



12th European Expert Meeting on Self-Help Support

Florence, 19 - 22 June 2013

SELF-HELP AND INSTITUTIONS: *Projects and Experiences Among Different Countries*



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Introduction

The 12th European Expert Meeting on Self-Help and Support was organized in Florence by the Tuscan Coordination of Self-Help Groups “*Coordinamento Toscano Gruppi di Auto Aiuto*”. This association took part to this meeting for many years, representing the phenomenon of Italian self-help groups. Twenty-two participants coming from 10 countries (Germany, England, Norway, Israel, Finland, Netherland, Swiss, Austria, Greece, Belgium) joined the event in 2013.

The main topic discussed was the relationship between self-help groups and institutions in each countries. In particular, four thematic areas were examined:

1. The effectiveness and efficiency of self help groups.
2. The use of self-help method in the upcoming type of social malaise.
3. The effects and consequences of social-political-economic crisis on the development of self help-groups.
4. The analysis of self-help movement in the various countries participating in the meeting.

As has become the tradition at the European meeting, the participants were invited to visit one of the historical self-help organization in the host country. In this occasion participants visited the Alba Association of Pisa, one of the most active reality in Italy in the Mental Health field. It was opened as a traditional self-help centre but in the last few years it has promoted initiatives to form completely self-managed groups, run by fellows with mental health problems.

As happened in every meeting so far, the variety and the quality of contributions were very interesting. The exchange of opinions among countries where self-help is consolidated and those where is still evolving, was very interesting.

Thanks to the heterogeneity of the experiences presented by each participant, the European Meeting could become an occasion to identify best practices for the implementation of self-help groups, especially in countries where this methodology is not consolidated yet.

In this historical moment of crisis, when the cultural differences among the European country seem to increase; the European Expert Meeting of self-help is a suitable place for sharing, respect and understanding of diversity across nations.

The participation of new members has also enriched further the exchange and the acquaintance among participants.

At the end of four days of work, all participants elected Greece as the following country hosting the next meeting in 2015.

A sincere thanks to all speakers who participated at the meeting in Florence and a best wishes to our Greeks friends and colleagues!

Francesca Focardi

Coordinamento Toscano Gruppi di Auto Aiuto, Italy

CHAPTER 1

EFFECTIVENESS AND EFFICIENCY OF SELF HELP GROUPS

1.1 Why it is useful to invest in mutual self-help (*Carmen Rahm- Swiss*)

Thousands of men and women share regularly and on equal footing their experiences concerning the handling of health conditions or social strains. The parties involved consist usually of those directly concerned, such as patients, and their relatives or caregivers. An increasing number of persons nowadays organize in networks or share information via self-help initiatives on the Internet. Mutual self-help offers all of them the necessary space to find understanding of their problems, to widen their knowledge and to share it with others. “The ability to communicate among peers, to share experiences and to be understood gives self-help group members a sense of belonging that influences their expectation of self-efficacy considerably. Studies not only show the benefits for the individual group members but also indicate additional value for society and the economy as a whole”. This added social and economic value becomes evident on various levels, thus, justifying public investments in the establishment of structures that support self-help as recommended by the World Health Organization (WHO).

Mutual self-help supports health competence and social skills

Anybody confronted with a chronic illness, emotional or social strain will handle his or her problems better if he or she knows more about them. Specialized medical scientific knowledge can be acquired from books, the Internet, counseling or from meetings with the respective specialists. Health competence, however, is more than expert knowledge. This includes also social skills and self-competence in how to deal with ill health and social problems. Mutual self-help makes it possible to analyze own experiences and the experiences of others regarding the same problem. With the support of a self-help group, those involved can become experts themselves, particularly if it concerns for instance a rare disease or a disease not extensively researched yet. This applies also to those who suffer from addictions or who are mobbed at their workplace. With the support of mutual self-help, the effects of an illness or strain can be relieved and those involved will be able to cope better with everyday life and on the job. Competent patients will do their part to widen the knowledge about certain illnesses beyond the circle of those directly concerned. Consequently, their input will improve the treatment of such illnesses.

Mutual self-help relieves those involved

In self-help groups, participants mutually find solutions for better coping with everyday life on a hands-on and psychological level. Sometimes knowing that others have the same problem is a relief per se and sometimes talking to someone who understands your fears and pain. When communicating with others who have the same problems, self-help group members experience appreciation, care and other forms of social support that are missing in their everyday life and when dealing with experts. Never the less, it is this kind of social support they need more than anything else. In addition to coping better with their day-to-day life, self-help group members experience an increase in self-esteem, social contacts and activities and communication skills. All these factors are known to have relieving and health enhancing effects.

