Special article

Empowering dialogues: the problems of service users, family members and carers' associations in Greece

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Abstract

The voice of people with mental health problems has historically been weak to express the demands for better care and end of abuse. In the effort to reform and improve mental health services in Greece, the lack of a social movement is often referred to as a central problem by experts. It is important to describe and study the problems that prevent mental health service users and their relatives from achieving their goals, contributing to the change that is clearly required and strengthening their word. A mixed methods study provides us insight to the basic problems of associations representing users and carers in Greece. These are: Available efficient space for meetings, service provision, administrative purposes, technical capacity, difficulty in clarifying and prioritizing purposes and goals, difficulty in engaging active members, and ambivalence towards the state and mental health professionals. We are interested at the qualitative characteristics of engagement and relationships between associations and other stakeholders. Proposals are made to further study and actions to strengthen the ability of clubs to achieve their goals and to promote reforms for better mental health care. A need to reconsider the attitudes and behaviors associations should foster towards a healthy democracy is emerging.

Key words: User Representation, engagement, ethnographic research method, organizational culture, institutional - group dynamics.

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Introduction

The advances in research in neurosciences are phenomenal and the need for an open and constructive dialogue between clinical neuroscience and mental health is becoming more and more evident (1). Systematic research is mapping the neurobiology of disease and trying to identify brain regions, connections, circuits and biological functions as basis for possible explanation and treatment of mental illness (2). Understanding serious mental health disorders, especially schizophrenia, has been a long-standing challenge, generating constant dispute, but also showing links between neurosciences, psychology, cognitive studies, even psychoanalysis (3,4,5,6). But who is talking on behalf of the "mental health" field? Who is representing the patients? In research conducted in recent decades, 95% of the cases pertain to objectives and methodologies that are not close to patients' preferences and priorities. The literature is therefore flooded by and relevant resources are tied to research on the effectiveness of psychotropic drugs, as well as on the genetic factors of mental disease, while service users would prefer to know more about the effectiveness of psychotherapy or methods of self-help (7).

WHO and EU directives and guidelines for the organization of mental health services (8, 9, 10, 11) highlight the importance of developing and implementing policies and strategies to promote the active engagement and participation of users of services and their relatives in the mental health system. However, the voice of people with mental health problems has historically been weak in expressing the demands for better care, elimination of exclusion, abuse and violence. In the effort to reform and improve mental health services in Greece, the lack of a social movement that supports the philosophy of the psychiatric reform is often referred to as a central problem by experts with different professional and institutional roles in relation to the psychiatric field (12, 13). It is important to describe and study the problems that prevent mental health service users and their relatives from achieving their goals, so as to contribute to both the systemic change, that is clearly required, and maximising their representation. The literature review shows that, while there is some quantitative data on the level and form of representation of associations in different fields, there is a lack of information concerning the regulations and the specific procedures followed by associations. Also, there is a need for evidence on the relationship between associations and other stakeholders and the qualitative characteristics of such engagements.

The Working Group for the Review of the Psychargos Program in 2011 held a focus group with vast institutional representation, aiming to record the problems and suggestions of service recipients and their relatives. The problems described are considered long term, unresolved, and are associated with problems reported in other European countries (14, 15). Our most recent study focuses on recording the challenges faced by service users, family members and carers' associations in Greece. Self report through questionnaires (16) reveals that the problems associations in Greece are facing are:

- Available efficient space for meetings, service provision, administrative purposes
- Trained staff (for secretarial support, drafting of proposals, communication - public relations)
- Equipment
- However research through focus groups (17) has also recorded the following problems:
- Difficulty in clarifying and prioritizing purposes and goals
- Serious difficulty in engaging active members
- Ambivalence towards the state and mental health professionals

In all cases, the problems that associations are expressing are part of the general social, political and economical situation in Greece.

Problems regarding the wider context

First, problems regarding the public mental health service system: lack of coordination, low efficiency, and lack of accountability (18, 13). According to the latest national epidemiological research, only 32% of those with a common mental disorder report that they visited a specialist in the last year (19).

The already low efficiency of the social protection system has been further affected by the economical and social crisis. According to OECD (20), in Greece people lose 55% of their net income when they are newly unemployed, and up to 96% when

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they become long-term unemployed. The percentage of people unable to cover their medical needs financially reaches up to 11% (21). In this unstable and problematic context people representing mental health service users and their carers need to increase their actions and make their voices louder.

