



Review Article

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Self – Help Groups and the Greek Paradigm of the Hellenic Observatory for Rights in the Field of Mental Health

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Abstract

Self- Help Groups (SHG) surfaced out of the dissatisfaction with the existing health care system (Katz & Bender, 1976). However, their increase in ontogenesis and their ratio nowadays can mostly be justified due to the social, cultural and political climate as a result of the social and political eruption of the 1960s (Levy,2000). In the present paper a short introduction and a brief history of SHG are given. Then a presentation follows of the Hellenic Observatory for Rights in the Field of Mental Health is given with the principles, goals, and actions of the group.

Introduction

Self-help groups have been around since the dawn of humanity in different forms, starting with the form of group shamanism, which is a form which predates specialised shamanism, followed by secret brotherhoods of the sick and guilds in the Middle Ages (Moeller,1999). The current form of self-help groups appeared first in USA in the midst of the economic crisis of 1935 and was the prototype for the several self-help groups that followed (Moeller,1999).

The World Health Organization (WHO), self-help mentions to typical (formal) or atypical (informal) configured groups, with a purpose for new answers for problem management, citizen autonomy, and humanitarianism in healthcare delivery (Flora, Raftopoulos, & Pontikes, 2010).

In 1976 Katz and Bender defined self-help groups (SHG) as small, self-imposed assemblies for the mutual aid and opus of a particular end. SHG are a homogeneous group of people, who meet to offer aid to a mutual need, as well as the encounter of a common set of problems that endanger the participants' well being and to facilitate a social and/or personal lasting change. It is believed that the need of the group can not be met by existing social structures. These groups underline the communication among members as well as personal accountability. Usually they provide well being strategies and emotional support (Flora, Raftopoulos, & Pontikes, 2010). The participants are oriented to the root of the difficulty, and at the same time to an explanatory system of philosophical understanding is purported to assist in the process of gaining awareness of their personal identity (Kickbusch & Hatch, 1983).

SHGs have been distinguished in three types based on different motives, goals and actions. The first one are the Insider-only, with uniformity in problem-type, motives and goals (e.g., AA; NA; diabetics). Then there are Groups which cooperate with interested individuals highly sensitive to the cause and inclined to volunteer their expertise. Last there are also Mixed groups with the involvement of professionals, insiders, and individuals sensitive to the cause (Flora, Raftopoulos, & Pontikes, 2010). According to Bairaktaris (1994) it's a very well organised and functioning endeavour of hetero and self help, whereas the therapist retains the entire managements.

Brief History of European Self-help Groups

Our journey in Europe starts around 1956 in Germany. Until 1975 SHGs were not noticed by the professionals and were deemed as patients in an outrage. In the end of 1976 scientists in the North West of Europe became aware of self-help groups as sub-culture ranging from people watching their weights to phobias as a way to find assistance from each other in attempt to overcome the stagnant welfare society with a failing system (Barath, 1991). Then, from 1976 to 1981 experts started to find interest in the utilisation of SHGs which resulted in the Health Conventions of 1981 in Germany and it was found that cooperation among experts and SHG can be beneficial and even necessary. From 1981

to 1984 SHG in Germany had been widely accepted and followed by a period after 1984 where SHGs were funded by the government (Moeller,1999).

Buda (1990 as cited in Barath,1991) has presented that some self-help groups surfaced impromptu in socialist countries during the 1980s. 'Groups are initiated either by active individuals with skills and experience in community development and leadership, e.g. by physicians or other professionals devoted to matters of general social welfare' (Buda,1990 as cited in Barath, 1991). An estimation coming from Hungary suggests that there were an estimated 300 self-help groups with 5000 active members. Additionally, the state had also 200 mutual and support groups, which also had 5000 members between them (Lantos, 1989; Zabardine-Antal, 1987 as cited in Barath, 1991). "In Europe the 'Self-help has not (yet) acquired clear and definite symbolic significance in society. It is, as it were, an empty expression to which all kinds of meaning can be attributed. At the same time, however, it serves as a mark of identification, a flag under which many ships aspire to sail' (Harberden and Lafaille, 1979 as cited in Barath, 1991).

The Greek Paradigm—Hellenic Observatory for Rights In The Field Of Mental Health

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The Observatory for Rights in the Field of Mental Health was founded in 2006 with the purpose of defending the rights of persons implicated in the mental health service system and promoting alternative, non-psychiatric ways of managing distress. It is a network of persons involved in the mental health system, that is to say users of psychosocial services, relatives, mental health professionals and employees, and is open to anyone who shares its philosophy and aims. The Observatory is based in Thessaloniki, Greece, but it accepts demands and complaints at a national level, and organises relevant actions, usually in collaboration with other organisations (Emmanoulidou, 2007 in Lehman, P., Stastny, P., Emmanoulidou, Alternatives Beyond Psychiatry, p281-289).

