding self-help groups and the empirical knowledge they produce, by causing confusion in taking up co-ordinative roles within groups, or by appropriating the self-help idea and practices. Self-help is in danger of being professionalised to the extent that it is used as a partial tool. Moreover the State might manipulate the self-help thought in its health policies.

In future we expect that the number of self-help groups regarding addiction, physical and mental health will continue to increase and that internet groups will flourish. At the background of the crisis of the Greek health system and the growing portion of immigrants, whose needs are unmet by the mainstream health system, a basic self-help tradition is due to gain a footing.

In the self-help scene the role of professionals is of the utmost importance. Changes in the attitudes of professionals could facilitate the start and the survival of self-help groups. The awareness of and support to self-help initiatives, as well as the recognition of experience based knowledge, could steer the health system away from the inadequate authority model between professionals and service users.

In my opinion we should trust the dynamics and the processes taking place in self-help initiatives and support them in a reactive way. After all, the quality of life and well-being of their members are at stake.

3.1.2 Results of the workshop

Discussion leader: Peter Gielen

The remainder of the workshop was dedicated to mapping the self-help support field in the participating countries. The participants gave an overview of the self-help field in their country by answering the following questions:

- What is your country’s population?
- What is the estimated number of self-help groups in your country?
- What are your support centre’s tasks and resources?
  - Number of collaborators
  - Annual budget
  - Geographical working area (national, regional, local...)
  - Is supporting self-help groups your centre’s unique task/job/duty or are there other tasks (e.g. volunteer centre, social work centre...)
- Are there other self-help support centres in your country (pure or mixed): number, FTE’s, estimated total budget spent on self-help support?

The resulting map is included in the annexes (annex 6.1: mapping the self-help field).
The participants were then asked to choose one of the questions below. This is what they answered:

1. **What would you do differently if you could do it all over again?**
   Self-help (support) in Hungary hasn’t been a success story. If I could do it all over again, I would write more about self-help groups to inform the general public; I would have approached policy makers in a more active way; I would have introduced the self-help idea into the curriculum of psychologists and social workers; finally, I would have set up more research projects (Bela Buda); I would have conducted more research in order to obtain political support (Dora Boror).

2. **What is the most important challenge for your centre on the mid and long term and/or next important aim/objective?**
   To conduct research that proves the need for (logistic) support for self-help groups at the provincial level in Flanders (Joze-fien Godemont);
   The survival of Kontaktstelle für Selbsthilfe- gruppen (Jürgen Matzat);
   To become a self-help support centre with a broader focus than drug addiction (Sotiris Lainas);
   To establish self-help as a focal point, to obtain financing to train people in NGO’s with regard to self-help (support) (Helena Pälojärvi);
   To get recognition for the centre’s professionalism (status as a knowledge centre) and linked to that to obtain financing (Jaana Löppönen);
   To reach more population groups (Arabs, Ethiopians ...), to expand the centre’s course services, to obtain financing for the centre (existential) and for the self-help groups and to conduct more academic research (Merle Guttmann);
   To obtain more financing and to provide vulnerable people with tools to fight for their rights (Dalit Binschtock);
   To promote formal collaboration with local institutions and to enhance self-help groups’ visibility (Francesca Focardi);
   To expand the self-help idea to professionals and train students in this regard (Solbjoerg Talseth);
   To stay a self-help support centre and to become a part of the health and social work system (Eli Vogt-Godager);
   To mobilise a new generation of self-help supporters and to set up more self-help support centres (Jannicke Kihlman);
   To involve the French speaking part of Switzerland in the self-help field in a non-paternalizing way (Vreni Vogelsanger).

3. **What are the two main issues/problems for self-help groups in your country (at group level)?**
   To get more visibility and recognition; the appropriation by professionals (Laura Mezzani);
   Self-help groups in terms of mutual aid, not professionally led ones - not just providing quick solutions, but guaranteeing continuity; more networking (e.g. establishing patient platforms) (Ruth Herzog-Diem);
   The colonisation of self-help groups by other organisations (e.g. Mac Millan Cancer Care); obtaining funding for self-help by providing politicians with evidence-based proof (‘evidence based commissioning’) (Mark Avis).

4. **What societal developments threaten the functioning/existence of self-help groups in your country in the (near) future?**
   The governments’ withdrawal from social and health problems (Cathrine Schauf);
   Self-help groups being hugged to death (e.g. by big cancer organisations, mutualities) (Annemie Vandermeulen);
   Self-help groups and professionals (Alexandros Georgiou).
3.2 Self-help support and the internet

3.2.1 Establishing and running self-help groups on the internet

Dalit Binschtock
Etza – Israel
(Verbatim text)

Abstract

Online support groups began to appear on the internet in the 1990s. Since then, in the wake of technological advances, psychological research and increasing practical experience, hundreds of thousands of online support groups have been established in the world at large, in which tens of millions of people are participating. These groups are frequently run by professionals from various disciplines, but the greatest majority function as online self-help groups and are run independently by the persons with problems. Research on these online support groups is intensive and prolific. Most of the researchers are from the helping professions – psychology, social work, counseling, nursing, medicine – and they are studying different aspects of what goes on in the groups. The many users of the online support groups find in them an important helping resource, often their only one for coping with their problems. The public of users of support groups on the net is greater and more varied than the public that attend independent support groups which meet face to face, due to the unique features of these online groups: anonymity, availability and accessibility. In Israel the internet has penetrated into most households and most sectors of the population. There are several local large portals that serve as a home basis for the forums, which include tens of support forums in many fields: health, mental health, difficulties that characterize key points in the life circle, and more. Etza – the Israel Self-help Centre is aware of the opportunities and challenges embodied in the world of self-help groups on the net: the management of the forums, the group processes, and the special characteristics of what happens on the net alone and the enormous advantages therein. This has brought us to develop a special course for managers of self-help forums on the net.

Vision and Mission of Etza

The Israel Self-Help Centre was established some 20 years ago and ever since has been giving services in the field of self-help to all of Israel’s citizens. Etza is located in the metropolis Tel Aviv. Etza also recently opened a new centre in Haifa which gives services both to local residents and to residents in the north of the country.

We recently defined our vision: “Etza – Israel Self-Help Centre is the professional body in the field of Self and Mutual Help in Israel which disseminates, nurtures and fosters organisational processes of social entrepreneurs, groups and organisations in order to ease their coping with mutual problems and to improve the quality of their lives”.

Defining our vision was a very exciting process for the board members and the volunteers who work in the office and for the staff members who underwent intensive and interesting sessions which we organised in-house. We consider the end result very beneficial in guiding us in where we want to be, what we want to do and how we want to get there. The sessions themselves had the very positive effect of having us all thinking together in an open and constructive way and in bonding us.
**Etza's Core Services**

Etza's core services include information services on self-help groups and organisations, organisational counseling to lay persons and professionals, and training courses of different kinds. We develop our services based on the needs of our clientele and aim for updated answers to these needs.

We are well aware at Etza that nowadays the internet is a place where people contact others, find information and gain support. Every day new self-help support groups come into being on the net. We are keen to get acquainted with the existing opportunities on the internet for those who are searching contact with others, who have a similar problem, and to understand the special characteristics of the net which are different from face-to-face contact. We want to see what help we, as professionals in the field of self-help, can offer to this area of involvement.

**The internet: definitions and background**

The internet went through a lengthy and fascinating process since it was founded in 1969 by the US Ministry of Defense. What was discovered as a mechanism to transfer information from computers in different locations became a network of communication for receiving and sending information, for doing business and for being in contact with additional persons. As human beings were behind the computers, and since a primary need of humans is to be in contact, the internet developed and became a place where people could meet. Different platforms to get into contact with others were created: websites, electronic mail, chat rooms, blogs, forums and so on.

We will deal mainly with what goes on in forums, specifically in support forums. These forums are in fact self-help support groups on the net. Within these online groups similar group processes as in face-to-face groups, with which we professionals are familiar, are going on. But online groups have additional processes, unique to the net, that derive from its special characteristics.

**Chief characteristics of communication on the internet**

I will relate to three main characteristics of communication on the internet and to their influences on the self-help groups on the net: unlimited accessibility, virtual anonymity and disinhibition.

The process of reduction of inhibitions occurs as a result of the first two characteristics, namely unlimited accessibility and virtual anonymity. These features enable self-help groups on the net to offer opportunities that do not exist in groups that meet face-to-face. These features bring along unique phenomena that are challenging both for the participants, but also for professionals who want to understand these processes and support the emergence and the activities of groups on the net.

There are additional features which we will not elaborate on. But they are certainly worth being referred to: the size of the group, the anonymity of the membership and so on.

**Accessibility**

The internet isn't limited by geographic borders. One can participate in a self-help group without going out of his or her home, without taking off his or her pyjamas. One can meet people from other countries in any language. Some examples:

A sick child wrote to her friends on the forum:
“I will probably undergo a kidney transplant in the summer. In my free time I am only on the computer as I don’t have any strength to leave the house. But in the summer I will make an effort to spend time with my friends who really worry about me and I know that”.

One can participate in a group on the net even when ill or physically handicapped. Or depressed or suffering from a social disorder that prevents meeting people or attending a group meeting.

Israel is a country of immigrants. There aren’t always face-to-face groups in one’s mother tongue available in the immediate surroundings. Many people who speak English prefer to meet in groups on Yahoo rather than in face-to-face groups which take place in Hebrew.

If one suffers from a rare illness and has difficulty in finding a self-help group in the area - near his home or even in his country -, one can meet people who are coping with the same illness anywhere in the world. In a small country like Israel, this is of great importance.

There are no boundaries of time either. One can write at any time of the day or night and someone can give support. Like this example:

“Just not to refine and to forget all these sensations, all these dreams. Just not to give in to fatigue and to lose one’s will. This hope.”

(Written by a woman on a forum for eating problems, at 02:15 AM)

I wish you could see just how wonderful you are, how much you have in you such that we have fallen in love with you virtually!.

(Answer by a friend on the forum at 02:38 AM)

“Never lose your hope! Let yourself rest…”

(Another friend at 09:05 AM)

As one doesn’t have to leave his home or commit to a fixed time and a fixed day, it makes it so much easier to participate in a forum. Therefore, the number of groups and their vast variety on the net, and the number of people who participate, is much greater than in face-to-face groups.

In a survey that was conducted last year in Israel, it was found that 90% of the youth and 64% of the adults, who were asked, use the internet. Of the total number of users of the internet, 36% said they participated in forums.

Virtual anonymity

Anonymity is a prominent feature on the internet. The general approach is that there is no need for good people to hide. There is much talk about the negative aspects of anonymity on the net: using a false or changing identity, cheating, taking advantage of people, committing (sexual) violence. These phenomena are frequent on the net and also on forums and they are a unique challenge for users of forums, for managers and also for professionals.

However, the anonymity also creates many opportunities. When the use of anonymity and virtuality are controlled, people let go of their feelings and anger, which gives them great relief. From a psychological point of view, the possibility to play with identities, each time bringing to the fore a different part of one’s ego, constitutes a healthy emotional examination.

The net offers you a second chance. If you feel you have disclosed too much, or that certain of your responses distanced other members of the group from you, you can always disappear and come back with a different nickname or a different identity.

In self-help groups, the anonymity enables many people who are not interested in identifying themselves or their problem or certain sides of themselves – such as the relationship within the family caused by the illness – to express their sentiments, to get support and to discover that there are other people who feel like they do.
No supervisory group

There is no large or central supervisory group on the internet which controls what is said. Within the forums there are laws and boundaries that each group decides upon. The general approach is to allow people to say whatever they like. This allows people to express their feelings and their thoughts which they wouldn't dare to express in another place. The big challenge is to allow everybody opportunities for self expression without causing damage to others.

On a particular Israeli portal of forums, I did a search by the words “to delete the message” and I found a lot of discussions on the different forums which were concerned with the question whether a manager of a forum should or shouldn’t delete a particular message that was seen as hurtful because: the message exposed the true identity of an anonymous member on the forum (outing); the message was hurtful or slanderous of one of the members of the forum; someone suggested a service which according to him could help other members with a medical problem or other type of problem, and other members claimed that it was fraudulent or latent advertising; or, somebody wrote a message and asked himself to delete it.

Disinhibition

The feeling of lack of boundaries and anonymity leads to another characteristic: disinhibition. Sitting at home, in an intimate setting, with or without pyjamas…creates the feeling of “being alone”. One can go wild, shout and do stupid things... No one will see or control this. One’s status is unimportant. Even if one is a respected businessman, teacher, psychologist, someone who has to behave according to social codes and be an example to others. On the net no one cares about status. It allows one to be whoever he would like to be and not who “he has to be”.

The disinhibition gives rise to extreme generosity. Disinhibition is most of the time linked to aggression, sexual extremism and so on. These behaviours exist too. But it is important to stress that accessibility and anonymity also lead to extreme generosity and sensitivity. People who don’t easily show their feelings nor feel like giving help to others, because of their tough image, discover sensitivity on the net which is not shown on a face-to-face level. The net generally and the forums in particular, are full of newly discovered feelings, support and even real help.

We surveyed the opportunities that the net gives to those interested in sharing their difficulties in order to get support and to meet people who are coping with similar difficulties. We also spoke about the unique challenges of the groups on the net.

In Etza – Israel Self-Help Centre, we feel that similar to the face-to-face self-help groups we should support the online groups with professional knowledge and give them the opportunity to discuss the dilemmas that arise in the group.

In cooperation with expert-professionals on the psychology of the net and in dialogue with the managers of self-help forums on the net, we have developed a course for managers of self-help forums. We very much hope that we will be able to hold the first course in the next few months.

Aims of the course

The course for managers of self-help forums on the net has the following aims:

- Getting to know the unique group processes that occur on the net;
- Getting to know the advantages and disadvantages of the self-help approach;
- Meeting colleagues who are coping with similar issues and processes on the net;
- Acquiring tools to cope with the complexity of managing a self-help forum.
Structure of the course

The course we have planned will entail 11 meetings. In each meeting there will be a lecture on a subject which characterizes what the manager of a self-help forum has to cope with. After the lecture there will be a discussion within the group which will be facilitated by two professionals, one from the field of psychology of the net and the other from the professional team of the Self-Help Centre. Apart from the meetings the course will be accompanied by a closed forum for the participants that will run for the entire period of the course and will be managed by the professional facilitators of the course. In the forum the participants will be able to seek advice and to share what goes on in their other forums. It will be easier for them to do so than in the face-to-face groups, as they can use links to demonstrate the live messages or announcements they would like to discuss and each of the participants can see them. But the most important thing is that this forum will constitute an experiential example of what goes on in forums and will allow the participants, with the help of the professional facilitators, to examine the different going-on's as well as to examine ways of coping with the processes that are taking place in the forum.