Purposes and goals

The forms of participation of users and their families are manifold:

Training of other users, family members or professionals, informing other users, family members, the general public and the mass media, self-help, support – provision of services, advocacy, evaluation of programmes and services, research. Two main areas of interest of all associations are providing self help and advocacy. Associations in Greece take all different kinds of initiatives. What is evaluated as most useful is self help for members: information about mental health disorders and treatment methods, support, social networks, sense of belonging. Focus group research showed that there is confusion between purposes, aims and goals, lack of prioritization and clarification.

The level of agreement between members on the purposes of the associations is a key factor of its organizational capacity. It is a predicting factor of an organization's ability to move from declaration of principles and 'pointing fingers' to taking action and filling the gap between needs and policies. Literature review suggests that there is no evidence of how associations manage this kind of change. As change we consider not only the desire to resolve problems, but also the practical use of experience, as well as the broadest possible incorporation of the available know-how. In addition, change is the minimization of the gap between the acquisition of new knowledge and its implementation, as described by Blisker et al. (22). A key factor in this is organizational readiness for change, as described by Weiner (23,24). In this particular field of research, we can trace an epistemological resemblance to the concept of readiness for individual psychosocial rehabilitation (25). Organizational readiness for change is assessed through the level of agreement between the members of the organization regarding its purposes, and technical readiness (available financial, human and technological resources). It's described as a commonly accepted psychological state in which the members of the or-

ganization feel committed to implementing an organizational change and are confident that they collectively have the skills required for it (24). There are tools for the quantitative measurement of organizational readiness in health (26), which have been used in research regarding hospital management. An ethnographical research in Greek associations will shed light on the levels of agreement between members and on possible institutional resistances to such change. It can also help us understand group dynamics inside and between associations and power relations. The ethnographic method allows us to place a strong emphasis on exploring the nature of a particular social phenomenon, rather than setting out to test hypotheses regarding it (27, 28).

Technical capacity

All associations participating in the study, regardless of the number of years of operation or the number of projects and actions that they have implemented, report difficulties concerning human and economical resources. More specifically, there're no available venues for administrative purposes, meetings or activities. Required equipment (computers, copy machines etc) is also lacking. Associations that have available spaces that are provided by other agencies would prefer other places, where there could be more autonomous. Regarding human resources, there is lack of trained personnel that would perform necessary tasks, such as secretariat, fund raising or communication.

Level and quality of representation

The World Health Organisation (29, 30) provides data regarding the extent of user and family involvement and representation (on the basis of whether there is representation or guidelines) in committees relevant to the services (in planning, implementation, review) and relevant to actions (in stigma, prevention, promotion of mental health). In the countries where they exist, family associations participate in the formulation and implementation of legislation in 34 % of cases on a regular basis, in 50 % on a non-regular basis and in 16 % never or rarely.

For the establishment or operation of associations, there is regular government funding in 15 out of the 42 countries. Of the EU15 countries, government support is not provided in Finland,

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Italy, Greece and Sweden. Users participate in committees related to the planning of services in 20 of the 42 countries (47.6 %), as do families. In committees for the implementation of plans related to the services, there is user participation in 15 countries and family participation in 18 of the 42 (35.7 %). For review of policies, participation in committees exists in 17 countries for users and 17 for families, out of the 42 (40.4 %). In committees related to actions (stigma, prevention, promotion) there are 12 countries, Greece included, where there is no participation at all. Namely, users and families are not represented at any action implementation level for mental health (planning, application, review). In Greece, service users are represented in the Special Committee of the Ministry of Health for the protection of rights of people with mental health problems following the Mental Health Law of 1992 (Law 2716). In 2017 the new law (n.4461) for the administrative reform of the mental health services supported the participation of user representatives at local level in the Sector Committees and local bodies for rights protection. However, actual representation is not ensured, either because in some Greek areas there are no willing representatives or because the procedure for the selection of representatives by the state is not transparent. This is obviously associated with the resistances, or rather the paternalistic stances, imposed by mental health professionals, especially psychiatrists, during the reform of the psychiatric services and model (13, 16).

The aforementioned WHO study for Europe does not inform about the quality of involvement. Representation may mean anything from a simple presence to participation in the decision-making. The actions and services to which we refer differ to a great extent between and within countries. From the comparative study of the data, W.H.O. arrives at a series of conclusions.