Moreover, the Observatory for Rights in the Field of Mental Health functions with a horizontal with out any for of hierarchy whereas every member is treated with respect and equality as a partner without any form of discrimination and the decisions of the General Assembly are taken not by majority vote but with consese More importantly, it should be noted that more than 50% of the members of the General Assembly are individuals with some sort of psychiatric, psychotic, or unusual experience in their lives. Furthermore, the Observatory for Rights in the Field of Mental Health tries to respond immediately to new needs of its members as they arise and takes action in order to create new groups or actions to achieve these needs.

Principles

While in the last few years legislation has been introduced in Greece with the declared intention of protecting persons with mental health problems from acts of violence and abuse, this has not been achieved in practice. Mental distress and experiences which deviate from the “norm” are attributed to a specific form of illness which, unlike other illnesses, is considered beyond the mental control of its bearer. Consequently, the management of this illness is assigned by the state to systems of social control and suppression, which are incompatible with notions of illness and treatment. This practice, based on the reproduction of the relevant mentality by mental health professionals and the ignorance and fear of the public, leads to mental distress being treated as something akin to an offense, for which the sufferer is punished through discrediting their speech, personality, capacities, wishes, dreams, personal and social rights and control over their own life (Emmanoulidou, 2007 in Lehman, P., Stastny, P., Emmanoulidou, *Alternatives Beyond Psychiatry*, p281-289).

The Main Principles underscoring the Initiatives are:

- The concept of personal and social rights of citizens, whether they become at some point of their lives users of psychosocial services or not, is valid over and above scientific or other interpretative theories, and this cannot be subject to negotiation
- The violation of these rights constitutes violence, personal and social, against the persons whose rights are violated
- The existing mental health system is largely structured in a way that produces and reproduces such forms of violence, primarily through the political and existential discrediting of its users, but also through specific daily practices, both in closed institutions and in the community
- This context of supporting violence affects inevitably, albeit in different ways, not only the users of services, but also their families as well as the employees in the respective institutions, when they are forced by their work context to violate the rights of other persons who find themselves in life crises. In this sense, society as a whole is also affected, since it maintains institutionalised practices of violence, ignorance and exclusion of its weakest members. We contend that this directly offends the ethics and culture of society as a whole
- As informed and concerned citizens, who do not wish to remain observers of this situation, exorcizing the evil and hoping that this will “always concern someone else”.

Aims

- To begin a public discussion concerning the social management of mental distress.
- To change the prevalent view regarding mental health and the so-called mental disorders.
- To inform the public on matters of the rights of users of mental health services and of workers within them.
- To resist the logic of institutionalization, social exclusion, exercise of any form of violence and violation of human rights in the field of mental health.
- To contribute to the development of alternative forms of the social management of mental distress.
- To defend and expand the rights of persons in distress both in and out of the mental health service system.
- To promote the participation of users of psychosocial services in all levels of decision making that concern their lives.
- To promote the view that the family members of persons in distress are individuals directly concerned with matters of mental distress, deserving equal attention, support and inclusion of their views along with the rest of parties involved.

Actions

Information gathering regarding violations of rights: Information is gathered concerning (a) incidences of abuse of inpatients in public and private mental health facilities, (b) cases of violation of rights of users or ex-users of mental health services, of their relatives, as well as of workers in this field (c) incidents and concerns regarding ethical issues, and (d) gaps in the mental health service system. On the basis of the demands or complaints it receives, the Observatory acts either collectively, through initiating formal complaint procedures, or individually, through supporting the persons concerned in defending their rights. The prerequisite for undertaking action of any kind is the concerned individual's consent, active participation and joint shaping of decisions at every stage of the management of information.

Complaint regarding violations of rights in private psychiatric facilities: In April 2008, on the basis of complaints by interested persons, the Observatory sent a written complaint concerning the "Violation of human rights in private psychiatric facilities" to the Committee for the Protection of Rights of Persons with Mental Disorders of the Greek Ministry of Health and Social Solidarity, demanding the investigation and restitution of the incidences and conditions reported therein. The Committee conducted an

investigation and made recommendations to the facilities concerned. However, according to information the Observatory has obtained from persons hospitalised in the facilities concerned, nothing has changed to the present with regard to the issues that the Observatory had raised. We are continuing to apply pressure to the Ministry and we have initiated a media campaign on the matter.