Content of the course

The subjects of the lectures and the discussions of the group are:

- Psychology of the net: typical psychological processes of interpersonal communication on the net;
- Self-help and knowledge through experience;
- Group processes – processes in the formation and development of a group;
- Group processes on the net – typical processes for groups on the net;
- The place and role of the manager of the forum – dilemma of the two hats of a manager who is also a participant;
- Coping with aggression on the net – flaming (writing rubbish, sequences of words that make no sense), floods, trolls (people who enter the forum ‘in disguise’ and write provocative messages), sanctions;
- Managing and moderating an online forum, two (or-more) managers or more at the same time;
- How to plan and to moderate the hosting of an effective expert on the forum;
- Recruiting new members to the forum and integrating them together with the veteran members;
- From ‘online’ to ‘offline’ – the passage from the net forum to face-to-face meetings for members of the group.

Additional thoughts

Other ideas we would like to develop in Etza – The Israel Self-Help Centre are:

- A database of self-help forums nationally and globally;
- Counseling sessions that refer people to the existing opportunities of the net (participation in forums, advertising on forums, establishing forums);
- A course for entrepreneurs who are interested in setting up a forum.
Professionalism and Humility

And in conclusion, some thoughts on humility and professionalism. Similar to other self-help groups we help self-help groups on the net on a day to day basis to work and continue working without us. Managers of forums spring up usually within existing forums and they have great intuitive knowledge about the way things happen on the net and on the way to deal with the challenges. When we want to help people to get to know the possibilities of the net or to improve their skills within their groups on the net, it is very important that we approach them with extreme humility and with professionalism. The field of support on the net is an ever-growing field and there is much research which we need to know about. After all, it is easy for us to learn what is going on in forums, because as opposed to groups that meet in rooms, there are hundreds of groups on the net which we can “visit” even without an invitation.

3.2.2 Discussion forums on the internet: the future self-help alternative?

Vreni Vogelsanger

KOSCH – Switzerland

(Verbatim text)

Abstract

I will present a so called ‘self-help forum’. This internet-project of the Swiss national clearinghouse has been realised in cooperation with a popular weekly magazine, “Beobachter” (Observer). Drawing on some clippings and actual discussions from the forum, I will point out some questions about the meaning of this project for self-help groups, the comparability of online and offline groups, and possible different needs of the participants. Some unexpected difficulties will bring the function of the projectleader and our organisation up for discussion. I will tell you why we entered in the project, why we decided to get out and how it works without us.

The project

Beobachter, a popular weekly magazine in German, had started a so called ‘self-help forum’ on their website. The initiators weren’t satisfied with the way it functioned. Therefore they asked KOSCH as a self-help support centre to join the project in order to increase the quality of the forum. Stiftung KOSCH cooperated earlier with Beobachter to edit the publication ‘Selbsthilfe in Gruppen: wie sich Betroffenen erfolgreich unterstützen’ (co-author: Ruth Herzog-Diem).

Whereas it is difficult to find funding for KOSCH’ core-bussiness, it turned out to be quite easy to get money for this project. The Swiss Health Promotion gave us a reasonable amount of money in the short term to join the project of Beobachter. We were able to employ a parttime projectleader. She was also a projectleader in our clearinghouse. She entered information on the forum about: What is a self-help group? What is a self-help organisation? What is a clearinghouse? What is KOSCH? How can you use the forum? What will not be allowed on the forum and immediately thrown out? And so on. She placed links to the existing self-help organisations. So, on this platform one can easily find all kinds of self-help groups. This is an important service.
Subjects of the specific forums

We then choose, together with Beobachter, five subjects for the specific forums. The subjects had to be popular in order to have enough people joining the forums. The second criterium was that self-help organisations had to agree to cooperate. Table 1 gives an overview of the discussion since November 2003 on the different forums.

Table 1: Subjects of the specific forums organised by Beobachter in cooperation with KOSCH

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Number of discussions since November 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divorce</td>
<td>461</td>
</tr>
<tr>
<td>Depressions</td>
<td>454</td>
</tr>
<tr>
<td>Eating disorders</td>
<td>242</td>
</tr>
<tr>
<td>Chronic Pains</td>
<td>118</td>
</tr>
<tr>
<td>Gambling addiction</td>
<td>56</td>
</tr>
</tbody>
</table>

Examples

I will now present some discussions I came across on the different forums to sketch a more vivid picture of online self-help groups. They made me reflect about professional help. I especially wondered if its role was ever discussed on the forums.

Chronic Pains

Person 1: tells a story about having had an accident. He/she is now entitled to an allowance for handicapped people. He/she says: “I suffer heavy pains every day. Now they want to cancel my pension and they want me to get into a rehabilitation project. How can I defend my rights? I wouldn’t mind working, but after an hour I need to lay down another hour. Does somebody know a self-help group?”

Person 2: advises person 1 to go to such and such organisation that will help him/her.

Person 3: “These rehabilitation programmes are not that bad. They try to find out what could be a feasible job for you and if it doesn’t work you will get your pension back.”

Person 4: gives a description of the political and legal situation of handicapped persons in Switzerland and offers help to find a professional who could sort out the financial situation of person 1.

Eating Disorders

Person 1: tells a personal story about eating disorders and self-hate.

Person 2: “Now it is your turn to have a few words. I like listening to you but you have to be patient in the next four days because I will not be online.”

In between she makes a huge analysis about what could sort out person 1’s problem. She asks a lot of personal questions.

Person 1: seems to be quite grateful for the answer she got from person 2 and answers all personal questions.

Person 3: tells her story and says: “I can’t talk about my problems with my friends, because they don’t understand my feelings”.

She seems to be interested to get in touch with person 1.

Person 2 to person 3: “Now it is your turn to read some words”.

No answer
Person 2 to person 1: “I want to know how you feel at the moment…”

Depressions
An example out of a long discussion in which ten persons participated. One of the participants, a consultant, is answering virtually all questions.
Here is a person getting in, saying: “What is the matter with you? Why do you add comments on all and everything? I can’t bear your teacherous style! You had better leave the forum and look for a new hobby.”
At first the consultant gets very angry: “I am much longer in this forum then you. Nobody takes profit from your rubbish!” Then he gets back to his role: “This could be a projection of your problems on me... But don’t worry, it is completely normal. Everybody does it. You should work at your problems (...). And please, begin every sentence with an ‘I’”.
What is funny, the two fighters get out of the forum and the others go on with the discussion as if nothing ever happened...

Online and off-line self-help groups
Can the forum be compared with self-help groups? My question after listening to Dalit is: what is a group and what isn’t? I see similar things as Dalit did.

Differences
- Written words;
- Outgoing from private homes;
- Slow communication
  I think the slow communciation can be a nice thing. You can think it over and then answer it;
- Low obligation;
- Low-step to enter and leave;
- Perfectly anonymous
  In this forum you couldn’t go under different names. You are registered and have one name;
- In public
  Everybody can read it;
- Unknown number of well informed passive consumers
  Dalit said there were four passive consumers for every active user.

Similarities
- Fellow sufferers;
- Exchange, mutual help, model-learning;
- Coming-out-situations – taboo-breakers;
- Information-pool;
- Community feelings
  For some the forum provides a community feeling, I don’t think for too many;
- Problems.
Is the forum an entrance to self-help groups?

Of course we don't know the effects of self-help forums yet. We don't know what the future holds. A lot of youngsters are online. Will they be entering online self-help groups in ten years? That is a question mark...

Different users with different needs

The number of self-help groups didn’t extremely increase since we had the forum. We rather think the forum users are different persons with different needs than members of face-to-face self-help groups.

Users of online self-help groups

We rather think that there are many persons in the forum that wouldn’t or couldn’t join face-to-face self-help groups. To point out some: youngsters, extremely loners (persons with special contact problems), consumers of specific information and of course mobility-handicapped persons.

But I also believe that the forum is an alternative help for off-line self-help groups. Hopefully for some an important one. I found quite a lot of positive confessions like “I am glad we have this forum”, “It is a big help”, things like that.

Some unexpected difficulties

Cultural collusion

The cultural collusion between the projectleader and the internet-journalist was much harder than supposed. The journalist soon found the projectleader's way of working rather complicated, hesitating and overprotecting.

Visibility

For the projectleader the visibility on the forum was not always easy to bear. All the colleagues in the field could see what she was doing.

Sponsors

We did expect to easily find a lot of sponsors, but after three years we ran out of money.

Position of KOSCH

Our starting position was: shall we enter this project and take the offered money, or leave it? No other choice! After the agreed three years of health-promotion support we ran out of money. The solution was that Beobachter took all the responsibility for it and a person from their consulting-service would fill in our earlier position. Since 2006 the forum goes on without our direct assistance. The self-help forum is a "nice to have" but not a core-business.

Personal comment

This was not my favorite project, and for some time I didn't bother too much about it. When I entered in it again, for this presentation I reckoned that it wasn't that bad and that it is a pity that we weren't able to make more out of it.
3.2.3 Results of the workshop

Discussion leader: Peter Gielen

(Verbatim discussion, abbreviated)

Drawing on the Israeli and Swiss experiences with self-help and the internet, the participants considered the challenges the net poses for self-help groups and self-help supporters.

Core-business of self-help support

Should online self-help groups be the core-business of self-help support centres or is it a totally different world outside the self-help methodology?

Internet is so much part of life today, for so many people, that we can no longer ignore it as self-help supporters. It can have a function in all stages of self-help. There isn’t a ready-made solution for everybody. The variety in services is an important thing. That is something self-help support centres should understand.

We have a responsibility in acquiring the knowledge how to use the internet for self-help, in coming out of the box.

Self-help clearinghouses are meant for face-to-face self-help organisations and self-help groups. That is in general. Of course there are limitations like people living in isolated communities.

I don’t think the internet should be central to self-help support. Of course people should have the possibility to express their feelings however they want. But the internet is merely a tool, a facilitator.

Consequences for face-to-face self-help groups

If you have a face-to-face self-help group or organisation and you offer people the possibility to meet face-to-face and to enter a forum that we manage, you lose them as paying participants - you lose the fee to build up your services - and you also lose them in terms of numbers, of how many people are involved. In terms of political pressure the first question always is: “How many people are you?” Is that a danger or just fiction?

There is a technical very simple solution for that. You can organise your forum on the centre’s website on a closed webpage. In order to get in you have to register and pay a fee. That way you can have the numbers.

I think the users of face-to-face self-help groups and the users of online self-help groups aren’t the same persons. The participants to face-to-face groups can go to a forum to look something up. On the other hand there are people who would never ever go to a face-to-face group and can easily join an online group.

In Norway we had telephone groups for anxiety problems. Some of the users joined face-to-face groups. So for them it was an important step in getting out.

Warmth and coldness on the Internet

I think my mission is to bring warmth into the world. So my mission in the self-help clearinghouse is to form face-to-face self-help groups.

I don’t agree that the internet is a cold medium. I participated in a forum for young mothers. It was my first experience with a forum. It was such a warm group. I found some of my best friends there.
I think emails can be warm. But the thing is: in what way is it changing me? I don't know...

Professional involvement

I think if ever you take this up, the Israeli way of working, with a facilitator of the forum that comes out of a self-help group, is better than we did in Switzerland, with a professional leader of the forum.

The outcome of online self-help groups

At the beginning I was a bit sceptic. Now I think that if an internet group is in line with the self-help philosophy, it can be very good.

What are the outcomes of online self-help groups? One of the puzzles I have is, how do you research internet based self-help? That seems quite difficult to me...

You never had access to so many transcripts on forums!

But beyond the observational studies. Actually going in and finding out what is behind that... What are the outcomes for individuals?

I am not quite sure if this kind of relationships makes me to solve my problems or make them go away. Maybe I am just nourishing my problems by telling them again and again...

I think that the internet is a substitution for communication which recycles loneliness and depression and emotional problems.
3.3 Self-help support and diversity

3.3.1 Remarks on working in a multicultural self-help centre

Jaana Löppönen

The Citizen Forum/Horisonntti Centre – Finland

(Verbatim text)

Abstract

This presentation will raise questions about the ideology of integration in the context of self-help groups that can no longer ignore the multicultural diversity in society.

The Citizen Forum

The Citizen Forum is broadly-based and goes beyond a self-help focus. The Forum was set up in 1993 by professionals. The historical background was one of a precarious socio-economic context. At the beginning of the 1990s the unemployment rate was very high compared to the 1980s, the golden era of the so-called ‘threshold social work’ (social welfare, health services and community work). The Forum is an independent national cooperation for voluntary work and self-initiated action for those aiming socially, economically and ecologically sustainable action; a kind of a free arena for initiatives, to give space and voice. The founding members had a dissenting vision on social work and social problems. It was their aim to organise society through the people’s voices (as opposed to organisation by the state). In this end it supports cooperation and networking, voluntarism, self-help activities and local activities that promote communal participation and employment.

The Citizen Forum offers numerous services. Its core-business entails training self-help groups, networking with volunteer and self-help group leaders, raising awareness and discussion on social rights and welfare and the “Areena” view on empowerment, keeping a nationwide register of low-threshold meeting places, voluntary centres and neighbourhood houses, publishing books and reports and spreading information of the European Voluntary Centre.

Horisonntti Centre – an arena open for all

The Horisonntti Centre started under the name ‘Unemployed People’s Organisation’. It is a local centre and has its base in Helsinki (approx. 100,000 inhabitants). It is a neighbourhood, activity or resource centre. Technically it isn’t a self-help centre. But we are member of the Citizen Forum. The forum offers various opportunities to move: from exclusion to inclusion, from diagnosis to a person with a name, from prejudices to understanding, from walls to open doors, and from no voice to the voice of experience.

More concrete the Centre offers advice and practical solutions for sharing and doing: handicraft workshops, a cafeteria, recycling and second hand shops, courses, voluntary work and salary based work, facilities for group activities and so on.
Horisonnti Centre uses numerous tools to this end. It digs knowledge/rights, policies, programmes (e.g. WHO Healthy Cities 2000), it uses the existing means for employment to create new co-operative and social enterprises, it participates in the ESR-programme (1995-99), in social projects against exclusion, in networks with other organisations, municipalities and politicians, and it reinforces participation in its own structures.

Remarks on diversity

Diversity is an umbrella-term, but maybe Horisonnti’s vision might help to get a hold of what diversity actually entails:
- Nobody wants to be labelled or diagnosed;
- Diversity is a normal phenomenon;
- Doing things together helps to accept differences;
- The media have an important role in establishing images of immigrants and refugees;
- In a multicultural society there still is a common language;
- By working together with immigrant, refugee and cultural organisations, diversity becomes concrete.