Mutual self-help relieves the social environment

Time and again, caregivers such as relatives, friends, neighbors or colleagues find themselves in

situations concerning a sick or mourning person that overstrain them. They would like to help, they feel responsible, but they cannot really see the problem from the care-needing person's perspective. This in turn puts stress on family and cordial relations. Self-help groups for those involved provide for the relief needed, they open doors for a more relaxed coexistence with others. Self-help groups for relatives can also contribute to deepening the knowledge and understanding of certain illnesses and behaviors. These groups also help caregivers to regain the necessary distance and to perceive their own needs.

Mutual self-help relieves the health care system

Mutual self-help is a factor in its own right of the health care system. It can be located somewhere between the professional medical care of the population on the one hand and the caring and supporting tasks ("care giving") within a family, the neighborhood and circle of friends on the other hand. Self-help groups also render an important service regarding prevention and health promotion. Members of self-help groups learn by themselves how to best change their health related behavior and how to improve the quality of their life despite health induced limitations. Hence, patients learn to cope with everyday life better when suffering from some mental illness (such as depression) while their relatives find relief of the strain on a family level. Patients suffering from chronic illness reduce their health related strains and actively contribute to avoiding consequential illnesses (such as diabetes). Competent patients need less care from professional health experts and, thus, contribute to the relief of the health care system.

Mutual self-help relieves the welfare state

Those burdened with health problems, social problems or living with a sick person run the risk of limiting their social contacts or even sever them entirely. Loneliness and isolation, however, are considerable health and socio-economic risk factors. Self-help groups create new social contacts. They are self-organized, which is why they promote the social skills and autonomy of their members. Thereby they render an important service in creating social networks and helping to break the negative spiral of illness, isolation and economic dependency. The health economist Anna Sax accurately describes the public benefits from investing in mutual self-help: *"An effective and wide infrastructure of self-help promotion produces efficiently and effectively the social capital which makes a society fit for the future. Self-help groups, in short, are educational institutions for health competence, they fight against social disintegration and poverty related problems as well as against the loss of social networks and personal isolation."*

Mutual self-help has potential

Mutual self-help does not appear out of the blue. It is the result of personal commitment and the will to take your life in your own hands. Self-help groups and self-help offers on the Internet are peer-to-peer systems and should remain that way. But, to unfold the positive effects detailed above, they need to be supported professionally with regard to coordination, distribution of knowledge, quality assurance and personal improvement. This needs a nationwide network of regional information offices where anyone can go who seeks a self-help offer or who wants to establish a self-help group. This needs an infrastructure, such as rooms, where all involved can meet. And finally, this needs a minimal expertise of conversational skills and group moderation. Once these prerequisites are met, a self-help group can unfold its full potential.

Mutual self-help needs appreciation and support

Supporting mutual self-help is an investment into the future of the health care system and the welfare state. The federal government and some cantons already recognized this and contribute to

the coordination and assistance of self-help groups. The Canton of Bern, for instance, supports the operation of four self-help information offices with well-known contributions within its canton area. It justifies this support as “rendering an important service to a modern and well-functioning health care and welfare system”. For a nationwide and comprehensive care, more resources and a programme for promoting self-help groups on a national level are needed. The Stiftung Selbsthilfe Schweiz (Self-help Switzerland Foundation) advocates that the achievements of mutual self-help are recognized in the political committees of the federal government and cantons and receives financial support accordingly.

1.2 Holland. More than just wooden shoes an example of self-experience *(Patricia Van Lierop – Netherlands)*

Maybe this time

Maybe this time, I'll be lucky

Maybe this time, I'll stay

Maybe this time

For the first time

I won't hurry away

I will hold it fast I'll be home at last

Not a loser anymore

Like the last time

And the time before

Everybody loves a winner

So nobody loved me; 'Lady Peaceful,' 'Lady Happy,' That's what I long to be

All the odds are in my favour

Something's bound to begin It's got to happen, happen sometime

Maybe this time I'll win

1.3 Effectiveness and efficiency of NOVAT- Self Help groups *(Helena Palovjarvi-Finland)*

NOVAT self-help programme

- An empowering one and half year programme in the field of early prevention of dependencies and addictions, easily reachable , closed group process . Any woman who feels a need to grow as a woman is welcome. The focus is group process in mutual aid peer group, weekly group meetings. The peer groups get support and counseling from personnel specially at the beginning and when groups have a need, but staff is not leading the groups.
- Self help group, common issues in programme not necessarily common individual problems at all.
- Have roots to AA and AA–critical movement, (Women for Sobriety) self help movement and empowering social work, but it is nowadays a Finnish model, started in Finland in mid nineties

Degrees of participating during one and half year

- The average degree of attendance in groups was 71 % in 2012 and 67 % in 2011.
- At the beginning some leave the group, but most who start also finish the program
- Later people leave mostly for the natural reasons (sick allowances, changes in work, moving to other place etc.)