Supporting individual persons in defending their rights: In cases of persons contacting the Observatory with complaints regarding violations of their rights during their involvement with mental health services or expressing intention to exercise their rights, the Observatory supports the persons concerned through **(a)** informing them on their rights and on legal ways of defending them **(b)** referring them to law or other professionals who can initiate legal actions on their behalf.

Operating a Public Information Office in the Psychiatric Hospital of Thessaloniki: Volunteer members of the Observatory work in the Public Information Office that the Thessaloniki Parents' Association for Mental Health operates in the grounds of the Psychiatric Hospital of Thessaloniki, informing hospitalised persons, their families and other persons concerned on their rights and supporting them in any relevant action they wish to undertake.

Promoting the psychiatric will: The psychiatric will is used in many countries as a way of safeguarding a person's self-determination during their compulsory admission to psychiatric facilities. This document, which is signed in the presence of a notary or lawyer, contains the person's decisions regarding what they allow and what they forbid to be exercised on their body and mind in the course of a prospective compulsory or voluntary psychiatric hospitalisation, according to their constitutional rights to individual freedom and self-determination. The person concerned can also name specific persons as legal representatives, who take on the responsibility to ensure, using all legal means, that the person's expressed will is respected in case of compulsory or voluntary hospitalisation in a psychiatric unit. The Observatory supports anyone who wishes to compose a psychiatric will through **(a)** providing relevant information, **(b)** providing a template of a psychiatric will in its website, and **(c)** referral to law professionals.

Support network for persons wishing to stop psychotropic medication: Members of the Network can be mental health professionals and persons with psychiatric experience wishing to support other persons in gradually reducing psychotropic drugs and the restitution or maintenance of their mental health without chemical means. The Network does not encourage anyone to discontinue psychotropic medication, but aims to support those who have already made the decision to do so, so that they achieve this through minimising, to the extent possible, the possible dangers to their health from a sudden and uninformed discontinuation.

Hellenic Hearing Voices Network: The Hellenic Hearing Voices Network has operated at national level since 2010 and is part of the international network of hearing voices, Intervoice. The part of the Network that functions in Thessaloniki operates under the auspices of the Observatory. There is a self-help/support group of persons who hear voices and/or have unusual beliefs in Thessaloniki. We also organise events and collect and translate materials regarding the specific approach to voices and unusual beliefs, which is available in the Observatory website and is forwarded to interested persons. Finally, we are planning training in individual support of persons who hear voices and/or have paranoid ideas, so that such support can be given to whoever requests it.

Providing support for setting up and running self help groups: There is already a self-help group for persons who hear voices and/or have unusual beliefs, supported by the Observatory, as part of the Hearing Voices Network. The Observatory can support the setting up and running of self-help groups through (a) providing information regarding self help (b) providing a space and infrastructure for the functioning of the group.

Promoting alternative ways of managing mental distress: With an aim to promote freedom of choice, which is fundamental to the exercise of rights of users of psychiatric services, the Observatory seeks and promotes alternative modes of managing distress through (a) producing and translating relevant information, which is made available via the Observatory website, (b) organising lectures, seminars and other public events (c) seeking, promoting and publicising existing alternative practices in Greece.

Training in the accompaniment of Individuals in Crisis: With the aim to train professionals and experts by experience in supporting individuals during a psychic crisis in their lives. Regular 2 years curriculum trainings takes place for a theoretical knowledge and practical advices in order to comfort and assist the person with their crisis and assist their families with the out-most respect.

Team for the Accompaniment of Individuals in Crisis: A team of trained experts which aims to relieve the individual in crisis with carefully selected adjustments in their own environment and fully support them in their daily needs with respect and compassion in order to avoid a psychiatric hospitalisation and the violence, which may happen there

Training for individuals who want to Reduce or Quit Psychiatric Drugs: With the aim to assist and train individuals and their families to reduce or quit psychiatric drugs the training offers theoretical knowledge of the drugs and the substances used, their effects, side effects and ways to reduce the dosage and even quit permanently by experts on the field of psychopharmacology in order to avoid prompt and dangerous quit of psychopharmaka.

Self-Help Groups

Grief and Sadness Self-Help Group, Monday 19:30-21:00

With the aim to assist members to deal with sadness, sorrow, vanity, and pessimism, experienced at some point in life. Negative emotions are also a sign that something in his life is wrong. There are numerous individuals in this city who feel or have felt this emptiness, and have seen their lives leave them. The goal of the group is to allow individuals to discuss their situation. The Self Help Group of people who have experienced or are experiencing sadness, melancholy, depression, bipolar disorder, etc. and would hear you without judging you. The "Free Fall" Self-Help Team "takes off" for free every week.