Empowerment

Next to diversity the concept of empowerment is very important to Horisonnti Centre. Empowerment often results from doing something unexpected that gives huge satisfaction (“We did it”). This experience strengthens self-management skills and feelings of dignity and respect.

Challenge

I would like to conclude by formulating what I consider to be the biggest challenge when it comes to diversity. It is to recognize the ‘invisible segregation’ and to do something about it.

3.3.2 Self-help and black and ethnic communities

Mark Avis

Self-help Nottingham and the School of Nursing (University of Nottingham) – England

(Verbatim text)

Abstract

We undertook a two year research project, funded by the Big Lottery Fund, to understand the reasons why people from black and ethnic communities are less likely to join a cancer self-help group. One purpose of the project was to develop research based guidelines to promote black and ethnic community involvement in self-help groups.
The project used a participatory research method based on extensive interviews and group discussions with people involved in self-help (68 individual interviews and 7 group discussions). Further evidence was gained through participant observation at local and national conferences, seminars and workshops designed to promote self-help (130 site visits). Analysis was carried out through a thematic approach of searching the data, supported by NVivo software, to produce explanatory themes that could account for the ideas expressed by the participants.

Three key elements of self-help were identified, regardless of interviewees’ self identified ethnicity: forming a sense of togetherness, learning from each other, and developing mutuality. We identified a number of issues that discouraged the participation in self-help of people from black and ethnic communities, including their assumptions about the nature of self-help, concerns about group meetings, recognition of limits to shared experience and difficulties finding common ground with other group members, and anxieties about racism. In conclusion, we recommend some practical ways to assist someone from a black or ethnic community to understand the benefits of self-help, to improve access to self-help groups, and to support inclusion and choice in self-help. We suppose the role of the supporters regarding the work of networking, and we discuss the risks and the advantages for the self-help groups in this development.

Introduction

I am afraid I am reporting on the research I presented at the last meeting, but I would like to add some aspects. This research is a partnership between Self-help Nottingham and the School of Nursing, University of Nottingham to mutually – I hope – beneficial ends.

Background

Dangers in terminology

I would like to start with sketching some potential dangers of the concept ‘black and ethnic communities’. Black and ethnic groups make up for 10% of the UK population. ‘Black and ethnic’ is a term which is really substantially disputed. The concept is a sort of common currency in the UK, but it is disputed by nearly everyone in the field as well. Black and ethnic refers to groups who have moved into England over the last 50 years. We have a pre-existing Irish community as well as more recent large scale periods of immigration: African-Caribbeans came in the 1950s, Asians came in the 1960s and the 1970s, more recently we got immigrants from African countries and from the Balkan states. Now in many cases we have the fourth generation of immigrants that arrived in the 1950s. For these people, for African-Caribbeans for instance, ethnic identity is only one aspect of who they are. They are also completely English. For this reason ‘black and ethnic communities’ has become a difficult concept for us to talk about, because it is not necessarily latching on to one distinctive aspect of the individual. In talking about black and ethnic communities we have to be really careful, because there are two dangers. One is that you overemphasize the similarities: people from black and ethnic communities all have similar interests. They don’t. They come from different social classes, backgrounds; they often have different religions… The other one is that we overemphasize differences between different ethnic groups. We all share some common interests as human beings. So we got to be careful about overemphasizing similarities and differences.

One of the reasons why we do talk about black and ethnic groups is because one of the distinctive features they all have is an experience of racism, in one way or another. I have to define racism: it is a systematic discrimination based on religion, colour, and country of origin.
Cancer in minority ethnic communities

In most cases the ethnic community populations have a lower rate of cancer than the indigent population, but they are all rising very fast and it looks like they are going to catch up and potentially exceed the indigent population. There are a number of reasons for this: changes in diet, and a lot of natural protective immunity that comes with cultural practices.

The other thing I would like to say about cancer in ethnic minorities is that the evidence we have suggests that they make less use of services than you would expect. Possibly because they don’t get referred, because of institutional racism, because of language difficulties, maybe because the assumption is often made that ethnic communities like to look after their own, that they all have extended families that provide care. That is not true, but it is an assumption that is widespread among social care and health workers.

Beneficial effects of self-help group’s membership

Membership of a self-help group is associated with reduced isolation, increased support, and promoting health-enhancing attitudes and behaviours.

Underrepresentation of minority communities

People from minority ethnic communities are underrepresented in self-help groups. The evidence of that is quite patchy. Some of the evidence is imported from the US which is such a different political context in the provision of health care. But people who run or support self-help groups in the UK are confirming as well that black and ethnic community members aren’t really taking part in self-help.

National policy context on self-help

The UK has an increasing burden of people with long term health problems as do many other European countries. People for whom there is no particular cure and who have to live with their condition. I think that it is common currency in the UK that people who have been living with a certain condition know more about it than the health professionals and have to help each other. There seems to be a consensus that the government needs to put more money into this idea of self-care and peer support. That is positive in a sense but it has also led to the ‘colonisation’ of self-help. I think that one of the distinctive features of self-help is that it is by people for people and not run by state organisations. I think that it is a concern to involve black and ethnic communities in emphasizing the importance of self-help.

Study Aims

The study aimed at exploring what people perceive to be the value of participation in a self-help group, why people from minority ethnic communities have not participated in self-help groups to the same extent as the majority community, and why people from black and ethnic communities who started their own groups rather than joining the mainstream self-help initiatives that already existed. The researchers also intended to suggest ways in which participation of minority ethnic groups in self-help can be increased.
Methods

The research used a participatory action approach. Self-help groups were involved in the steering group. The data collection used a qualitative methodology, namely semi-structured interviews. The respondents were recruited largely by Self-Help Nottingham and through a snowballing technique. Both cancer and non-cancer (A.A. and N.A.-groups) self-help groups, black and ethnic and indigent communities were included. In total 68 respondents were interviewed and the researchers attended 130 self-help events.

Findings

Value of Self-Help

The characteristic features of self-help that seem to be common to all members of self-help groups, regardless of their ethnic background are forming a sense of togetherness, learning from one another, and developing mutuality.

Barriers

Reasons why people from black and ethnic communities in particular might be deterred from participating in self-help included practical issues such as venues (Christian churches, public places) and mobility problems, negative perceptions of self-help as ‘a white, middle class, western, individualistic view of life’, and concerns about confidentiality and trust.

Encouragements

What encouraged people from black and ethnic communities to join existing self-help groups rather than starting up new ones was being recognized as different, but having something (cancer) in common and being listened to without imposing assumptions (e.g. ‘You weren’t really discriminated’).

Varieties of sharing in groups

Some of sharing in groups was very activity-focused (sowing circles, lunch clubs, and health classes). We found that putting the label self-help on something was often unnecessary and too restricted. Self-help is going on in all sorts of venues and situations that aren’t called self-help. That may well be related back to this idea among some ethnic communities that self-help is seen as too individualised. Whereas when it is called something else, it may well be going through the process of self-help without being called self-help.

Diversity in self-help

One of our main conclusions was that you really can’t recommend one way to manage diversity in self-help groups. I think there has to be some way of helping existing self-help groups to become more multicultural, more accepting to people from different ethnic backgrounds. We need to help those self-help groups to be more welcoming of diversity, encouraging them to listen more openly, be less judging, recognize the different stories.

People didn’t necessarily always want to go to a self-help group particular for people of their ethnic community. Because having cancer to them was more important than where they were from. But equally there were people who felt that the only way someone could share their experience was to come from the same ethnic background. So you have to be an African-Caribbean with diabetes to understand how African-Caribbeans with diabetes feel.
So we have these two opposed views. Our conclusion was: we have to do better. We have to give self-help groups the opportunity to start and be maintained based on particular ethnic groupings, but also we need to help existing self-help groups to become more accommodating to people with different ethnic backgrounds.

Discussion

We saw numerous accomplishments of the power of storytelling as a learning model that effects behavioral change.

Sometimes ‘just’ having cancer wasn’t enough to connect to other people. Ethnicity wasn’t the most important factor. In fact, age sometimes was among the key ones. We did notice that there were limits to sharing experience. Not everyone can meet in a multicultural, multi-age group and find connections with the other people there.

I think the question about self-help and mutual aid is a very interesting one. What we observed from the literature – and I think we have heard stories about it earlier today – is that immigrant communities, communities who share a cultural heritage, often have a degree of closeness. There is a real sort of sense of community solidarity and they do, to some extent, look out for one another. And you would think in a sense that that’s what self-help is all about, trying to help people to find social networks that give them strength and encouragement to manage social issues. And obviously a lot of immigrant communities were doing that. But when it comes to things like cancer and social concerns, the strength of the community is actually a discouragement. In taking part in self-help groups we found that people talked about the pressures not to go outside the community to talk about their problems. People felt reluctant to go outside their community to talk about their problems, but equally they couldn’t talk it over in their own community either. So, on the hand, mutual aid seems to be a philosophy that fits with self-help, but we found ways in which it became problematic, especially in closed communities.

Conclusions

There are four simple things we can do to increase the participation of members of ethnic communities to self-help.

1. Targeted information about the nature and value of self-help for ethnic minority communities
2. Recognize the value of personal recommendations about self-help groups
3. Encourage sharing as an activity - but it doesn’t always have to be about personal stories
4. Choice in self-help should be encouraged - including socially diverse groups and those based on particular social characteristics

Since the research was completed (at the beginning of 2006) further initiatives to implement the findings have been taken by Self-Help Nottingham:

- Seminars with health professionals: we organised a series of seminars for health professionals to encourage them to understand what self-help is. Health professionals are very often trusted and respected persons who talk about self-help to people and who might refer them;
- Appointment of a training officer to lead off black and ethnic groups;
- Networking with groups: to make sure the groups know about Self-help Nottingham, about each other, about some of the issues to do with inclusion of black and ethnic communities;
- Making materials appropriate to minority communities by translating, using images and making sure the terminology isn’t exclusive;
- Helping self-help groups to welcome ethnic minority members;
- Exploring spirituality (broader than religion) in relation to self-help.
3.3.3 The NOVAT programme: characteristics and assessment of the programme from the point of view of self-help

Helena Pälojärvi

Citizen Forum/Women Together Against Addictions – Finland

(Verbatim text)

Abstract

The NOVAT-programme has its roots in an American, tailor-made self-help programme for female alcoholics. It was developed in Finland by the NGO "Women Together Against Addicitions". As a practitioner I have been actively involved in this developmental work. In my presentation I will talk about the NOVAT-programme and about the assessment made by Dr Jaana Jaatinen (2005-2006) from the point of view of self-help and professional social work.

The programme is based on self-help, peer support, study material about "women and addictions" and on professional (social work) support of peer groups. The NOVAT-programme is a one and half year lasting programme for women, who feel they have problems with their life control, who feel bad, have perhaps dependencies especially with substances, and risk obsessive or substance behaviour. In the Finnish model women don’t have to have any diagnosis or call themselves alcoholics/substance abusers etc. to get into this programme. A will to start this programme is enough. The NOVAT-programme is tailor-made for women and is easily accessible. The costs to participate are minimal. As a practitioner I wondered, what kind of women are reached, why women become interested in this programme, what they get out of it and how they use other treatment services. We also made our own inquiries and got a researcher to make a scientific assessment. We wanted to find out why women join the NOVAT programme and what they get from it. One of the most important outcomes of the research was that most of our female clients (over 60 %) don’t find any other support or treatment at all in our traditional male-orientated treatment system. Also peer support is very important.

Women Together Against Addictions

The organisation was established in 1922. It is a national (NGO) non governmental organisation representing women and is specialized in women's dependencies. The organisation is financed by Finland's Slot Machine Association. Its aims are to prevent women's early stage dependencies, to support women's everyday life control and to pay attention to the quality of alcohol and drug treatment services for women.

NOVAT Self-help Programme for women

The NOVAT programme is easily accessible, empowering and a preventive treatment method that offers mutual aid and peer support. It is based on the theory of women’s addictions and how women can get rid of their dependencies or recover using their own resources. It lasts about 1 to 1,5 years and uses study material which is based on essential issues concerning women’s addictions. The peer groups receive weekly support (group skills, information, lectures, internet forum) and counseling from professionals. Individual counseling is also provided.
Effectiveness assessment, client feed-back by Ph.D. Jaana Jaatinen

Background
Practitioners wanted to know, what factors cause women to participate in the NOVAT-programme, what type of women participates, what the effects are, and if participants use other treatment services.

Data in the research
Data were collected in three different ways: 1. Surveys among participants who had started the group process (75 completed surveys (11 groups) in 2005, 82 completed surveys (11 groups) in 2006); 2. Thematic interviews (12 in 2005 for 7 different groups, 23 in 2006 for 11 different groups) among participants who had (almost) finished the process; 3. Written life stories of 9 NOVAT-participants.

Methods
The semi-open questions referred to life situation, life control, expectations regarding the NOVAT-programme, the relevance of peer group for women, the use of other services. The researcher conducted a qualitative content analysis and a discourse analysis in two categories with different themes: 1. The NOVAT-programme as a group method, and 2. the experiences of NOVAT-women.

Profile of women participating in the NOVAT-programme:
- The participants were aged from 24 to 68 years, 60 % were married, a third had children, all professions were represented, a quarter of them were outside the work life;
- Almost half of the participants reported that they had suffered some kind of dependency, a fifth had an alcohol addiction, a third suffered from family members’ alcohol problems;
- Over 60 % reported that they had not used any traditional service in the field of alcohol and drug service. They had heard about NOVAT from newspapers, friends and health care. Before participating in NOVAT, about 70% had asked help from doctors, occupational health care professionals, private psychologists and so on;
- When starting the NOVAT-process, women still had control over basic things (careers and homes), but they felt dissatisfied and out of control. They experienced feelings of alienation and anguish, but had managed to conceal these;
- Women have very different problems compared to men. Traditional services and AA didn’t meet these women’s needs; their problem perception and coping mechanisms differ from those of men;
- Women participated because they wanted to find new perspectives in their life, grow spiritually and share their lives with other women;
- That the programme is tailor-made for women was regarded as essential. The feeling of acceptance by the other group members and being part of the group as well was seen as very important;
- NOVAT offers specific support in everyday life. For example some women reported that they got received in getting rid of emotionally or physically abusive relationships.