The extent of representation and support is consistent with the available resources as well as each country's model of services. If there is involvement in an area, there is increased possibility of similar involvement in more areas of action. Users and families are represented and supported equally. The WHO concludes that what is missing are regulations, specific procedures, study of the involvement and relationship characteristics between associations and other involved bodies.

Members' engagement

Associations of users in Greece exist since 1984, while the first families' association formed in 1999. They consist of 130 members on average. However, civil society in Greece is considered "cachectic, atrophic or fragile" (31). Only 4% of respondents in a world scale survey said that they have volunteered (32), bringing Greece in the last position among 135 countries. In a 2008 European Social Survey, 59.8% of Greek participants claimed that «we must be careful» in relation to trust in others, where the average was 38.8%. Associations seem to be ambivalent and in a confusing relationship with the state, and with with family and political parties as institutions (33). All these concern a state that, as described (34), follows an ineffective, irrational and morally unacceptable mode of operation of its institutions. This situation is Greece must be considered as a part of the European context, which is characterised by a deficit of democracy and furthers social inequalities.

The role and support of carers

Even though in recent years there is capacity building training available for NGOs through associations like HIGGS or Social Dynamo, there is still lack of adequately trained association members that would help in the development of their associations. Such training could involve skills in leadership, project management, group dynamics, etc. Furthermore, 93% of carers report they do not receive care themselves (35). A recent study by COFACE Families Europe on the challenges and needs of family carers in Europe with 1160 participants reports: 80% of care work in Europe falls on family members, who are left without adequate financial compensation, social support, or a pension scheme. Family carers face significant challenges when it comes to reconciling their professional and personal life, accessing community-based services, and also concerning their financial situation, health, administrative procedures, and social recognition. It is especially concerning that 73% of the respondents do not receive any financial compensation for their work, as carers, and almost 2/3 of them don't have access to any kind of social benefits (36). Family carers are Europe's invisible workforce representing one of the most silenced, socially excluded groups. Furthermore, poverty is a big threat for carers: 1 in every 3 respon-

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dents stated that they had difficulties to make ends meet as a consequence of their caring role. Since there are often no flexible time arrangements in place at work, many family carers faced challenges in reconciling work with care, and had to leave their job or reduce their working hours. In Greece, 96.5% admit that the economic crisis has created insurmountable difficulties for families with a disabled person (37).

Discussion

Undeniably, there is a need for further data that will help us understand the dynamics of the organizations representing users. Data should be provided in a way that association members would be able to use them as feedback for the improvement of their actions and management of required change. Establishing procedures and respecting institutional rules are essential steps towards ensuring the viability of the organizations. In this framework, the example of the Alcoholic Anonymous is useful. They started in 1935 by two people. In 1939, the first teams had 100 members in 2 cities. By 2007, it's estimated that 2 million members participate in more than one hundred thousand teams all over the world. In the beginning there was a challenge: "Our Society then entered a fearsome and exciting adolescent period. The test that it faced was this: Could these large numbers of erstwhile erratic alcoholics successfully meet and work together? Would there be quarrels over membership, leadership, and money? Would there be strivings for power and prestige? Would there be schisms which would split A.A. apart? Soon A.A. was beset by these very problems on every side and in every group. But from this frightening and at first disrupting experience the conviction grew that A.A.'s had to stick together or die separately. We had to unify our Fellowship" (38). We see that the fears and threats that AA members face decades ago remain central problems in the development of representative organizations. Dilemmas regarding the nature of change (micro vs. macro, static vs. dynamic, incremental vs. revolutionary etc.) make the ability to see beyond change imperative (39). Collaborative research on the complex underlining group and institutional dynamics, as well as on the resistances they create, is needed.

Wider and active engagement of members is a difficult task and it's strongly related to trust towards institutions. A critical approach to social capital development is needed. We need to reconsider the attitudes and behaviors associations should foster towards a healthy democracy (40). Scarcity of resources in the public health sector raises the responsibilities that citizens and group of shareholders must undertake. A rise in the level and quality of patients' representation in decision making process and the creation of a new paradigm in social capital development could increase the level of health democracy in our country (41). Such efforts combined with fighting stigma could bring about a shift in the mental health care system as a whole. Undeniably, empowerment of participation and representation of people belonging to vulnerable groups is an effective method of treating pathologies of power and social violence (42).

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