Effectiveness assessment, client feedback (by Ph.D. Jaana Jaatinen)

- We (practitioners) wanted to know, what are the factors that make women to participate NOVAT- programme, what kind of women participate, how the NOVAT-programme works among women and how they use other treatment services?

Data in the research:

1) Inquiries for those, who had started group process (75 filled inquiries - 11 groups - 2005); 82 filled inquiries - 11 groups – 2006).

2) Thematic interviews (12 in 2005 for 7 different groups, 23 in 2006 for 11 different groups) for those who were advanced or had finished the process.

3) Written life stories of 9 NOVAT-women

- Questions (semi-open) that referred to life situation, life control, expectations to the NOVAT-program, the meaning of peer group, how they used other services - the researcher tried to get to the sources of woman's experiences.
- Qualitative content analysis and discourse analysis in two categories with different themes:
 - 1) The NOVAT-programme as a group method
 - 2) Experiences of NOVAT-women in NOVAT-groups

Effectiveness assessment, client feedback (by Ph.D. Jaana Jaatinen 2005)

- Profile of women participating NOVAT-programme: Age from 24 to 68 years, 60 % were married, third had children, women represented all professions, quarter of them were outside the work life.
- Relations to alcohol, drugs and other dependencies: Almost half of the participators told that they had suffered some kind of dependence and fifth of them had an alcohol addiction, third suffered from family members alcohol problem.
- Profile of service using: over 60 % hadn't 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 NOVAT, about 70 % had asked help from different places like doctors, occupational health care professionals, private Psychologists etc.
- Life situation when starting the NOVAT-process: Women still had control to basic things (careers and houses), but they had felt discontented and feelings of losing control of life. Many felt, that they were controlled by outer expectations. Feelings of alienation and anguish gave symptoms to women, but they had concealed those feelings inside and managed to organize their everyday life.

Effectiveness assessment, client feedback (by Ph.D. Jaana Jaatinen)

Women have very different problems compared to men. Traditional services and AA are not what these women want, because women's ways to look at their problems and their survival attempts differ from men.

- Reasons to participate: Women wanted to work with themselves, find something new in their life, grow spiritually and share their lives with other women.

- The programme is tailor-made for women. This was regarded very essential. Feeling to be accepted by group members and to be part of the group was also very important.
- NOVAT offers concrete support in everyday life situations, for example getting rid of emotionally or physically abusive relationship.

Effectiveness of the NOVAT-method:

1) Difficulties women have can lead to alcohol or other addictions. Women don't necessarily need traditional treatment institutions but space for sharing their feelings with other women in confidential atmosphere.

Effectiveness assessment, client feedback (by Ph.D. Jaana Jaatinen)

2) In NOVAT group women learn to identify their own needs and feelings and they begin to feel meaningful. Their self-esteem improves and they start to think positively

3) Women who had closed the NOVAT-process told, that with the help of NOVAT they had made outer (domestic or career related) and inner changes in their life circumstances

4) Critics: Those who had interrupted the process, criticised the lack of adequate support from the personal and the way group instructions are taught

5) NOVAT-programme functions as a preventative 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

6) NOVAT gives the frame to women to meet other women regularly. Confidentiality and sharing feelings in groups are the key elements of the programme and these can't be compensated by one or two-time interventions made by traditional professionals.