Effectiveness of the NOVAT-method
- Difficulties women have can lead to alcohol or other addictions. Women don’t necessarily need traditional treatment institutions; for some, space for sharing feelings with other women in a confidential atmosphere suffices in overcoming dependencies;
In a NOVAT group women learn to identify their own needs and feelings and begin to feel that their life has a meaning. Their self-esteem improves and they start to think positively;

- Women who had finished the NOVAT-process reported career related and relationship related changes in their life circumstances;

- Those who had interrupted the process criticised the lack of adequate support from the personnel and the way the group instructions were being taught;

- The NOVAT-programme functions as a preventive and healing method in the field of alcohol and other addictions. Support of the NOVAT-group prevents addictive behaviour and helps women to manage their everyday lives;

- NOVAT gives women a possibility to meet other women regularly. Confidentiality and sharing personal feelings in peer groups are the key elements. These can’t be compensated by one or two-time interventions by traditional professionals.

3.3.4 Results of the workshop

Discussion leader: Jozefien Godemont

The presentations dealt with multiculturalism (Jaana and Mark) and the gender perspective (Helena). They centred on the accessibility of self-help groups for certain minority groups or the lack thereof. Two approaches to enlarge the accessibility for these groups came to the fore: one was to work with the existing groups and to stimulate them to be more welcoming towards certain minority groups; the other was a group specific approach: the tailor made programme for women in Helena’s presentation.

Hot issue for self-help groups?

Speaking from the perspective from locally based initiatives (small town) it practically never happens that the diversity issue is raised. But it is a major issue in political talk. Now all agencies – schools, kindergartens, universities – are into diversity.

General or group-specific approach?

There are communities that prefer to have their own groups, because they centre on a rare disease or because they share a common language (e.g. language based groups in Israel for immigrant populations). I don’t think there is anything wrong with having separate groups.

The attention paid to diversity is a political question that greatly depends on the available funding.

Opportunities for diversity in self-help

Self-help is seen as a typical Western, middle-class idea. But some time ago I gave a speech in an area in Flanders with a lot of immigrant inhabitants. There were mixed self-help groups (Arabs, Italians …). That is because the region where these people live is a region where diversity already exists.

Barriers for diversity

There is a lack of communication between specialist organisations for ethnic minorities and self-help clearinghouses. They might have a different interpretation of what self-help is.
**Proactive or reactive self-help support?**

I think we ought to stimulate self-help groups to be open to cultural minorities.

Shouldn’t it be our goal to tell certain groups that self-help (support) exists?

A subtle reach-out approach to certain minority groups by providing the information in their own language.

Other organisations are taking care of these minority groups. They will contact us if necessary.

There are separate organisations for immigrants. We aren’t the specialists for immigrants. What they do isn’t self-help. So it’s more of a cultural thing. Health is a cultural thing.

Sometimes the solution isn’t self-help. I don’t think we ought to try joining in self-help somehow, someway… We are just a little piece in the whole welfare system. There are lots of specialists who know more about cultural issues than us. I wouldn’t feel comfortable in giving advice, because I lack the knowledge about multiculturalism… We should translate the information, but leave the rest to the specialists.

Self-Help Nottingham gets questions from self-help groups: what are we going to do about diversity? How do we get more young members in? So again, it is responsive. Self-Help Nottingham also gets questions from individuals: “I don’t understand the language”, “They don’t share my experience”, etc.. “What can I do?”, “Can you create a new self-help group for people like me?” Self-Help Nottingham feels some kind of moral responsibility to at least make people more aware of what is available. It touches on the reactive stance that they take.

Are we going to sit back or are we going to be more accommodating and create some cultural versions of self-help? There are two things that I have noticed in the research. One characteristic of self-help that cuts across cultures is the non-hierarchic sharing of experiences in self-help groups. That is a process issue most self-help groups share. The other thing is that self-help groups are about trying to achieve change in some way, in their lives, in someone else’s lives, in the political system etc.

**Dimensions of diversity**

We have another kind of problem with regard to diversity, concerning the city versus the rural regions. There are probably a lot of other systems of support in the rural regions.

**Middle class phenomenon or tool against social exclusion?**

We seem quite accepting that self-help is a middle-class phenomenon. I wonder if we shouldn’t discuss whether we want to close in into this framework of acceptance or whether we ought to define a broader use of self-help.

May I remind you that in Germany only up to 10% of the people that suffer from cancer attend self-help groups. It cannot be the task of the self-help scene to produce resources, because they also rely on these resources. You should be modest.
3.4 Self-help support and ideology

3.4.1 Self-help in Norway: tasks, challenges and experiences outside the box

Solbjørg Talseth and Eli Vogt Godager
Norsk Selvhjelpforum – Norway

Abstract

Self-help groups have been looked upon as the most common way of practicing self-help for many years. To understand the more complex definition of self-help it is useful to see its value also outside self-help groups. As an ideology, self-help is a useful tool for people struggling with their everyday life. But it is as useful for professionals in their everyday work and in the way we understand our health. It is necessary to help health professionals to understand and make use of the ideology and its methods through education. We need to communicate information and knowledge to the general public and to politicians and policy makers so that self-help can be used as a tool in understanding and working at the public health. How do we communicate self-help as an ideology? The Norwegian contribution will present experiences about working with a national plan and a national nodal point for self-help.

The Norwegian Society

The Norwegian welfare state is ranking on top of the ‘welfare list’ but at the bottom of mental health.

The Norwegian Self-Help Forum

The Norwegian Self-Help Forum (NSF) was set up to collect information on the few self-help experiences in Norway. That has been quite an exciting piece of work. We struggled a lot during the first years to find funding. In Norway we had to struggle and to fight as well. We never demanded money, but tried to introduce quality knowledge into the government and the public health sector. We gave them notice of the work we were doing and offered them the opportunity to get involved.

Today we have two centres. The first centre is the national nodal point. Those of you who came to the Oslo meeting (2005) received the National Plan for Self-Help. This plan is quite an historical one, because it was ordered and subsidized by the state, but made by the Self-Help Forum. We succeeded in making them agree to our strategy of the self-help plan. The NSF is consulted by the ministry of health when it writes different kinds of plans that concern the health field.

When I was at the meeting in Denmark (1993) I was asked: “How did you get the politicians, the health professionals to consider and support self-help?” Well this is how we did it.
When we were at the meeting in Switzerland (2003) I was very confused. I didn’t know how to tell people what self-help is all about. I talked about the quality and the beauty and what is special about self-help. It is not a supplement, but an integral part of our welfare system and our health system. One month after the Oslo meeting we started the national nodal point as a project. On the 8th of March of this year we convinced our politicians to take the discussion about the self-help field into parliament. The health minister decided to finance the nodal point on a structural base.

The Learning Information Networking and Knowledge

The Learning Information Networking and Knowledge (LINK) is a local clearinghouse for self-help. It is based in the municipality of Oslo and has two staff members. The centre gathers 25 self-help organisations from Oslo in a network. These organisations meet in the centre and exchange experiences. It is the first time I have ever experienced the A.A. joining a network. The health professionals of the municipality of Oslo meet in another network to use self-help in their work.

In a western district of Norway we started a pilot project. We created a network with representatives from NGO’s, the health system, the church, the voluntary centres. It gathers about 15 different actors.

Self-help is known as an ideology all over Norway now. We hope to be able to maintain self-help in its pure form.

Tasks in the nodal point

In September 2007 an experimental research project will start at the university. It aims, among other things, at developing an education programme for self-help supporters. NSF delivered the literature and will be giving lectures; university will coordinate the programme.

The following tasks will be part of the education programme: coordinating and organising network activities, providing information, training, distributing empirical knowledge about self-help, and stimulating net-based solutions for self-help.

We received 350,000 euros for this research project from government. We are eager to define the main research questions. The government seems to be very interested in the effects of self-help for the treatment of the primary diagnosis of depression and anxiety.

Experiences

So far we acquired experience in:
- Establishing dialog with politicians;
- Establishing networks developing knowledge, from different arenas working with self-help (e.g. conference on self-help in 2008);
- Establishing self-help education for professionals (at university level);
- Establishing research;
- Setting up model-experiments for local clearinghouses (e.g. Oslo and two pilot project in the North and West);
- Supporting self-help groups without a common problem (‘mixed’ self-help groups)

LINK supports self-help groups that bring together people with all kinds of problems (drug addiction, HIV positive status...) but with the common experience that everyday life isn’t going as planned.
Public Health

In Norway public health is an important part of the societal discourse. The national self-help plan was presented for the first time to government in the domain of public health. The plan was preceded by a plan for mental health. There has been some struggle about what mental health is. In Norway ‘mental health’ is most of the time associated with psychiatry. We included mental health in our plan, but interpreted it not as psychiatry. We believe that self-help groups centre on mental health. Mental health is the tool we use.

We define public health as following: in a public health perspective, mental and psychological health is a central element and closely connected with such terms as mastery, the ability to change, and quality of life. It concerns the personal resources of individuals in day-to-day life, the ability to resist psychological and physiological trauma, and the ability to manage one’s life.

A way of understanding our health?

If self-help is a way of understanding our health, it could be useful tool for people struggling with their everyday life. But it is as useful for professionals in their everyday work and in the way we understand our health. Communicating the value of self-help is difficult. We have to tell people from the general public what is in it for them. But we might have to tell them first about the ideology and later on about the practical use in their everyday life. To me self-help is something interpersonal that doesn’t necessarily require an organised group.

Challenges we would like to discuss

We would like to discuss some questions with you and think outside the box. First of all, we wonder how the perspective of self-help supporters relates to that of other societal actors, such as policy makers, health professionals, social work, economists and politicians. In answering this question we have another one, namely: what do the societal actors need to know about self-help in order to establish self-help? Furthermore, we ask ourselves how we should communicate self-help as an ideology. This was a topic in Oslo: self-help isn’t ‘sexy’ anymore. How do we communicate it then if it is not sexy anymore?

We also have some questions on self-help and professionals. In Norway we see the role of the ‘traditional helper’ as the most threatening role, not the role of the professional per se. What is the role of the traditional helper? A traditional helper is a helper that helps you to facilitate everything in life and makes you dependent. If the professional represents this traditional helper role then the professional is a disaster. Not because of his professionality but because of his helping skills. You see the same phenomenon in the voluntary world. What is the role of the self-help supporter? What is the similarity and difference between self-help and traditional social work? I think we sometimes mix these things. Self-help is not to be taken over. I think it has to be very well-defined. What are the similarities and differences between promoting self-help work and attracting people to attend self-help work? What do the others outside the box need to know about self-help?

We can never reach everyone, but I think we have to go outside the box to tell as many people as possible about self-help.
3.4.2 The underlying danger of cancelling self-help groups’ revolutionary notions: the paradigm of Narcotics Anonymous

Sotiris Lainas

Self-help Promoting Programme – Greece

(Verbatim text)

Abstract

The autonomous, and in some cases, different practice and ideology of self-help groups as opposed to the mainstream ideologies and policies, elevated them as one of the important social movements of the 20th century. There are a lot of paradigms of self-help groups or self-help movements that are characterized by innovative and revolutionary ideas. Self-help groups or movements as A.A. and N.A. or the one of users and survivors of psychiatry changed the quality of life of the people involved and influenced the scientific paradigm and the health policies. However there are a lot of factors in the current function of self-help groups that might phase out their revolutionary ideas and practices. In the current presentation we will focus on N.A. self-help groups to illustrate the underlying dangers of cancelling its revolutionary notions.

Introduction

We started working on self-help six years ago at the Aristotle University of Thessaloniki. Our main focus was drug addiction. We tried to facilitate people in attending 12-step groups. We were very enthusiastic back then about the 12-step groups, how they functioned and helped people. I personally thought they were the best tool I ever encountered. I still believe in these groups, but after all these years we have seen and read a lot of things and we have become more critical. In this presentation I will present some thoughts regarding the specific components of these groups. These components used to have great advantages. In our opinion they might not be as advantageous anymore. We focus on specific elements of the groups that used to be revolutionary. Right now we think there are some dangers attached to abolishing these self-help groups’ revolutionary notions.

Self-help’s revolutionary characteristics

A main characteristic in the field of self-help is that there is no specific typology that integrates all the types of self-help and mutual aid groups. The huge expansion in the diffusion of self-help’s notions and practices led to the creation of many and different efforts. Some were characterised by revolutionary ideas and practices. These efforts humanised care and offered solutions without undergoing psycho-social interventions in the public health system. In our opinion the revolutionary notions of the self-help movement refer to specific components.
The way that self-help groups function

The collective effort, equal and genuine human relationships, mutuality and solidarity, active participation and the consequent absence of passivity should characterise every self-help initiative and are, by nature, revolutionary notions. These are opposed to the mainstream ideology of self-centredness in personal human relationships, of passivity and of competition. In this way self-help groups constitute an important cause of resistance and confrontation to the main causes of several psycho-social problems.

Alternative proposal to the mainstream health policies

In the field of psycho-social problems, group initiatives as A.A. and N.A. offer possibilities to overcome problems in a non-medical way.

Organisational structure of the groups

The organisational structure is characterised by the absence of bureaucracy and personal relationships and by the community function.

Democratization of knowledge

Through the experiences of the members of self-help groups new knowledge is produced about the causes and the ways of dealing with problems. This empirical knowledge sometimes influences the ways of giving help. This is the case for drug addiction: the knowledge that came out of A.A. and N.A. groups was taken up in professional programmes.

N.A. and A.A. revolutionary characteristics

N.A. and A.A. self-help groups constitute a central example of the self-help movement. They significantly influence both the self-help concept and practices and social and health sciences in some cases. The knowledge produced about these groups in contraction to our experience of working with members of these groups the last 60 years allows us to make some hypotheses and draw some conclusions. The self-help groups of A.A. and N.A. were characterised by some researchers as one of the most important movements of citizens in the 20th century.

Dissolution of the medicalized aspect of addiction through their practice

A.A. and N.A. virtually disallowed the medicalized aspect about addiction, since they helped people to overcome their problems through a non medical approach. Historically the start of these self-help groups was the first time that addicts got help.

First time emphasis on spirituality

By giving emphasis to spirituality, as one of the main dimensions of the problem, they pointed out an aspect hardly considered and studied. The existential approach of the anonymous philosophy along with the mutual aid philosophy introduced by 12-step groups constituted also the basis for the most effective professional programmes for addicts. New knowledge was produced coming out of the experience of the addicts. This experiential knowledge supplemented in some cases the scientific knowledge in the field of addiction.
Anarchic and anti--bureaucratic way of organisation and functioning

According to several researchers the absence of hierarchy, the emphasis on the collective effort and the active involvement, the total independence of each group and the anonymity, the autonomy from any outside source of funding are typical for N.A. groups. The frame of the 12-step tradition in general is innovative and worthy to be studied as a frame for the formation and functioning of any group.

Constitution of communities of persons

In our opinion the most basic revolutionary element of N.A. is the emphasis given to the deep human relationships, the genuine mutual interest, equality and solidarity and the consequent constitution of communities of persons. In these communities what seems to happen is a total change in the way of life of the participants, not only the confrontation with their specific symptom of addiction.