Self-help Group of People Who Hear Voices Tuesday 19:30-21:00

People who hear voices and / or have unusual ideas or beliefs have an experience that is not like that of many of their fellow human beings. This difference often leads them to isolation in a way that makes it difficult for them in their daily lives and creativity. They are usually treated psychiatrically with disastrous results for their lives: psychiatric incarceration, involuntary pharmacotherapy, social exclusion. An alternative is self-help groups. There they meet people with similar experiences "without masks" and chat with others who have been "there", at the point of "other experience". Self-help groups are not a cure, but a place where one can be listened to and receive encouragement, confirmation and support. Someone comes out of the isolation they may be experiencing. (S)He shares his fears, worries and effective ways of managing his experiences. (S)He realizes how different everyone's experiences are, but also that many emotions and issues are common. (S)He has the opportunity to support others, but also to receive support himself. A negative attitude toward life is neutralized, which is a frequent consequence of voices and paranoid ideas.

Dealing with voices and paranoid ideas can be a long and difficult process, but the goal of a group is to know that you're not fighting alone.

Self-help Group for Individuals with Psychiatric Experience, Tuesday (online) 19:00-21:00

Former users of Psychiatric care meet in order to offer assistance to each other through sharing their experiences without the presence of a specialist. In a safe environment of acceptance and equality, the members of the group bravely speak out and break free from isolation. With respect and solidarity, they take active responsibility for themselves in a collective.

Self-Help Group Seminar on Psychosis, Wednesday (in person) & Thursday (online) 19: 30-21: 30

The purpose of the Seminar on Psychosis is to create a dialogue between people with direct experiential experience, people with indirect experiential experience, and mental health professionals. The exchange of experiential experiences, well-being strategies, the empowerment of the participants as well as the expression and sharing of experience are key features of the seminar.

The On Psychosis seminar is an informal group of people who come together to deal with their common problems. While the seminar may mean focusing on the individual, an important feature of the team is the idea of mutual support. The seminar can serve many different purposes depending on the situation and the need.

Members provide emotional support to each other. The belief behind the team is that the shared experience of team members is extremely valuable in promoting understanding and healing.

Joining the team can have some direct and indirect benefits in quality of life and in reducing symptoms. Attending the seminar can also be effective in strengthening social networks that provide social support.

- Each person can contribute to the team
- Each person decides which activities and tips will work for their individual needs
- The team facilitates open and honest communication in a non-critical environment

In general, each person speaks based on their experience, how it makes sense, how they manage it. The ultimate goal is to seek solutions to personal problems by sharing the stories of people who have faced or are facing similar difficulties in order to activate and build a network of solidarity. The team provides support not treatment. The attendance is free.

Cinema Team, every second Friday.

The film team started in 2017 based on the principles and philosophy of the self-help groups that have been operating at the Observatory for many years. The films selected for screening have themes related to the mental experience and mental pain of people of any kind. Their peculiarity, however, is that they record a different perspective, a "different look", a different look at diversity, which is always the cause and catalyst of the reflection of the team that follows each screening.

In the film group at the Observatory we say that.... we watch movies about souls... that speak to our souls and after the screening, in reflection, we share their gifts.

Reading Group once a week: on texts which are chosen or are written by the members themselves, with the goal to share, stimulate and discuss their thoughts and experiences. Started at 2022

Self-education group: In this group the members study and discuss important texts on alternatives to institutional psychiatry as well as philosophical text, since 2017, with the goal to create a common ideological basis for the actions of the Observatory.

It is important to mention that all these groups were made by persons with psychiatric experience and not by proposals of professionals.

Discussion

In the sections above we described briefly the origin and the definition of Self-help Groups (SHG) in Central Europe and some of the phases in their evolution. Afterwards, we gave a presentation of the HELLENIC OBSERVATORY FOR RIGHTS IN THE FIELD OF MENTAL HEALTH, founded in 2006 with the purpose of defending the rights of persons implicated in the mental health service system and promoting alternative, non-psychiatric ways of managing distress, based in Thessaloniki, Greece (Emmanouilidou, 2007 in Lehman, P., Stastny, P., Emmanouilidou, *Alternatives Beyond Psychiatry*, p281-289). Also, it functions with a horizontal without any form of hierarchy whereas every member is treated with respect and equality as a partner without any form of discrimination and the decisions of the General Assembly are taken not by majority vote but with consensus. More importantly, it should be noted that more than 50% of the members of the General Assembly are individuals with some sort of psychiatric, psychotic, or unusual experience in their lives.