Also kind evaluation and assessment study about NOVAT - programme

- Helena Palojärvi, University of Helsinki, Department of Social Policy. Licentiate degree within the specialisation education programme in social work, special field: community social work. December 2009
- Peer support as a tool for group- oriented social work – how NOVAT groups help and support women who are not well (English language abstract about the study can be asked from Helena Palojärvi)

How NOVAT-groups help and support women who feel bad/ some results of the study made by Helena Palojärvi

- Combination of peer support and empowering social work is important
- There are no professional leaders in groups, only contact persons - Palojärvi 2010

Some effects on women's' live according to the study of Helena Palojärvi about NOVAT - programme

- Bad feelings are over and women feel empowered after the NOVAT-programme
- The women's relationship to their problems changed as they learned practical coping skills for everyday situations.
- These positive results were based on the fact that the women participated in defining their problems and solving them from the beginning to the end. This study shows that the combination of peer support and professional help can produce inclusion and feelings of empowerment. The extension of the subjective action space was reflected in the women's everyday decisions in many ways. Thanks to peer support the women felt they had become individuated and, because of this, they were able to make changes

Continuous NOVAT – self evaluation at Naistenkartano Ref

- Continuous self - evaluation/assessment for attenders in Novat-groups - questionnaires at the beginning and at the end of the NOVAT-group process
- The amount of attenders to groups have grown after 2005 study so that most attenders finish the programme
- Also self evaluation about virtual version (on internet 14 weeks NOVAT-course)

1.4 Effectiveness and efficiency of Self-Help groups (Peter Gielen- Belgium)

As part of a government funded research and educational programme to foster collaboration between self-help groups and professionals, *Trefpunt Zelfhulp* in 2010 undertook a review of international research literature on the effects of self-help groups. Research on the effects of self-help groups can serve to legitimize their existence. Documenting their positive effects will send a strong signal to authorities and professionals. This could lead to more acceptance, recognition and support. Of the countless publications on the effects of self-help groups, 35 were selected based on their methodology (longitudinal, comparative, process analytical and socio-ecological). A brief overview is presented on the effects found in different categories of groups (physical illness, addiction, coping & others), and on the effects on group leaders, family and society. Negative effects and what kind of groups enhances positive effects is also briefly presented.

The second part of the presentation is drawn from the results of an online questionnaire held in 2013. It focuses on how groups themselves perceive their effects and achievements, and on what hinders them to perform better or do different. These “hindrances” will serve as the roadmap for our support work on the midterm.

In closing, a glimpse on how the KU Leuven and others acknowledged the commitment of the Flemish self-help groups at the occasion of *Trefpunt Zelfhulp*'s 30th birthday, is presented.

1.5 Self-Help and mental health in Tuscany: connection with services and different meanings of effectiveness (Fausto Petrini- Italy)

The effectiveness of the self-help groups for mental health is one of the most controversial topic in the community psychology literature: although a little number of studies proves their efficacy (Brown, Shepherd, Davidson et al., 1999; Burti et al. 2005; Francescato, Tomai e Foddis, 2002; Pistrang, Barker & Humphreys, 2008; Wituk & Meissen, 2008), many issues about methodologies and research designs emerge (Kennedy, Humphreys & Borkman, 1994; Lieberman & Borman, 1976; Toro, 1990). Some of the authors in this field tried to work on the topic using qualitative methods, in order to enclose in the scientific perspective the subjective point of view about effectiveness (Beeble e Salem, 2009; Humphreys, 2000; Kloos, 2001; Leung & Arthur, 2004; Munn-Giddings e Borkman, 2005; Petrini et al., 2012; Pratt, Halliday e Mazwell, 2009; Randall e Salem, 2005; Salem, Reischl & Randall, 2008; Schutt e Rogers, 2009). An exploratory research has been conducted in Tuscany with a mixed methodology involving qualitative and quantitative approaches. The aims are: to describe the community model of develop of groups in this region and the network among groups and institutions; to describe the subjective perception of participants, facilitators and key actors about what are the determinants of effectiveness in their group; evaluate how the group's characteristics may influence the individual subjective and objective outcomes.

In the first qualitative step of the research we identified implicit models, objectives, perceived benefits, coordinator's role and the relations among the different social actors. This results shows

also the existence of two implicit theoretical approach to the self-help conceptualization, in many cases depending on the different role of formal clinical services in the organization group and on other organizational characteristics.

In the quantitative study we used scales about psycho-social characteristics of the participants (empowerment, psychological wellbeing, perceived social support, adjustment) and an ad hoc questionnaire in order to understand their link with the group. By means of a cluster analysis methodology we selected a number of basic and a-priori variables about the organization of the group that seems to strong affect its efficacy.

The study verified the possible existence of sub-categories of groups in the Tuscan context. Results show that participants *perceive* higher effectiveness in groups which meet in a formal context (hospitals, clinics, etc.) and are leaded by a coordinator not directly affected by the problem (usually a nurse or a professional), but this perception is not supported by objective and quantitative proves. The study represents a first step towards a more suitable definition of different kind of self-help groups, in order to identify best practices and understand the success indicators for next programs.