By functioning this way the N.A. works as a course of resistance against the dominant aspects of self-centredness and depersonalisation. In other words through their practices they confront the main mechanisms of addiction.

Evolution of N.A.

Today N.A. groups are one of the main organisations for the problem of substance abuse.

Starting from a small effort of some people to overcome their problem, based on A.A. experience, N.A. groups evolved to the second most numerous self-help movement in the world. There exist approx. 21,000 groups worldwide. This expansion happened in less than 30 years.

N.A.'s evolution in relation to health practitioners

In the evolution of N.A. groups the relation to health practitioners changed a lot. In the beginning there was a total dispute from the side of the health professionals, followed by the face of tolerance of existence and functioning and later on: silent acceptance. In the last 10 to 15 years we are facing the fact of total acceptance and sometimes the effort of incorporation into the traditional health system, as another therapeutic proposal. We see the professional effort to transform the 12-step programme into a well documented scientific tool to mobilise drug addicts.

Focal questions

- Do N.A. groups retain these revolutionary characteristics?
- Are they influenced by the dominant societal values?
- What does this huge expansion of N.A. mean for the future of the groups?
- Our main hypothesis – to start from the second question – is that N.A. groups might have incorporated certain dominant societal aspects and practices to such a degree that the groups' revolutionary character is being cancelled.
Areas of criticism

The criticism tries to contribute to a genuine dialogue concerning one of the most important movements of the 20th century.

Medicalisation of Addiction

The first point of criticism refers to the way in which N.A. groups contribute to the medicalisation of addiction. One of the main problems in the addiction field is the dominance of the scientific model in the interpretation and confrontation of the problem. This model constitutes the dominant axis of planning and implementation policies regarding substance abuse even if it is not well documented or evidence based. This model doesn't produce good results; it poses a lot of problems. The programme of N.A. itself is based on the concept and the assumption of personal responsibility. However, N.A. groups are identified with the dominant scientific belief that addiction is a brain disease. This is also the conviction of many N.A. members. A conservative and false understanding of the problem is being promoted. A belief that objectifies every human being and disregards its right of free choice and to build self-determination.

This fact is totally opposite to the reality of the groups themselves, whose members everyday choose to fight, to be self-determined, to confront their problems through a non-medical approach.

Danger of professionalisation

The danger of professionalisation doesn't directly refer to the core functions of the groups that are protected by the 12-step tradition. We witness a lot of phenomena, in Greece too, that reverse the basic helping mechanism of the genuine and unselfish interest and love for a human being that confronts similar problems. I will give you some examples of the last years. The appearance of treatment centres, that are based on the 12-step programme and that are staffed mainly by older members of the 12-step groups, is causing problems. These people continue to attend the meetings and at the same time work at a centre that tries to attract as many clients as possible. These treatment centres are private businesses that offer treatment at very high prices. All this happens around the group: they use the social network of the groups, the older members of the groups. And that creates problems.

We also witness the creation of an enormous percentage of addiction counselors, people that have solved their addiction problem in a 12-step-group. Some of these counselors are educated, others aren't. In Greece you don't need a formal education to practice as an addiction counselor. They base their practice on the innovative tool they possess: the 12 steps. In order to gain more liability and clients they overestimate the value of the tool. The possession of their knowledge was made possible through a very difficult, painful personal journey. There are several aspects of this journey that ex-self-helpers who become professionals choose not to remember: the social networks, the helper-principle and self-determination, the essence of self-help. They leave all that behind and claim that they work with the 12-steps. But the 12-steps without all the self-help aspects, isn't self-help.

Consequences in the everyday functioning of groups

These last years the cancellation of the main organisational principles of the N.A. is being observed. These principles are the totally anarchic structure, the absence of bureaucracy, the independence etc. All these characteristics aim at minimalising the accumulation of power and authority. The big development of the groups and the fact that they have become a part of the dominant model regarding substance abuse proves the positive dimension of the groups but at the same time is a slippery slope. The expansion of the groups has led to the appearance of bureaucracy that reverses the basis of their innovative characteristics.
This is a paradoxical situation: these groups give up some of their core innovative elements in order to obtain methods of organisation and communication like the professional programmes, with poor results. The appearance of bureaucracy is also apparent in the accumulation of the procedures of decision making by the world services of N.A. in the U.S.; the small representation in the world services from other countries, apart from the U.S; the sophisticated textbooks; and the emphasis on tools and techniques.

In conclusion

The main concern that exists with regard to N.A. and A.A. groups is whether they will be adapted or not by the dominant ideology. The N.A. and A.A. groups are at a crucial point these last years. In 1978 there were just 200 groups in three countries around the world. In 2005 there were 21,500 groups in 116 countries. The huge expansion and dynamic of N.A. movement is a fact and influences its core values. It is for the groups and the members themselves to make the choice, whether to ensure the basic helping mechanisms of their effort by confronting these dominant values, or to put in danger the effective function of the groups by choosing the adaptation and incorporation of these ideas by the dominant system.

3.4.3 Results of the workshop

Discussion leader: Jozefien Godemont

Terminology

In my opinion self-help is a value, not an ideology.

We don’t use the word ‘ideology’ in Norwegian. We only use it in English. We always talk of the ‘understanding’ and of the ‘principle’ and the ‘value’ of self-help.

I think self-help is an ideology and a methododology.

The message

Is it about making sure that everyone has the opportunity to participate? Or is it about making self-help seen as a player in policy making, in the decisions taken, in where resources go?

I think that there is a strange tension of lip service (“Self-help is important”) towards self-help groups and the counterforces today with regard to that lip service. From various societal levels people are getting the opposite message: “To feel good you have to rely on products, on health professionals, on holidays ...” In the (mental) health field there is a strange tension between people who help people because it is their job and the fact that helping them too much by saying “You can do it yourself now!” could cause them to lose their jobs. There are some very different messages being spread: “You can do it on your own” and another part of society is saying: “If we make people dependent, pamper them, we earn money.”

When you go out spreading your message you have to know very well what you want. We need the money but we also need a change of mentality.

The audience

Should we tell the general public what self-help groups are doing or should we be going to politicians to tell them how important the work they do is? I think we should do both.
I think we shouldn’t be too sophisticated in thinking: oh, just we have this idea of emancipation, of empowerment. I think a lot of other professionals have this idea too: social workers, health workers, and so on. They have similar thoughts. I think we should look outside the box and try to find ourselves some partners to cope with the challenges of the health system. There is an increasing amount of chronic patients. We should work together instead of sticking to the idea that our ideology is the best and that professionals are just holding the patients down. I think a lot of them do, but not all of them.

How can health professionals and self-help supporters produce synergy? It is absolutely right that they have mutual interests.

**Threats**

If we speak about the value of emancipation, we should be aware of the political impact. Politicians might think: if they start doing emancipatory work, we might encounter problems with patients that come knocking on our doors. I am just at a point of thinking that we shouldn’t speak too much about it. We should find other terms to tell that it is a good thing. And I wouldn’t stress the moneyside, the moneysaving possibilities, too much, not selling self-help as a cheap alternative.
3.5 Self-help support and cooperation

3.5.1 Issues concerning the cooperation and network of self-help groups: the Italian case

Laura Mezzanini and Francesca Focardi

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Abstract

This year the landscape of self-help groups in Italy has been updated. Since 1999 the number of groups increased from 1603 to 3265. The data show us heterogeneity between groups, lack of cooperation and little visibility at the regional level for almost all of the groups. There are some good experiences of cooperation between self-help groups, health services and professionals. To develop this cooperation we ought to establish clearinghouses at the regional level and increase the visibility of the groups and their empowerment compared with the formal organisation of the health system. We discuss the role of the supporters regarding networking and the risks and the advantages for the self-help groups in this development.

Introduction

The aim of our contribution is to present the data concerning self-help groups at a national level and in particular in Tuscany. The Tuscany Regional Coordination Centre of Self-Help Groups was founded in 1996. It is made up of associations, agencies of the social-private sector and citizens fostering self-help initiatives. We have been constantly monitoring and observing the self-help methodology in Italy and especially in Tuscany, refining promotional strategies and tools and developing network interventions. Especially in the last few years, we realised that it was important to feed the research in the domain of self-help. The research identified some weaknesses in self-help groups and gave us a crucial input for fostering groups in Tuscany, as we will present in short.

Research objectives

The national research objectives were to update the data from 1999 onwards, to identify new self-help experiences at the local, regional and national level, to identify new requirements emerging from self-help groups, to carry out a quality analysis of the networks supporting self-help groups, and to document new self-help experiences (fields, applications ...).

Research areas

We developed a questionnaire and administered it following these areas: general data (place and time of meeting), participants’ classification, characteristics of group organisation, activities beyond the self-help group activities, documentation produced by groups, and the assessment of weaknesses.
Geographical distribution of groups

Self-help experiences are heterogeneously distributed over the national territory: 63% of the groups are in the North, 24% in the centre, 9% in the South and 4% on the islands (Sicily and Sardiny).

Compared with the 1999 study, there is a growing number of groups in areas where self-help experiences were underdeveloped: a growth of 400% on the islands (Sicily, Sardinia), of 300% in the South and of 141% in central Italy. These are mostly rural communities in which informal networking is important.

3265 self-help groups were detected by the research. There is an increase of 203% compared with the data collected in 1999 when 1603 groups were identified.

Intervention areas

Groups are heterogeneously distributed as for the problems they deal with.

Table 2: Intervention areas of Italian self-help groups (1999, 2007)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>New addictions</td>
<td>3</td>
</tr>
<tr>
<td>Organ transplant</td>
<td>11</td>
</tr>
<tr>
<td>Specific life experiences</td>
<td>11</td>
</tr>
<tr>
<td>Lifecycle-related problems</td>
<td>17</td>
</tr>
<tr>
<td>Social unrest</td>
<td>22</td>
</tr>
<tr>
<td>Gender identity</td>
<td>27</td>
</tr>
<tr>
<td>Self-actualization</td>
<td>34</td>
</tr>
<tr>
<td>HIV positive people</td>
<td>34</td>
</tr>
<tr>
<td>Violence against women and minors</td>
<td>39</td>
</tr>
<tr>
<td>Minors’ unease</td>
<td>43</td>
</tr>
<tr>
<td>Depression</td>
<td>48</td>
</tr>
<tr>
<td>Love addiction</td>
<td>48</td>
</tr>
<tr>
<td>Gambling</td>
<td>48</td>
</tr>
<tr>
<td>Mourning</td>
<td>64</td>
</tr>
<tr>
<td>Family crisis</td>
<td>78</td>
</tr>
<tr>
<td>Cancer</td>
<td>82</td>
</tr>
<tr>
<td>Adoption and fostering</td>
<td>84</td>
</tr>
<tr>
<td>Smoking addiction</td>
<td>102</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>120</td>
</tr>
<tr>
<td>Pathologies</td>
<td>146</td>
</tr>
<tr>
<td>Disability</td>
<td>173</td>
</tr>
<tr>
<td>Food disorders</td>
<td>290</td>
</tr>
<tr>
<td>Mental disorders</td>
<td>292</td>
</tr>
<tr>
<td>Psychotropic substances addiction</td>
<td>442</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>1015</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>3265</strong></td>
</tr>
<tr>
<td></td>
<td><strong>1603</strong></td>
</tr>
</tbody>
</table>
New self-help experiences

Compared with the 1999 study, the number of groups that face new and very specific conditions is increasing. There are groups on different kinds of addictions besides alcohol and drugs (pornography, internet ...). There is also an increase of groups that deal with chronic conditions, rare diseases and with conditions related to the lifestyle.

Table 3: New self-help experiences in Italy

<table>
<thead>
<tr>
<th>Problem</th>
<th>Number of groups</th>
<th>Problem</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obsessive-compulsive disorder</td>
<td>1</td>
<td>Compulsive shopping</td>
<td>2</td>
</tr>
<tr>
<td>Double diagnosis</td>
<td>1</td>
<td>Asbestos exposition</td>
<td>2</td>
</tr>
<tr>
<td>Study difficulties</td>
<td>1</td>
<td>Cystic fibrosis</td>
<td>2</td>
</tr>
<tr>
<td>Pornography addiction</td>
<td>1</td>
<td>Ataxia syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Bullying</td>
<td>1</td>
<td>Autism</td>
<td>3</td>
</tr>
<tr>
<td>Learning disorders</td>
<td>1</td>
<td>Work stress</td>
<td>3</td>
</tr>
<tr>
<td>Internet addiction</td>
<td>1</td>
<td>Aphasia</td>
<td>3</td>
</tr>
<tr>
<td>Near-death experiences</td>
<td>1</td>
<td>Menopause</td>
<td>4</td>
</tr>
<tr>
<td>Alternative Therapy techniques</td>
<td>1</td>
<td>Immigration</td>
<td>4</td>
</tr>
<tr>
<td>Celiac disease</td>
<td>1</td>
<td>Coercive Groups</td>
<td>7</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>1</td>
<td>Stammering</td>
<td>7</td>
</tr>
<tr>
<td>Retinitis Pigmentosa</td>
<td>1</td>
<td>Existential and personal growth-related problems</td>
<td>7</td>
</tr>
<tr>
<td>Cranial trauma</td>
<td>1</td>
<td>Pregnancy and maternity</td>
<td>9</td>
</tr>
<tr>
<td>Male self-consciousness</td>
<td>1</td>
<td>Monoparental families</td>
<td>9</td>
</tr>
<tr>
<td>Psycho-physical wellbeing</td>
<td>1</td>
<td>Self-esteem</td>
<td>9</td>
</tr>
<tr>
<td>Relational disorders</td>
<td>1</td>
<td>Loneliness</td>
<td>14</td>
</tr>
<tr>
<td>Ictus</td>
<td>2</td>
<td>Dyslexia</td>
<td>15</td>
</tr>
<tr>
<td>Child psychomotor pathologies</td>
<td>2</td>
<td>Support to parental role</td>
<td>24</td>
</tr>
<tr>
<td>Mobbing</td>
<td>2</td>
<td></td>
<td>TOTAL 148</td>
</tr>
</tbody>
</table>

Groups' life cycle

We observed that some groups have a limited lifecycle and that most continue functioning for a longer period. 87% of groups don't have an end-date. Only 13% of the groups terminated over time. These are initiatives with short-term objectives, aiming at facing a very specific problem, such as smoking addiction, anxiety disorders, organ transplantation, mourning, adoption etc.
Activities of the groups

Many groups have a legal status. 74% of the sample state that apart from meetings there are other ways of support the group organises. Many self-help initiatives start within volunteer associations, whose participants act proactively in order to provide support to other members. The most widespread activity is providing information about both self-help groups and the problems they are dealing with.