On the other hand is the psychiatric experience that is proposed and followed around the western world. The centre of the interactions between psychiatrists and directly interested parties is the exploration of symptomatology to define a diagnosis and the pharmacotherapy to be prescribed. It is easily understood that through this kind of interaction there can not be a common ground that places the patient and the doctor as equals, with a relationship that can be synergetic and equal (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, *Alternatives Beyond Psychiatry*, p305-326). Rather it gives the doctor absolute power and turns the scales of obedience and control to her. Moreover, it places the focus of the therapy in obedience by the patients in order to facilitate the devouring of prescribed medication. Thus, psychotherapy is diminished and becomes psycho-education and loses its liberating and therapeutic effect (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, *Alternatives Beyond Psychiatry*, p305-326). Psycho-educations have as a primary goal to transform the directly interested individuals and their families into experts on the mental disorder, the disease or handicaps, but what it actually accomplishes is to internalise the biological models and the associated theories, proposed by doctors and pharmaceutical companies (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, *Alternatives*

Beyond Psychiatry, p305-326). Furthermore, another part of the psychiatric experience is the involuntary hospitalisation of the individual and poses one of the biggest problems of psychiatry. The traumatic experience of the forceful institutionalisation of the individual can be extremely traumatic and can be compared with the experiences of rape, torture and sexual abuse (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, Alternatives Beyond Psychiatry, p305-326). The mental and physical injuries that escort these experiences could be translated in the therapeutical speech as a core state of lack of control in the life of the individual and abuse of power (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, Alternatives Beyond Psychiatry, p305-326). The individual experiencing the involuntary hospitalisation goes to a state of palindrome whereas childhood fear resurfaces and takes over the person and the trauma by that experience results in the feeling of existential helplessness (Rufer, 2007 in Lehman, P., Stastny, P., Emmanouilidou, Alternatives Beyond Psychiatry, p305-326).

So, what is the role of the expert in all these? What is our purpose and our function as experts in our fields? What can we do in order to alleviate the suffering of the individual from a severe mental condition, not facilitate to their traumatic experiences and treat them with respect as equal members of our society? How can we turn the scales of equality and respect? What are the alternatives? In the Eye of Power (2008), Michelle Foucault states: "The role of the intellectual is not any more to be in front or sideways in order to express the silent truth for the rest of the people. It is probably to fight against the faces of authority, whereas the intellectual becomes an object and at the same time a tool: in the areas of knowledge, truth, consciousness and speech.... It is a struggle against authority, a struggle to demonstrate authority and to offend it in places where it is invisible and insidious. It is a struggle not for the realisation but for the undermining and conquest of power, next to, side by side with those that fight for it and by far in order to enlighten them". Foucault also understands that "power is not limited to the state mechanism, and nothing will ever change in the realm of society if the mechanisms that exert power, and operate outside of the state format but underneath them and next to them in a lower level of daily life, do not change". In his seminal work Dr. David Cooper "The Language of Madness" (1980) states several proposals on how to move forward to a better healthcare system and practices. He starts with the goal of overthrowing the rules of the psychiatric procedures, moves to the abolition of the hierarchical authoritarian structure of the psychiatric system, then moves to the avoidance of interventions, and then to the abolition of sexual oppression (Cooper,1980).

In this spirit, the HELLENIC OBSERVATORY FOR RIGHTS IN THE FIELD OF MENTAL HEALTH is trying to tip the scales for all the involved and interested parties. In favour of respectful, equal and humanitarian healthcare. It takes actions to educate, train, express and facilitate an evolutionary process, that is so much needed, in the formation of mental health care and create the opportunity for everybody to be heard in terms of equality, solidarity and respect. We believe that this is the future of mental health care and the visions and work of this communal, free-speech space can be replicated and further developed. It is important to create and have islands of freedom in our lives and the HELLENIC

OBSERVATORY FOR RIGHTS IN THE FIELD OF MENTAL HEALTH is such an island for people with unusual experiences, their families and experts. And as virgin ecosystem, it must be treated with respect and admiration and the out-most care.

Thus, even if our presentation and ideas presented in this paper, might seem heretic, nonconformist and derivative of the Deutche Romantik period and the revolutionary spirit of the 60s, we would like to remind you of a revolution in the mental healthcare that started in the midst of the previous century but was never completed, with small exceptions to some policies and practices. Hence, the purpose of this article is not to demolish the progress of psychiatry or medicine and dismiss all its efforts, but to re-ignite a conversation for better mental health practices and policies, that have been massively delayed.

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