1.6 Research on Self-Help work in Norway (*Hilde Nokleberg- Norway*)

The research is a part of The National Plan for self-help. Research highlights and documents factors that are effective in the self-help work and may help to utilize and further develop the self-help work in various arenas. In Norway funds for research is managed in cooperation between Self-help Norway and The Norwegian Directorate of Health.

- Professionals often need to legitimize self-help by the use of research (Effectiveness)
- Research can make the *self-help concept* more known and accepted.
- Descriptions done by others are useful in the work with education and dissemination of knowledge about self-organized self-help.

Challenges

- «Effectiveness» vs research on self-help as a part of the development in society.
- To get the researchers to understand the structure of the self-help work, the history (development) and what self-organized self-help really means? (content).
- The results are often obvious for us, not new knowledge, the research finds what we already know... and research takes time.... but can be useful in regarding to arguments mentioned earlier – accept, legitimization.

Ongoing projects

The research projects are conducted by a cluster of researchers from different research centers.

1. Cooperation in the development of self-organized self-help work.
2. Self-help in mastery of chronic illness.
3. Experienced based vs. professional knowledge
4. Self-help in the local society
5. Effectiveness of participation in self-help groups

1.7 Enhancing 12-step self – help groups: Implications for adequate psychosocial interventions and the role of health practitioners (*Sotirid Lainas- Greece*)

During the last decades the field of addictions has been very concerned with the different ways in which 12-step self help / mutual aid groups could potentially be used. This is mostly due to the fact

that these groups provided very encouraging results in their work. Also, health professionals have contributed as much as possible to the potential utilization of these groups. This paper will briefly present the findings of a long term research (nine years). This research was designed in two stages. The first concerned the creation and evolution of a professional psychosocial intervention that supported members of 12-step self-help / mutual aid groups. The second stage concerned the evaluation of the intervention by the people who were directly involved, who were the members of 12-step self-help/mutual aid groups themselves. The structure and the involvement of this research was based on the action research principles, which were combined with the grounded theory methodology for the analysis of the collected data. The findings of this research propose a specific context within which professional psychosocial interventions that support the 12-step self-help / mutual aid groups can be designed. More specifically, these findings reveal the importance of designing interventions based on values that are common to those of the self-help groups. Furthermore, this paper argues that it is essential to deconstruct the traditional beliefs about the role of health professionals. Alternative scientific approaches regarding the interpretation and therapy of addiction are discussed. Finally, the human-centered characteristics in the context and process of psychosocial support of the members of the 12-step groups are at the center of the research findings.

CHAPTER 2

SELF-HELP AND NEW DISEASE: WHICH POSSIBILITY OF DEVELOPING

2.1 Holland. More than just wooden shoes. How smooth a new group can be founded (Kees Van Rest- Netherland)

I am Kees, I am a recovering addict.

Addiction to me, is a deadly chronic disease. I am oversensitive for the effect of alcohol and drugs. But especially my clumsiness in everyday things, makes that I, ever since 2003 till today, must maintain recovery.

After 2 years of the regular addictioncare, my recovery came to a dead end. But the 12-step-groups, like AA, Supportwork and The Kroon, save my life. The Kroon is what we talk about today; the foundation of selfhelp network in Eindhoven .

I am able now to lead a different way of life. I look at myself differently and I take full responsibility for my life.

It all started, of course, with quitting all alcohol and rugs.

I am going to tell you how easy it is to start an experience-expert self-helpgroup in Eindhoven.

2.2 Self-Help groups around the fringes of long term health conditions (Lara Marano – England)

Structured peer education programmes for people living with long term health conditions including mental health, cancer, diabetes etc have become increasingly popular as a tool to support people to self manage their condition. As the emphasis grows on patients and careers becoming more resilient and self reliant to reduce strain on the national health system, such programmes are being promoted as [art of the solution. In 2011, SHN undertook research in to the after effects of self management

programmes and uncovered that participants suffered from the 'what next' syndrome when the programme finished and the group no longer met. In an attempt to develop a new model for self management programmes, SHN has partnered with leading experts in the field to develop a model which integrates self help support groups, online support and peer mentoring to deliver longer acting benefits to structured education and to improve people's access to support and ongoing change of behaviours.