<table>
<thead>
<tr>
<th>Other activities</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
<td>15</td>
</tr>
<tr>
<td>Local initiatives</td>
<td>18</td>
</tr>
<tr>
<td>Educational activities</td>
<td>18</td>
</tr>
<tr>
<td>Awareness-rising activities</td>
<td>19</td>
</tr>
<tr>
<td>Hospitality</td>
<td>27</td>
</tr>
<tr>
<td>Relationships with services</td>
<td>29</td>
</tr>
<tr>
<td>Rehabilitation centers</td>
<td>30</td>
</tr>
<tr>
<td>Prevention</td>
<td>42</td>
</tr>
<tr>
<td>Creative/expressive activities (theatre, laboratories, etc.)</td>
<td>50</td>
</tr>
<tr>
<td>Therapeutic/rehabilitative activities</td>
<td>65</td>
</tr>
<tr>
<td>Nursing</td>
<td>121</td>
</tr>
<tr>
<td>Relationships with local associations</td>
<td>125</td>
</tr>
<tr>
<td>Quality-of-life promotion</td>
<td>145</td>
</tr>
<tr>
<td>Home assistance</td>
<td>208</td>
</tr>
<tr>
<td>Recreational activities</td>
<td>227</td>
</tr>
<tr>
<td>Medical assistance</td>
<td>284</td>
</tr>
<tr>
<td>Social assistance</td>
<td>384</td>
</tr>
<tr>
<td>Rights protection</td>
<td>440</td>
</tr>
<tr>
<td>Regional/national meetings</td>
<td>457</td>
</tr>
<tr>
<td>Legal counseling</td>
<td>551</td>
</tr>
<tr>
<td>Socialization/reintegration</td>
<td>807</td>
</tr>
<tr>
<td>Psychological support</td>
<td>949</td>
</tr>
<tr>
<td>Active listening (phone line)</td>
<td>1256</td>
</tr>
<tr>
<td>Training</td>
<td>1384</td>
</tr>
<tr>
<td>Information</td>
<td>2110</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>9909</strong></td>
</tr>
</tbody>
</table>

Documents produced by the groups

Groups were asked to identify the informative materials they produce and disseminate. In 35% of cases, the material is organised on a website. The use of the internet has increased the visibility of groups; in the previous research, the use of websites as a means of dissemination was much more limited. In 28% of cases, information booklets are used to inform people at a local level. Written material is seldom collected because it is not perceived as an important activity. The Tuscany Regional Coordination Centre has designed a specialised Documentation Centre aiming at gathering and disseminating material at a local and national level.
Assessment of weaknesses

70% of the sample states that they encountered different kinds of problems during the lifecycle of the group.

Types of difficulties encountered

There are many kinds of difficulties, caused both by internal and external factors.

<table>
<thead>
<tr>
<th>Problems encountered</th>
<th>Number of groups</th>
<th>Problems encountered</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unspecified (many)</td>
<td>4</td>
<td>Dependency on the facilitator</td>
<td>34</td>
</tr>
<tr>
<td>Associative difficulties</td>
<td>6</td>
<td>Relational difficulties within the group</td>
<td>35</td>
</tr>
<tr>
<td>Health problems</td>
<td>8</td>
<td>Big differences among participants</td>
<td>36</td>
</tr>
<tr>
<td>Difficulties in defining the role of the facilitator</td>
<td>8</td>
<td>Search for a place/venue</td>
<td>40</td>
</tr>
<tr>
<td>Too big groups</td>
<td>9</td>
<td>Difficulties in embracing the self-help vision</td>
<td>51</td>
</tr>
<tr>
<td>Passive attitude/low participation in the group</td>
<td>10</td>
<td>Communication problems</td>
<td>56</td>
</tr>
<tr>
<td>Scarce visibility of the group</td>
<td>12</td>
<td>Relationships with Institutions</td>
<td>58</td>
</tr>
<tr>
<td>Physical distances</td>
<td>12</td>
<td>Economic problems</td>
<td>59</td>
</tr>
<tr>
<td>Lack of autonomy</td>
<td>17</td>
<td>Complex personal conditions</td>
<td>72</td>
</tr>
<tr>
<td>Relationships with the outer world</td>
<td>19</td>
<td>Organizational difficulties</td>
<td>74</td>
</tr>
<tr>
<td>Distrust towards Institutions</td>
<td>23</td>
<td>Involvement of new members</td>
<td>89</td>
</tr>
<tr>
<td>Low motivation of participants</td>
<td>24</td>
<td>Attendance drop-out</td>
<td>184</td>
</tr>
<tr>
<td>Search for a new facilitator</td>
<td>27</td>
<td>TOTAL</td>
<td>967</td>
</tr>
</tbody>
</table>

Self-help groups in Tuscany

In Tuscany we detected 283 self-help groups, dealing with different kinds of problems.
Table 6: Self-help groups in Tuscany

<table>
<thead>
<tr>
<th>Problem</th>
<th>Number of groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minors’ unease</td>
<td>1</td>
</tr>
<tr>
<td>Family crisis</td>
<td>1</td>
</tr>
<tr>
<td>Organ transplant</td>
<td>1</td>
</tr>
<tr>
<td>Violence against women and minors</td>
<td>2</td>
</tr>
<tr>
<td>Social unrest</td>
<td>2</td>
</tr>
<tr>
<td>HIV-positive people</td>
<td>3</td>
</tr>
<tr>
<td>Gender identity</td>
<td>3</td>
</tr>
<tr>
<td>Mourning</td>
<td>4</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
</tr>
<tr>
<td>Self-actualization</td>
<td>5</td>
</tr>
<tr>
<td>Lifecycle-related problems</td>
<td>8</td>
</tr>
<tr>
<td>Gambling</td>
<td>6</td>
</tr>
<tr>
<td>Love addiction</td>
<td>8</td>
</tr>
<tr>
<td>Adoption and fostering</td>
<td>10</td>
</tr>
<tr>
<td>Disability</td>
<td>11</td>
</tr>
<tr>
<td>Depression</td>
<td>11</td>
</tr>
<tr>
<td>Food disorders</td>
<td>13</td>
</tr>
<tr>
<td>Organic pathologies</td>
<td>13</td>
</tr>
<tr>
<td>Anxiety disorders</td>
<td>15</td>
</tr>
<tr>
<td>Smoking addiction</td>
<td>16</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>43</td>
</tr>
<tr>
<td>Mental disorders</td>
<td>50</td>
</tr>
<tr>
<td>Psychotropic substances addiction</td>
<td>56</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>283</strong></td>
</tr>
</tbody>
</table>

Distribution by province

In Tuscany there are 10 provinces. The majority of the groups is located nearby the province of Florence, where the Tuscan Co-ordination Centre works more actively in fostering groups.
A formal convention has been established this year between the Tuscan Self-help Coordination Centre and the Education service of the Health Service of Florence whose role is to foster and to support promotional activities carried out at a local level. This represents an important step in order to reach self-help groups’ visibility within social and health service institutions.

**Difficulties encountered in Tuscan groups**

The difficulties reported by Tuscan groups are:
- The newly constituted groups are small informal realities and do not have a defined associative identity, they don’t have any link with umbrella organisations;
- Little visibility at an institutional level;
- Little networking among the groups of the same area;
- Lack of promotion by professionals.

**Development**

The Regional Coordination Centre receives many requests for support and supervision by groups wishing to expand their visibility at a local level. However, it is difficult to work at a distance in other provinces. Thus, in the Tuscan provinces, it is necessary to promote a network model allowing us:
- To promote the development of groups;
- To foster groups dealing with problems/issues that are less represented;
- To carry out awareness-raising activities addressed to local communities;
- To identify strategies for building up formal partnerships with local institutions.

**Creation of local coordination centres**

In order to overcome the difficulties, the project aims at strengthening the network among all self-help groups in our region through the creation of Province Coordination Centres capable of working at a local level. The Tuscany Regional Coordination Centre will enforce the above objective through the following actions:
- Identification of one self-help association in each province willing to manage the local coordination activity;
- Establishing a dialog with local politicians;
- Periodic meetings among province coordination centres leaders;
- Fostering occasions of supervision, exchange and discussion in each province in order to support self-help groups;
- Research on political strategies to foster cooperation with professionals and institutions;
- Connections with provincial delegations of the CESVOT (Centro Servizi per il Volontariato della Regione Toscana), Centre for Volunteer Services in Tuscany;
- Organisations of awareness workshops on the self-help methodology addressed to professionals, traditional volunteers and citizens;
- To establish a ‘Regional Day of Self-Help’.

We know that we still have a long way to go, but it is an amazing work. So we like to keep doing this job with passion.
3.5.2 Self-help in Austria: in or out the box?

Cathrine Schauf

ARGE Selbsthilfe Österreich/ Selbshilfe Salzburg, Dachverband der Selbsthilfegruppen – Austria

Abstract

In this presentation the speaker will introduce herself, sketch the landscape of self-help support in Austria, its organisational structure, its objective and targets. She will go into organized networking, the opportunities and threats this poses. She concludes by giving a future outlook.

Introduction

I work at Selbshilfe Salzburg – Dachverband der Selbsthilfegruppen. Today I will be presenting ARGE Selbsthilfe Österreich and I will show you a bit how we are organised in Austria.

Landscape of self-help in Austria

In Austria the self-help movement consists of different kind of self-help initiatives:

- Theme orientated non associated groups (small: 3 to 5 persons)
- Theme orientated associated groups (bigger and nationwide)
- Self-help-support: umbrella organisations and contact points for every county (there are 9 counties in Austria)
- Self-help-voice: Working Union (ArGe)

We established ArGe in 2000. All the self-help service institutions are represented in this umbrella organisation. Our objectives are to defend the interests of all these self-help groups and to strengthen their position in our country. We see ourselves as a kind of turntable for the topics that are specific to self-help groups. The interests of non-affiliated individuals are not represented in our working group, but those of the wide majority of individuals who are organised in self-help groups, are.
ARGE Selbsthilfe Österreich is a self-help support centre. For me it is very important to distinguish between self-help supporters and self-help groups and their tasks and not to mix them. We are supporting the self-help groups from the outside.

Objectives and targets

We have created professional standards for self-help support in order to have a quality support for ourselves and to show others, who don’t know us, what we are aiming at. They entail rules of how to work in the self-help support. They also describe the methodology of self-help support. Basic democracy, independency, self rule and autonomy are very important values to me with regard to self-help groups. We guard these principles of the self-help movement. We are supporting the groups in different ways. The support you can offer as a support centre depends from the resources you have. This is what we offer groups:

- Exchange of relevant information between all involved groups;
- Giving support in developing relationships with politics and industry;
- Creating and distributing „Professional Standards“ for self-help;
- Marketing and enhancing the knowledge about self-help movement;
- Giving support in fundraising with governmental institutions and industry;
- Support networking at all levels: national and international.

Networking in and out of the box

- Creating a structure that is capable of networking
  We have been doing this in Austria and it is a lot of work. We are going out to different organisations, to the professionals. Then we have to present ourselves.
- Representing SH in health political forums and panels
  We have achieved that we are a member of the Ethic-commission on country-level. We attend medical fairs and congresses. We participate in health related local networks and platforms, and EU supported health projects. We are also research members of the “Gesundheitsplatform”, which is a governmental organ. It decides how health policy in Austria is organised.

- Initializing and creating contact with industry-partners
- Influencing national health insurance institutions
  We have a voice there and try to influence them: “Now you have self-help groups”.

Some institutions don’t know us or perhaps would like to create boxes for us. They see self-help as a separate box. But we are not in one box. Because we are experts with regard to various boxes and we go out and talk about all the other boxes.

**Opportunities and threats**

Some opportunities in the self-help field in Austria are that the basis is growing constantly and getting together more on a national basis. The continuous work of the past seven years seems to be paying back. The international networking for rare diseases also offers opportunities.

Threats for self-help initiatives are that the government retreats from health and social responsibility, that politicians use the self-help movement for their own purposes, that industry is muscling into the self-help movement, and finally that money still rules.

**Conclusion and outlook**

We cannot expect professional health and social workers and politicians to leave their little boxes and come out to find us. We have to develop a pro-active attitude towards them and reach out to shake hands with all of them. Furthermore we cannot expect them to be too enthusiastic, but at least we should try to accomplish that they are not afraid of us anymore. We are not to be ignored. So, get together and keep up the good work.

**3.5.3 Results of the workshop**

**Discussion leader: Annemie Vandermeulen**

In your opinion as a self-help supporter, at this moment what is the most relevant topic in networking and collaborating with other organisations? Is there a challenge in the near future, a goal that your organisation wants to work towards?

**Visibility**

They are afraid of us and we are afraid of them, these health professionals. It is important to say who we are. I think we have to announce ourselves. In our country the self-help methodology is rather new. The 12-steps groups are better known.
Patient – professional conferences

I know Germany has conferences between patients and health professionals. I was wondering if other countries have experiences with this type of conferences too. How do you get on with it? In Switzerland we have really very small discussion groups. On a very personal level the patients talk about their treatment, the lack thereof, their experiences and the doctors or the psychologists tell about their experiences. So it is a very personal approach. Doctors better understand the patients’ side. But you can’t go on with that type of conferences and I was wondering in other countries what kind of development there is. You can go on with that system, but at the same time you should try to open it up and not only have these discussion groups. It is also a question of social insurance, so you should have officials from social insurance too.

Threats

I think that these are all very high expectations: to change the minds of the health professionals, to change the world ... I am very anxious about these expectations. Not only could you or should you expect that a health professional tries to do a good job because he earns money and has his standards of quality. Do we want these kinds of quality standards for self-help groups?
Introduction

I always think it is helpful to make clear from the beginning what I mean when I use the word ‘self-help’. It refers to a collective form of self-help, in groups or organisations. People who buy aspirin to relieve their headache are carrying out self-help as well, but not collectively. I might say that in Germany it is a bit tricky to use the term ‘collective’ – or ‘ideology’ – because it is associated with ‘something they did in East Germany’.

1953: The first A.A. group in Germany was founded by American soldiers

The German self-help system has one of its main roots in the 12-step movement. The first A.A. group in Germany was founded in 1953 by and for American soldiers. Ever since the A.A. programme has been widespread in Germany and worldwide.

1968: The “Bundesarbeitsgemeinschaft Hilfe für Behinderte” (BAGH) (i.e. Federal Working Group Aid for the Handicapped) is founded

The year 1968 is a highly symbolic year for Germany. It was the year of the students’ rebellion. By the way, in East Germany this year has a completely different association, namely the Prague Spring. In West Germany it is a symbolic year because of the major societal changes that occurred from then on, not so much in the economic basis of society as in its cultural structure – in the way parents deal with their children, teachers behave towards their students, women and men relate to each other etc.

This was the year the Federal Working Group Aid for the Handicapped (BAGH) was founded. Besides the anonymous 12-steps addiction tradition in Germany we have this very early, strong tradition of organisations for handicapped persons and their families. At the outset they formed an umbrella organisation that initially had eight member organisations, but soon grew very rapidly; now it has over a hundred member organisations with roughly one million members. There exists a self-help group for practically every severe or chronic disease, and the groups have connections with each other. Our NAKOS (Nationale Kontakt- und Informationsstelle zur Anregung und Unterstützung von Selbsthilfegruppen; National Contact and Information Centre for promoting and supporting self-help groups) in Berlin issues every year what we call the ‘green addresses’, the addresses of self-help organisations working nationwide. The directory is available free of charge.
1970s and 1980s: self-help organisations of handicapped and chronically ill persons mushroomed

In the years following 1968 many self-help organisations of handicapped and chronically ill persons came into being on local, regional and federal levels. At the same time philanthropic activity in the field of addictions, traditionally embedded in the social work activities of church-run associations, started to change. In the past – though they still exist today – there were a number of non-12-step groups for alcoholics and drug dependents within the church tradition. In 1968 the highest court in Germany decided that addiction was a disease whereas earlier many people had seen it as bad behaviour or even a sin. This caused a shift from benevolent caring to a self-help approach in the field of addiction.

1976 - 1977: The first textbooks on self-help groups in the US

Between 1976 and 1977 the first American textbooks on self-help groups were issued (Katz & Bender, Caplan & Killilea, Gartner & Riesman). Having a textbook in your own language can be very important for the development of a national self-help movement. It is a kind of ‘lighthouse’. Everybody can be advised to read it or at least some chapters or pages. People can refer to the text and therefore a sort of identity can be formed. It was a turning point when Prof. Michael Lukas Moeller published the first book on self-help groups in Germany. He was a psychoanalyst and, even more important, a group therapist. When traveling in the US he had learned about self-help programmes and wondered if it couldn’t help patients to do some group work on their own. An important part of the cultural background in Germany was the fact that encounter groups – “self-experience” was the common term there at the time – were very popular, as was psychoanalytic thinking.

Psychoanalytic thinking is still pretty popular in Germany, which might not be the case in other countries. Sigmund Freud is still referred to when talking about psychology in a popular way. He has, however, almost completely vanished from academia, and his ideas are hardly taught any longer in universities. Which I find a shame, of course.

1977 - 1979: Research projects in Giessen, Hamburg, and Heidelberg begin

Prof. Moeller started the first research project on self-help groups in Germany. The specific type of self-help groups we explored were the so-called ‘psychological-therapeutic’ ones. The term ‘psychotherapeutic’ was avoided because we were afraid that this might create considerable problems with professional group therapists. However, it expresses the idea that self-help groups can offer people something close to psychotherapy. This research project, by the way, was part of the large scale reform of psychiatric care in Germany. The research report was published by the state, carrying “the Federal Eagle”, the state coat of arms, on its cover. Self-help was no longer something dirty, tucked away in the red-green, alternative, and anti-authoritarian corner. A Ministry supported research on self-help groups. That was quite a message to the public and to the professionals.

The research project in Giessen was followed by others in Hamburg and Heidelberg. The Giessen research team was no longer alone. That was very relevant.

Two of these research projects were located in departments of psychosomatic medicine and psychotherapy, one in medical sociology. Here the field of medicine was connected to psychological and sociological thinking, perhaps causing a little crack in the concrete block of the medical system.

All three research projects had a kind of action research philosophy. The researchers were not just collecting data to put into computers to produce numbers as a result. They wanted to see how they could support people in forming self-help groups. What kind of guidance or supervision could we offer them, while still respecting their autonomy? That was our question.
At the time of these research projects we developed what we now call a 'clearinghouse'. Of course that term didn't exist at the time, nor indeed did the German word “Selbsthilfe-Kontaktstelle”. But we simply came together and wondered what kind of support activities we could offer. This is the moment when the clearinghouse idea was born in Germany.

The next step was the development of Deutscher Arbeitsgemeinschaft Selbsthilfegruppen (i.e. German Working Group [for the Support of] Self-Help Groups). In the beginning it was only a very informal circle of people devoted to self-help groups, coming together, partly from these research projects, but including other interested persons as well. We met whenever we could; we met at conferences, where some of us were for other purposes, to sit together for an afternoon and exchange ideas. What about self-help groups? Can they work without professionals? What are the risks? What will they do (all commit suicide?) when we are not there to supervise them? Dare we cooperate with them as professionals, or should we completely withdraw and avoid any contact? Are we going to poison them as soon as we meet them? It was highly moralistic thinking in those days. Of course this excessive caution was in reaction to our own professional dominance as university staff members.

Out of this informal circle – again, this was very important to us, not feeling we were loners, lunatics or outsiders – the first generation of informal self-help clearinghouses emerged. The term wasn't even coined then, there were simply people trying to support self-help groups on local level.

1980s: Courses on self-help groups at the IUC in Dubrovnik sponsored by the WHO-Europe

By the 1980s we also had some international support for our thinking from the WHO-Europe (the WHO regional office in Copenhagen, not the headquarters in Geneva). They brought together an international group of experts in Höhr-Grenzhausen, Germany, and here in Leuven as well. The recommendations these experts produced were a very welcome form of support. Whenever I went to German politicians I could mention that the WHO was supporting our ideas. It made us aware of the fact that we were not alone, internationally. In Germany we might have been among the forerunners, but there were activities in other countries as well. Quite a support and encouragement for us. That is why I have so much enjoyed our European meetings ever since.

1977-1982: Phase of curiosity and resistance

A small minority of professionals were pretty interested from the beginning. I can confirm what Solbjørg Talseth from Norway said earlier about "professionals being human beings too". My advice is not to try to convince the medical profession in total, but rather Dr. Miller or Dr. Smith as individuals, the ones who are already interested. On the other hand, self-help did immediately provoke very strong resistance among professionals. The president of the German Doctors Association, for example, publicly warned that the funding for self-help could lead to lower income for doctors in private practice. That was of course an oversimplified remark, but at the time it was really a voice that found hearers, an important expression of resistance.

Another field of resistance was formed by the psychotherapists. What we promoted, self-help groups, particularly "psychologico-therapeutic" self-help groups, was indeed very similar to what they did. The psychotherapists believed, wrongly, that self-help groups might become rivals.

During that period we elaborated what a self-help clearinghouse is supposed to do (and what not); we created the model for a new type of institution.
1982-1987: Phase of acceptance and idealisation

In 1982 the informal circle of Deutsche Arbeitsgemeinschaft Selbsthilfegruppen became a registered society. It was preceded by an interesting discussion: should we or should we not become a registered society? Should we form a board, write a constitution, and have elections, or should we remain in the spirit of self-help, meaning informal, grass-root minded? Personally, I was not in favour of formalising in the beginning. But it became a registered society for the simple reason that this makes it much easier to receive money.

One year later, in 1983, a new social policy was introduced in Berlin. Berlin is both, a city and a federal state. Germany is a federation with 16 states, and Berlin is one of them. In 1983 Berlin was surrounded by walls and fences. This new policy was developed by a conservative politician. He was of the opinion that the particular situation in Berlin with enormous social problems and political tensions could best be dealt with by cooperating with the new approaches offered by self-help groups, citizens’ initiatives, voluntary work of non-governmental organisations and so on. The policy makers were in search of a respectable organisation that could be part of this new programme, and they found the Deutsche Arbeitsgemeinschaft Selbsthilfegruppen (because we were a registered society). They offered us money under the condition that our activities were carried out in Berlin. That was the opportunity to open a national clearinghouse. And that is the reason why it happened in Berlin, which was an island then, far away from the rest of the country.

WHO’s recommendations were very helpful in setting up a national centre. So we first formed a registered society of self-help supporters and promoters, and then we founded an institution.

1987-1992: Phase of institutionalisation and professionalisation

In 1987 rumours about self-help had reached the federal government. It made inquiries to find out what it could do. According to the German constitution health matters and social matters aren’t regulated on federal but on state level. Therefore we recommended the federal government to carry out what we call a programme of pilot projects. The idea behind this is that the federal level, not really being responsible, funds certain projects for a limited time. These projects are evaluated by independent experts in order to learn about their usefulness. There were 18 projects all over Germany, one of them in my town Giessen, quite well financed by the federal government for four years. Was their effectiveness proved? Of course, one could not prove effectiveness in the strictest scientific sense. However, those evaluating the projects could show that in areas with clearinghouses the number of groups increased significantly, the number of people participating in self-help groups increased, and most of the groups were stable over time.

From then on we could say that to support self-help groups in general through local clearinghouses is useful and valuable. In some federal states the clearinghouse idea was taken up, in others not. That’s how it is in a federation.

In 1991 our series of European Expert Meetings started in Frankfurt. It was just a lucky coincidence that we heard of another organisation that had received government money to organise an international conference on any social work topic with it. We were immediately ready to suggest a topic (self-help support), and over and above that we offered a list of potential participants. Everything was accepted, just unbelievable.
In 1992, after unification, a second government programme was introduced in East Germany. There were not many self-help groups there at the time. No groupings independent from state organisations had been allowed by the regime. But very quickly the same system developed in the East. In the beginning among those who founded or joined self-help groups were many who had also been active in the political movement that led to the fall of the Berlin Wall and to unification.

A convincing proof of the effectiveness of self-help clearinghouses was provided some years later by Jürgen Stremlow, a researcher in Switzerland. He went around to all the clearinghouses in Switzerland and asked them how many staff members they had. He also counted the number of self-help groups per 100,000 inhabitants. There exists a clear statistical relationship between the number of groups per 100,000 inhabitants and the number of staff members per clearinghouse. The message is simple: the more staff members you can pay, the more groups you have. Moreover the diversity of groups will increase which means: more topics are dealt with by a specific local self-help group. This is a very simple research finding, but if you show it to a politician, he gets a very clear message.

Another finding comes from Bremen (a city and port in the north of Germany). Over the years the number of people contacting the Selbsthilfe-Kontaktstelle (self-help clearinghouse) with psychological problems had been increasing whereas those calling with regard to chronic disease and handicap had been decreasing. What does this mean? I don’t think that the number of handicapped persons has come down in Germany. It means – here we come back to the internet – that people can find a lot of information on diseases and conditions on the internet, instead of turning to a self-help group. And secondly, it indicates that more and more professionals do give information about self-help, particularly in fields like alcoholism or cancer. At the same time an increasing number of calls refer to rather unclear, vague psychological states (I don’t feel well, I feel lonely ...). Thus an additional function of clearinghouses is to provide a kind of minimal psychological counselling service for screening and clarifying psychological problems and showing ways through the jungle of our health and social service systems. I call this the “piloting or signposting function” of Selbsthilfe-Kontaktstellen.

2000: Financial support by statutory health insurance funds

A very big change occurred – and there is a great deal of talk about this all over Europe – when money from Germany’s gesetzliche Krankenkassen (statutory health insurance funds) came into the game. You should know that the German health system is not paid for by tax money but by the contributions of the insured. Almost everybody in Germany has to be insured in one of these statutory health insurance funds. At the present time there are some 200 of them. You are free to choose one, but in practice they all provide the same services. The traditional situation is that the working father is what we call a “member”, i.e. from his salary a certain percentage is taken as his contribution, and his wife and children are insured without paying separate contributions. There is a public law which regulates what this money should be spent on. In 1999 we had a change from a conservative to a red-green government. The new health minister, a woman from the Green Party, understood the self-help idea quite well and supported it personally. She initiated a law which regulates that the gesetzliche Krankenkassen (statutory health insurance funds) have to support “Selbsthilfegruppen”, “Selbsthilfeorganisationen” and “Selbsthilfe-Kontaktstellen”. These are the technical terms we used in our self-help jargon, and now they are written into the code of social law. Self-help organisations are nationwide and formally organised; self-help groups are small, at the local level, and offer face-to-face communication; and self-help clearinghouse are professional agencies promoting and supporting self-help groups. When the statutory health insurance funds spend their money on self-help, so says the law, they have to consult representatives from the self-help movement. Who are these representatives of the self-help movement? Four associations were recognized: one umbrella organisation for handicapped people, one from the field of addiction, one from social welfare, and our Deutsche Arbeitsgemeinschaft Selbsthilfegruppen.
Germany has 82 million inhabitants of whom about 90% (70 million) are insured in these schemes. That means that the health insurance funds have to spend 70 million Deutschmarks, approximately 35 million Euros, on self-help.

This was not only a big jump in terms of funding, but in terms of recognition as well. The German state had agreed that self-help has positive effects and started to support it substantially. But the state decided not to do it from its own resources (every citizen’s tax money), but required the statutory health insurance to do so.

To illustrate the leap forward in terms of the recognition of self-help, let me show you the cover of *Deutsches Ärzteblatt*, May 2003 edition, the official journal which goes to all German doctors (ca. 250 000) every month. On the cover is written “Ärzte und Selbsthilfe: Zusammenarbeit verbessert sich” (i.e. “Doctors and self-help: Cooperation is improving”). That is, of course, not a description of actual progress, although things are slightly improving, it is rather a political message from the Doctors Association: this is what we want to happen! In this issue you can find articles describing the four most important umbrella organisations in the self-help field. It provides all doctors with information about self-help structures. The self-help structures refer, more or less, to the directories that our NAKOS compiles of nationwide self-help organisations and of local clearinghouses. Maybe you remember the “green addresses” and the “red addresses” I have shown you earlier. So from then on every doctor has had the possibility to find addresses of self-help groups and clearinghouses for their patients. This didn’t bring in one Euro for our NAKOS, but now we could show doctors that their own professional umbrella organisation was in favour of self-help.

**Patient participation in the German health system**

In the German health system you have different players that are involved in the negotiations: the providers, the physicians’ representatives and the Hospital Association on one side, and the statutory health insurers on the other side. For a long time all decisions in the German health system were made in a closed circle called the “joint commission”. This is a basic principle in Germany, ‘self-governance’: the state doesn’t interfere; the providers and the statutory health insurance are self-administered. These bodies negotiate about which health technologies like drugs, diagnostic or operation methods, psychotherapy etc. they accept as effective and are ready to pay for. In Germany this is not a political or governmental issue, it is decided between the care providers, doctors and hospitals, and those who pay, the statutory health insurance.