CHAPTER 3

SOCIAL-POLITICAL-ECONOMIC CRISIS AND SELF-HELP: THE EFFECTS AND CONSEQUENCES

3.1 Beyond Self-Help: social-political-economic crisis and solidarity (*Alexandros Georgiou – Greece*)

Self –help groups and movements arose because of the lack of sufficiency, if not the abuse in some cases, by the scientific and professional community, dealing with health and psycho-social problems. Focusing on mutual aid, humanistic values, self-orientation, common issues, fulfilling basic human needs, solidarity. A different example of support was formed (giving and receiving help by themselves), taking control and responsibility, and questioning the power and authority of the professionals. This is rather a political act. Has to do with direct democracy issues. The growth, the establishment and the prosperity of self-help groups (along with the stability concerning welfare, insurance) led at some point to the assimilation of a large part of self-help initiatives and the distortion of many structural elements regarding their function, philosophy and ideology. Social, economic, political crisis means the falling apart of social welfare state and the reduction of social rights. Lack of access to health services, insurance, education, labor. This social condition bring us to a point to reconsider the basic values, functions ideas of self-help, to keep things simple . Being political and active is supportive. So, what we do is try to focus on common issues and the common ground of people dealing with problems and being excluded, to create solidarity interventions.

3.2 Framework and structures for self- help in time of crisis. A report in the current development in Austria (*Gamsjäger Renate – Austria*)

There are approximately 1.700 self help groups and organizations with 250.000 members. Generally this number is increasing. We notice a tendency to increasing percipience, appreciation and inclusion of self help organizations in our health care system.

- a) **Federal level.** On the federal level the ARGE Self Help Austria, a national work study group, formed in 2000 by the self help support organizations of the federal countries, strengthened its position by becoming an association in 2009. In November 2011 there was the first formation and in 2012 the ARGE started to establish a federal office in Vienna.

The main duties of the ARGE on the federal level are:

- mouthpiece and point of contact for self help organisations
- networking and cooperation(s)
- quality development and quality management

- minimum standards for relevant national wide active self help organizations.

Prime concern of the ARGE is to consolidate self help by an own federal statute. In 2010 the ARGE organized a conference with representatives of the Federal Ministry of Health Affairs and Federal Ministry of Social Affairs and of the Main Association of Social Insurances. As a result of this meeting developed a catalogue of general criteria as a precondition of the statutory consolidation. Therefore the ARGE presented a “Declaration of Positions” to describe the suggestions and expectations concerning the statutory consolidation of self help. The main aim is a public financing base of the self help organization on the federal level and as a second step that one of the relevant national wide active self help organizations.

b) Federal countries. The federal countries have a strong competence in social affairs and health care matters. Local relevant self help groups and self help support institutions have very different conditions and requirements in different federal countries. Generally all self help support institutions operate on a basement of professional-standards for self help support, published by the ARGE. The range of services differs according to the personal, structural and financial framework. Some best practice examples of framework for relevant regional active Self help group:

1. Self Help friendly Hospital
2. Support of secondary and tertiary prevention in self help groups
3. Patient representation and advocacy.

3.3 The rising importance of self care support and the growth of Self-Help groups in the UK (*Sarah Collins- England*)

Challenges to the health and social care economy in the UK have led to a range of policy shifts which aim to place patients at the heart of services and reduce costs to secondary care. This requires a cultural and structural shift within the health service and amongst our population to embrace self care and self management of long term conditions to reduce the stress of an aging population on our health care system. Self Help Nottingham has been working with government and other partners to shape the role of self help groups and the broader self care support sector in improving outcomes for patients and promoting self care.

CHAPTER 4

WHAT IS NEW IN YOUR COUNTRY?

4.1 New name and Self-Help by internet (*Carmen Rahm- Swiss*)

New name, new position, new strategy, new projects

Three columns:

- Consolidation and refreshment
- Promoting of the networking and cooperation based on partnership
- Community Self-Help and internet based self help

Based on:

- transparency and exchange

- networking and grouping

Consolidation and refreshment:

- Conferences for the staff and for the counsels of the self-help centres
- Seat in the counsel of the foundation
- Common projects with Self-Help Centres (national project for courses and workshops for members of self-help-groups, initiating a project for peer-support)
- Promoting for development of new centres
- Initiating a study national as a promotion measure and indications measure
- Communication concept (including Social Media)
- Newsletter, Intranet
- Last but not least: Fundraising, negotiations....