The new Green minister in 1999 remarked that all these negotiations claim to centre around the patients, but – and isn’t that quite strange? – the patients themselves are not represented in the decision making process. The crucial new structure that came into being is the “Patientenbeteiligung” (i.e. “patient participation”), a representation of patients on the joint commission.

The question that now arose was who these patient representatives ought to be. The law says: “sachkundig” (i.e. well informed) persons. They are to be nominated by patients’ self-help organisations (for cancer, rheumatism, diabetes etc.) or by professional organisations working in the field of self-help support or consumer advice. The idea is that these persons bring together not only their own personal experience, but the experience of their respective organisation in its totality. The second idea is that they have experience in committee work, negotiations etc. They shouldn’t be the ‘revolutionary’ type, only being after reproach and confrontation. They should also have contacts with other organisations. It is not all about say rheumatism only (i.e. their own disease), they have to speak for say diabetics as well. It is not about simply demanding better treatment or better doctor-patient interaction, but about the health system in total, including its financial limitations. So they must understand the health system – which is rather complex and complicated. Later on, another requirement turned out to be relevant: they should be able to understand the scientific and technical language of evidence based medicine (randomised controlled trials) and understand statistics (e.g. probability). So the expectation was pretty high.
The government accredited four patient organisations, one of which was our Deutsche Arbeitsgemeinschaft Selbsthilfegruppen. These accredited organisations have to agree on the “well informed” persons they have chosen to send to the joint commission which creates a stronger democratic representation. The Doctors Association represents the doctors, no questions, the Hospital Association does the same for the hospitals, but patients do not have the kind of umbrella organisation, which can assure genuinely democratic representation.

One of the accredited organisations is Deutsche Arbeitsgemeinschaft Selbsthilfegruppen, the organisation I work for. They suggested – to give you a concrete example – that I should be a patients’ representative in the subcommittee on psychotherapy. That had to be checked with the three other organisations. And then I found myself sitting there in this strange world.

Patients’ representatives have three rights: The first right is the right to speak out whenever they have something to say. That is different from public or parliamentary hearings in the past. In a hearing people could ask me for my opinion, but if they didn’t, I could not share my thoughts. The second right is to put topics on the agenda. As a patients’ representative I can propose a topic, and the other partners can’t say that is rubbish. The third right is the right to be present during the vote is held. Patient representatives cannot vote themselves. In the end the decision is made without them, but it happens in their presence, and that makes a difference. To put it in a metaphor: ‘If a family is quarrelling and fighting, as soon as a guest shows up, they behave differently’. In other words: a system changes if you add a completely new element. And patients as players in the system, that is something new.

Risks and side-effects

I think it is clear to everyone that money coming in triggers human behaviour of all kinds: envy, corruption etc. This is true for the patients’ representatives as well. Who are these persons who want to work on the committee? Is it the elite of self-help? Is it a certain type of personality? They are always subject to some sort of influence or even at risk of corruption.

Discussion on such questions culminated in the big pharmaceutical debate we had last year in Germany. To what extent are self-help groups influenced by the pharmaceutical industry? That is really meant to be a warning to everyone who has not yet been confronted with this danger. Some old-timers here in the room may remember that I already tackled the topic of pharmaceutical industry influence during our meeting in 1997 in Bruges. It has become ever more acute since.

And the future?

It is always difficult to make predictions about complex systems, such as our health system. But here is a very critical comment of a friend of mine: “Einbau gelungen – Selbsthilfe tot?”, i.e.: “integration completed – self-help dead?” The challenge will be to become a player within the system and at the same time to preserve the critical distance of an opposition, to organise powerful patient representation on national level and at the same time to offer personal encounter in groups on local level, to keep the precarious balance between political and psychological needs.
This closing lecture of the European Expert meeting 2007 in Leuven, Belgium was given as an impromptu speech, sometimes taking up subjects that were mentioned or discussed during earlier sessions of the meeting. It was given by a non-native speaker who apologizes for his limitations. Thanks go to Jozefien Godemont, colleague of our hosting team of Trefpunt Zelfhulp in Leuven, who took the trouble to transcribe the text from an audio tape, and to my friend Dick Wilson, Cambridge, who helped (more than a little) to touch it up stylistically. However, the sole responsibility for mistakes and unclear points, for possible risks and side-effects of the text remains with the author.
5 SUMMARY, CONCLUSIONS AND EVALUATION

5.1 Summary and conclusions

The exchange of knowledge and experiences surrounding the overall theme “Thinking outside the box: expanding the boundaries of self-help support in a changing society” were ample evidence for the liveliness of self-help support activities in the represented countries. Since dynamics always come with fields of tension, a considerable part of the expert meeting – perhaps not enough – was dedicated to discussion. In conclusion of this report we will try to sketch some of the ‘fault lines’ that came to the fore. They all boil down to the question whether self-help supporters ought to take a reactive or a pro-active stand.

5.1.1 Supporting self-help groups or self-help

The terminological confusion between self-help and self-help groups seems to be a recurrent problem on the European expert meetings. Some participants interpret self-help support in a broad sense and see it also as their task to actively disseminate the philosophy of self-help among a large audience. Others interpret self-help support in a narrower and more pragmatic sense; they focus on guiding self-help groups and providing them with the preconditions of their functioning.

How to adopt a middle course and avoid a ‘blurry’ description of support centres’ tasks?

5.1.2 Supporting face-to-face or online groups

The internet is going like a bomb. The same goes for the numerous internet applications in the self-help field and for self-help fora in particular. Whereas some participants reckon it is impossible not to take up the support for online self-help groups, others do not consider guiding these groups as their core-business. Prejudices abound: face-to-face groups set intransgressible thresholds for certain problem groups (e.g. persons with contact problems); the internet is a cold medium that recycles emotional problems but doesn’t solve them.

How then can the quality of online and offline groups be assured in a self-help field that is due to keep track with the internet revolution?

5.1.3 Supporting protoprofessionalised or autonomous self-help groups

Professionalisation is a key concept for every self-respecting organisation nowadays, self-help groups included. The meaning of this term is two-fold: approaching something in a professional way and calling in professionals. Self-help groups do both and these activities are highly intertwined. The participants’ opinions differed on the extent to which professionals ought to be involved in refining self-help groups’ skills. Some feared that professional input would restrict self-help groups’ autonomy or that professionals would appropriate the self-help method making groups redundant in the end.
5.1.4 Self-help groups as a tool against social exclusion or an asset for the happy few

Diversity has acquired a footing in today’s political and societal discourse. Although diversity is often equated with multiculturalism it also entails differences on the basis of age, sex, sexual orientation, socio-economic status, handicap and so on. The diversity issue doesn’t seem to have trickled down into the self-help field to the same extent yet. The participants to the meeting related diversity to the enlargement of the accessibility to self-help groups for certain vulnerable groups. Two rather opposed positions with regard to the diversity issue came to the fore. Some participants didn’t consider it self-help support centres’ task to pro-actively lower the thresholds to self-help groups for certain vulnerable groups; others saw self-help as an excellent tool to fight social exclusion.

How can self-help supporters become co-owners of the diversity concept and reach a consensus about the desirability and feasibility of the underlying principle?

5.2 Evaluation of the Ninth European Expert Meeting

The Ninth European Expert Meeting was evaluated in a very down-to-earth manner and resulted in some recommendations for the organisers of the next meeting. The participants passed comments on the practical organisation, the method of working, the contents, the participants and the follow-up of the meeting. We made an attempt to summarise all the remarks in a surveyable way.

Practical organisation

Participants were pleased with the solid organisation of the expert meeting both in the build-up to and during the event. Some remarked that the notification about the meeting’s date was too short-term. They presumed that this, rather than the event’s period (pre-holiday), might have put off some of the invitees.

Method of working

Plenary

This meeting’s organisers decided to have all lectures and workshops in plenary. The opinions on this method of working were divided. Some participants deemed the number of participants adequate to be exchanging ideas in plenary and appreciated the time-saving effect of not having to change working groups regularly. Others remarked that discussions in smaller groups could have proved to be useful to focus on specific issues that participants are dealing with in their everyday work.

Discussion

All participants agreed that there was too little time for discussion after the lectures. They suggested to plan fewer presentations and reserve more time for discussion.
The opinions on the way discussions were led, varied. Some participants regretted that there wasn’t scope to elaborate on themes flexibly. Others remarked that both discussion leaders and participants ought to focus more on the topics under scrutiny.

Suggestions
Some suggestions were made to develop other methods of working during the meetings:
- Panel discussions with representatives of different countries on well-delineated issues;
- Lectures followed by comments of referents;
- Presentations by professionals who aren’t active in the field of self-help support.

Contents
Participants observed that the meeting at times departed from the overall theme and as a result missed focus. One participant remarked that it might help to have a free discussion at the beginning of the meeting to set the focal points for the days to come.

Most of the lectures aroused interest, but some were judged as not being to the point or lacking new insights. Unfortunately the organisers don’t always have the luxury to select relevant presentations out of the limited number of contributions that is sent in. Therefore participants agreed that responsibility for the contents should be assumed by both organisers and participants.

Participants
Some participants would have liked more countries represented at the meeting. The organisers invited representatives from 18 countries out of which 12 accepted the invitation.

Follow-up
In order to prolong the exchange of ideas during the meeting the organisers promised to set up an e-mail contact list and to make the power point presentations of the meeting available on the closed page of Trefpunt’s website (www.zelfhulp.be).

Some participants wondered what had come about of the idea of an international website on self-help support that was launched at the previous expert meeting (2005) in Oslo. Jürgen Matzat informed the participants that a staff member of NAKOS, the Berlin centre, is working on the website (self-help group.eu). Since there is no extra funding for this initiative the interference by the webmaster will be necessarily kept very minimal. More concrete, it will be an interactive website on which you can place material or download material from. The website will be drawn up in two languages: English and German.

The participants agreed that it would be good if the organisers of the (next) expert meeting(s) would get some financial support. Different sponsor possibilities (WHO-Europe, the EU ...) were run through, but quickly dismissed for practical reasons (e.g. big workload for a highly uncertain outcome).

5.3 The Tenth European Expert Meeting

In two years NAKOS will be celebrating its jubilee. On behalf of the Berlin centre Jürgen Matzat invited all participants to Berlin in 2009 for the Tenth European Expert Meeting. The attendants gladly accepted his invitation.
6 ANNEXES

6.1 Mapping the self-help support field

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>Population (million)</th>
<th>Estimated number of shg</th>
<th>Comment</th>
<th>SUPPORT CENTRE</th>
<th>Number of collaborators (FTE’s)</th>
<th>Annual budget (Euros)</th>
<th>Geographical working area</th>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>8.5</td>
<td>1200</td>
<td></td>
<td>Arge Selbsthilfe Österreich</td>
<td>4 (3.75)</td>
<td>40,000</td>
<td>local</td>
<td>pure</td>
</tr>
<tr>
<td>Belgium</td>
<td>10</td>
<td>1250</td>
<td>local shg's included</td>
<td>Treftpunt Zelfhulp vzw</td>
<td>417,000</td>
<td>local regional</td>
<td>pure</td>
<td></td>
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<td>Germany</td>
<td>82</td>
<td>17,000 to 100,000</td>
<td></td>
<td>Kontaktstelle für Selbsthilfegruppen</td>
<td>3.5</td>
<td>40,000</td>
<td>local</td>
<td>pure</td>
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<tr>
<td>Greece</td>
<td>11</td>
<td>100</td>
<td>80%: 12-step groups for addiction</td>
<td>Self-Help Promoting Programme</td>
<td>3 (1)</td>
<td>150,000</td>
<td>mixed</td>
<td></td>
</tr>
<tr>
<td>Finland</td>
<td>5.7</td>
<td>250 to 1000</td>
<td>250 people were trained to activate shg's</td>
<td>The Citizen Forum</td>
<td>325,000</td>
<td>national</td>
<td>pure</td>
<td></td>
</tr>
<tr>
<td>Hungary</td>
<td>10</td>
<td>400 to 1000</td>
<td>in function for at least 1,5 year meetings</td>
<td>National Institute for Drug Prevention</td>
<td>3</td>
<td>national</td>
<td></td>
<td></td>
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<tr>
<td>Israel</td>
<td>6.5</td>
<td>400</td>
<td>A.A and N.A groups excluded</td>
<td>Israel Self-Help Centre</td>
<td>5 (3.5)</td>
<td>50,000</td>
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<td>pure</td>
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<tr>
<td>Italy</td>
<td>56</td>
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<td></td>
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<td></td>
<td>depends on the definition</td>
<td>Norsk selvhjelpsforum</td>
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<td>2,000,000</td>
<td>local</td>
<td>pure</td>
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<td>Sweden</td>
<td>9</td>
<td>5000 to 10000</td>
<td>great variety: non-profit, church, self-help centres</td>
<td>Fenix</td>
<td>430,000</td>
<td>Metropolitan Stockholm</td>
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</tr>
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<td>7</td>
<td>2000</td>
<td></td>
<td>KOSCH</td>
<td>3 (1.9)</td>
<td>260,000</td>
<td>national (umbrella organisation for regional centres)</td>
<td>pure</td>
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<td>UK (England)</td>
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<td>5000</td>
<td>blur in defining shg's</td>
<td>Self-Help Nottingham</td>
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<td>250,000 to 270,000</td>
<td>regional</td>
<td>pure</td>
</tr>
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<td>Country</td>
<td>Other Support Centres</td>
<td>Number of Collaborators</td>
<td>Estimated Total Budget of Other Support Centres (Euros)</td>
<td>Estimated Total Budget of Country (Euros)</td>
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<td>2 (0.5)</td>
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<td>243,000</td>
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<td></td>
</tr>
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<td>yes</td>
<td>1 national (NAKOS) 8 local/regional</td>
<td>1 - 2 (per local/regional)</td>
<td>1,000,000 (national) 30,000,000 to 50,000,000 (local/regional)</td>
<td>31,120,000 to 51,120,000</td>
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<td>Greece</td>
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<td>Finland</td>
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<td>Hungary</td>
<td>no, but apart from the National Institute for Drug Prevention there are other institutes where experts are aware of the importance of self-help groups and try to initiate and support such groups within their areas: the National Institute for Health Promotion and the National Institute for Social Policy and Work-related Human Problems</td>
<td>10</td>
<td>0</td>
<td>0</td>
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<td>Italy</td>
<td>yes</td>
<td>10 (2 per centre)</td>
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<td>500,000</td>
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<td>Sweden</td>
<td>yes</td>
<td>7</td>
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<tr>
<td>Switzerland</td>
<td>yes</td>
<td>20 to 30 (12 to 15)</td>
<td>1,140,000</td>
<td>1,400,000</td>
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<td>UK (England)</td>
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</tbody>
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