Promoting of the networking and cooperation based on partnership:

- Sensitization about “community self-help”
- Initiating and converting Table Rondes (for German speaking and an others for the French/ Italian speaking)
- Built up cooperation groups with representatives of Self-Help Organizations > Online Survey about the attitude and care of community self-help > national conference next year

Community health and internet based self- help

- New Website
- Option to search on your own the group you need
- Communication concept
- Promoting of rooms for chat, social media with covering the offers of other players
- Own room for chat, specialized for self-help (e.g. NAKOS)

4.2 Holland. More than just wooden shoes. Proudly presenting new ways of peer contact (*Wim Venhius- Netherland*)

Self-aid in Holland is developing, with the energy of a new generation self-help people!

The Dutch situation is one of a social society. On the principle of solidarity every citizen is insured for his healthcare.

Self-help groups are existing of course everywhere in the Netherlands. But only in the south of the Netherlands they are organised in networks so they can easy be found. In Eindhoven, you find the *Zelfhulp Netwerk* (Network of Self-help) which is founded almost 30 years ago, by you maybe know her, Joke de Haas, our Dutch ‘mother of self-help. She did a fabulous job, starting with two groups meeting in a bedroom, nowadays more than 50 subjects and 3-4000 ‘members’(participants), a wide network with all health organisations in the region and 5 locations in the south of Brabant. It is a volunteer-organisation.

What is so special on this self-help people?

New is: Growth (of self-help)

Like most of our countries the economic situation in the Netherlands is also painful.

Together with an ageing population and fast increasing care-costs there is a growing interest in self-help. The government chooses to bring the responsibility of care back to the individual. Each person is owner of his own problem or illness and the care professional will help him to explore the

possibilities.

New is: the project ‘immigrants on their path to self-help’

Although we have a multicultural society, the amount of immigrants participating in self-help groups is remaining far behind.

New is: a nationwide foundation

To spread ‘the word of self-help’ all over the country this year started a new foundation: Selfhelp Netherland.

New is: a short education film

Last year we produced a small film to explain the meaning of self-help in 20 minutes.

New is: Intensive education of primary health care

Primary health care in Holland means the general practitioner, nurse practitioner and welfare workers. They are the first people to be trusted when someone is first confronted with a problem or illness. Especially they should know what self-help can do. But during a pilot 3 years ago it showed that only 2 % of the professionals knew about self-help. Or where to find it. So that was the reason to start a project of 2 years to educate the primary health care of the southern region Brabant.

New is: Innovation

Eindhoven – we have many slogans! We want to develop new quality tools but everything starts with communication. We are finally starting up a newsletter.

New is: and the most important, are the new groups

In the last 2 years the amount of groups grew from 30 different subjects until 57 now. (totally 102 groups – 18 x AA)

That’s our greatest NEW success!

4.3 Peer support and professional work in Finland (*Irja Mikkonen- Finland*)

Over recent years peer support has become an essential aspect of well-being and it has been recognized as a suitable method of support in various situations of life. The connection between support and professional work is significant. Using peer support as a method of support has become more popular and it has extended from the traditional support for those with long-term illnesses to other situations of life. Another important factor is the professionals’ experiences on peer support. In recent years research and theses on peer support in social-and healthcare have emphasized the functions between peer support and professional support or the significance of peer support compared to professional support. Also the professional, especially public sector social-and healthcare functions have been combined. Perhaps this has increased the healthcare professionals’ knowledge on peer support. The research and theses have also examined the significance of peer support as rehabilitating, as a part of the pathway, as a communicator and as an empowerment.

4.4 Self-Help meets evidence based medicine. On self-Helpers involvement in clinical guidelines (*Jürgen Matzat- Germany*)

This presentation deals with the participation of self-helpers – here in the role of patient representatives – in the development of clinical practice guidelines in Germany. Key technical terms like “evidence based medicine” and “guideline development” are introduced. The historic path which lead to this involvement is outlined: the development of Germany’s self-help movement, it’s recognition by the government, the substantial support by statutory health insurance funds, patient

participation in the “Federal Joint Committee” (the paramount decision making body in Germany’s health system), and now the participation in guideline development. Relevant qualifications of patient representatives in guideline committees are discussed. And finally some of the author’s personal experiences will be shared, using the example of a guideline on “unipolar depression”. While face-to-face group work on local level still is the basis of collective self-help, some patients have left this setting, went out to the public, joined various committees, and some met evidence based medicine.

4.5 Develop self help centres in peripheral areas in Israel (*Anat Moshe- Israel*)

This talk is about the establishment of local independent Self Help centers in Israel. Pilot project of Self Help, lead by "etza" in cooperation with the Ministry of Social Affairs and the local municipalities. The project aims to assure a future and wider use of Self Help in Israel. Its goals are to develop accessible and effective municipal centers, to pass on responsibility to citizens, professionals and elected officials. Each center is designed according to each city's population and their specific needs. The centers will encourage local initiatives and provide consultation, training and hot house services. These measures are meant to guarantee the continuity of this project on a national basis in Israel. Additional goals are the creation of a national forum comprising all the local Self Help centers, to increase the number of Self Help groups/organizations in Israel, and to create local roof bodies of the groups/organizations that function in the city. The approach to this project is systemic, which means that it encourages the cooperation of departments in the municipality, in the social services and in the community at large. Some of the actual steps that will be taken are training of a local team in the principles and practices of Self Help, giving lectures to various groups in the community and training courses for leaders of S.H groups.

4.6 New experience on Self-Help work in Norway (*Godager Eli Vogt- Norway*)

The presentation will focus on the work done in the period from 2006 (establishing a national resource center for self-help) up till today.

1. Development in self-help field over the years
2. Today’s status and how we got there

Important tools:

- Support in public documents and plans
- Public information actions
- Good strategies
- Documentation
- Dedicated workers with solid knowledge
- Extroverted activity and attitude

4.7 Young self help in South Tyrol presentation of the project (*Irene Gibitz- Italy*)

In the, at the present, existing self help-groups, people aged between 18 and 30 hardly are represented, even 30 to 40 year old people are underrepresented. Although there would be a lot of reasons for young people to organize themselves in self help-groups. This statement made us reflect about what steps could be taken to promote young self help. 2011, inspired by the German project

(NAKOS), our agency for social welfare – in particular the day center for self help-groups – started the project JOIN-LIFE. The concept JOIN-LIFE, for the promotion of young self help, is supported by 5 pillars: sensibilization and public relation, qualification and formation, foundation of self help-groups for young adults, the build up of virtual self help/social media and finally the networking with multipliers and “*Dranbleiber*”/helpers. In the presentation of the project JOIN-LIFE we will explain which general frame conditions have to be taken account of, how to sensibilize young people, how to get to them and what settings could be attractive for them. Young self-help does not happen by itself. The day center and the professional services have therefore to stay at it, the approach has to be activating, searching and initiating. Therefore you have to invest a lot of energy. Besides, for a small day center like ours, you have to deal with the available resources. To be motivated to participate at the self help-groups, young people need an appropriate setting: weekend or evening meetings, meetings in block (time) or in attractive places. It is also important to find the appropriate setting: the classic setting of “talking” self help-groups. The classic setting, nowadays, is often substituted by informative-groups or groups chaperoned at the start, training groups, group of regulars, leisure groups and virtual self help-groups. All these different group settings can be arranged in a variety of mixed settings, knowing that, young people, generally, are attracted by new things.

4.8 Developing independent Self-Help groups for people in recovery from drugs and alcohol addiction (*Miriam Walther – England*)

Independent self help groups of people affected by drug and alcohol abuse are not new, however they have often operated under the radar of treatment providers and have often emerged in response to a dissatisfaction with the 12 step model of support. In the UK, a new peer led support model, SMART Recovery has started to emerge as a new and generic addition to the recovery environment. Self Help Nottingham has been working with independent groups, 12 step and SMART recovery groups to develop the Recovery Network which for the first time brings together diverse methodologies, philosophies and style of groups to add richness to the support on offer to people in recovery.

4.9 NAKOS focus on Young Self-Help. How to support it? An overview of Nakos work on a new challenge (*Miriam Walther, Germany*)

In 2009 NAKOS started its work on self-help engagement of young people. With funding from the German Federal Ministry for Families, Seniors, Women and Youth NAKOS did research on the role of young people in the work of self-help associations and clearing houses, conditions of young people’s engagement and existing programs and strategies. Other elements were a workshop, a brochure for clearing house professionals, and the development of informational materials (postcards, posters, website: www.schon-mal-an-selbsthilfegruppen-gedacht.de („have you ever thought of self-help groups“). Since 2010 NAKOS deepened its work in two ways: Informing young people on self-help (website, Facebook and Twitter, sticker, bookmark) and supporting young peoples’ engagement in self-help groups (in part in cooperation with three regional clearing houses). The presentation will show examples of NAKOS work and give an overview of the lessons learned.



The dinner organized by Alba Association in Pisa, Tuscany



Visit to the “Miracles Square”, Pisa, Tuscany