



Self-help/mutual aid as active citizenship associations: A case-study of the chronically ill in Italy[☆]



Guido Giarelli^a, Elena Spina^{b,*}

^a Department of Health Sciences, University, Catanzaro, Campus "Salvatore Venuta", Viale Europa, Località Germaneto, 88100 Italy

^b Department of Economic and Social Sciences, Piazzale Martelli, 8, 60121, Ancona, Italy

ARTICLE INFO

Article history:

Available online 27 August 2014

Keywords:

Civil society
Third sector
Citizenship associations
Chronically ill
Self-help/mutual aid

ABSTRACT

Contrary to the most widespread conception that considers self-help/mutual aid as a component of the 'third sector', an approach is proposed which assumes, on the basis of the specific nature of the social bond and of the social action that characterizes it, it can be more properly considered as part of the 'new civil society' as it has been configured during the time in Western societies. This implies its location in the public non-state and non-systemic space that it has been created in the specific form of associations of citizenship. An interuniversity research project is then presented which, using this approach, studied the case of self-help/mutual aid associations for the chronically ill in Italy, offering some of the findings regarding the origin, structural characteristics, geographical distribution and activities of these associations in order to at least partially verify the heuristic value of this approach and its implications for the processes of reform of the health systems.

© 2014 Elsevier Ltd. All rights reserved.

1. The active citizenship approach

Self-help/mutual aid (which is the most general term chosen by the International Conference held in Ottawa in 1992 and that we shall adopt here) is undoubtedly a widespread social phenomenon, at least in Western countries (we shall not consider here similar kinds of social phenomena, such the microcredit, typical of non-Western countries, which are usually matter of different disciplines and approaches). One of the most interesting issue this particular type of collective social action raises in the current debate is its peculiar nature and location in the societal context. In fact, the answer to this issue brings with it a number of implications both theoretically and practically significant: however, they often remain implicit and unquestioned. Usually, self-help/mutual aid is considered as a component of the so-called 'third sector': a term first used by some scholars in the United States in the early 1970s (Seibel and Anheier, 1990:7). This seems to imply a conception of

society as founded on three sectors, generally defined as state (of public nature), market (of private nature) and third sector. Sometimes, some authors (Dekker and Van den Broek, 1998) also add a fourth sector, identified with the community, including households and neighbourhoods. The nature of the third sector is, in a controversial manner, defined according to the different authors as voluntary (is most commonly used in Great Britain, see Baggott and Foster, 2008), non-governmental (in Poland, e.g., the term 'self-help' is synonymous of non-governmental organization; whereas in Western countries the latter term is used in the context of the international cooperation), social-private (used in Italy, see Donati and Colozzi, 2004), non-profit (the definition of which has been made at the international level by the scholars of the Institute for Policy Studies at Johns Hopkins University in Baltimore, who consider the prohibition of the distribution of the profits from its activities as the most important element of the third sector; to it, some scholars such as Anheier and Seibel (1990) and Salamon and Anheier (1994, 1996), add other four additional elements: the existence of formally constituted organizations, with statutes and rules governing their internal relationships; private legal nature, self-government with the election of its managers, and the voluntary nature of the choice of those who participate). Probably, this variety of definitions is the outcome of the range of different specific historical, political, economical and cultural contexts in which the social construction of what is termed as 'third sector' has taken place, as the long history of this concept can show (Laville, 2000).

[☆] This paper is the result of the joint work of the authors. However "Guido Giarelli" wrote "The active citizenship approach", "A new civil society and public space" and "The research project on self-help/mutual aid for chronically ill" while "Elena Spina" wrote "Research findings". The "Conclusions" were written by the two authors.

* Corresponding author. Università Politecnica delle Marche, Department of Economic and Social Sciences, Piazzale Martelli, 8, 60121 Ancona, Italy.

E-mail addresses: guidogiarelli@tin.it (G. Giarelli), e.spina@univpm.it (E. Spina).

We assume that the idea of ‘third sector’ is an institutionalist vision of economical matrix which reduces the scope and meaning of social phenomena such as self-help/mutual aid to a simple component of a ‘sector’, albeit considering it as endowed with its own particular characteristics. Assuming that the notion of ‘sector’ can be considered as an equivalent of system or subsystem – and this is also problematic, since for example Evers (2000) defines the third sector as a component of the public space in civil societies – this takes no account of the mostly non-systemic nature of agency of the phenomenon. Moreover, it does not consider the more complex reality of the post-industrial societies, whose social subsystems cannot be reduced to simple ‘sectors’ of single nature, but imply a plurality of social relations: the political systems, e.g., does not coincide with the state, of public nature, but also includes a private component (lobbies, pressure groups, representatives of various stakeholders, etc.) and a civic one (political parties, movements and political associations, etc.). In the same way, the economic system does not coincide with the market, of private nature, but also includes a public sector (state-owned industries, etc.) and a civic component based on social economy (and this is most probably what can be actually defined as ‘third sector’). Finally, a tripartite vision of the society does not consider the enormous development that, over the last century, have had on the one hand the welfare systems and, secondly, the telecommunications, media and information technology: and this is the rationale which makes nowadays necessary to recognize the differentiation of two new social subsystems, which can be respectively defined as social and health care (which includes the more or less integrated system of social and health services) and communications-cultural system (including the media techno-structure).

A more sociological approach could start from what Borkman (1999:2) identifies as the most distinctive element which underlies the social phenomenon of self-help/mutual aid: the ‘circle of sharing’, that is “a small number (usually less than twenty) of people with the same predicament, disease or disability sit in a circle, sharing personal stories of their suffering and their attempts to cope with and resolve the problem”. The sharing circle confronts us with a conceptual difficulty which represents, from the sociological point of view, a theoretical challenge which calls into question the well established concepts of ‘private’, ‘public’ and ‘society’ itself. What is the actual nature of the circle of sharing? If we consider the kind of problems addressed – directly related to the sphere of the body, disease, disability, sexuality, family, life, death, feelings and attitudes, life styles – it can possibly be ascribed to the private sphere of primary relationships; but the relationship established between the members of a self-help/mutual aid group hardly could be regarded as of a private nature, since it is neither based on kinship nor neighbourhood, friendship or affection.

The theoretical approach we followed in our study is based on the idea of ‘active citizenship’ (Moro, 2005; Active Citizenship Network, 2007), on the basis of the consideration of the individual as a *person*, that is a unique human being and not just a social role-complex (patient, user, consumer, client), and as a *citizen* with rights and responsibilities towards the local community, the nation-State and humankind (whereas the definition of the rights is clearer since they are written as part of laws, national constitutions and of the Universal Declaration of the Human Rights of the United Nations, responsibilities are not as well defined and the debate is open as to what the responsibilities are toward the local community, the State and the humankind). An active citizen is someone who fulfils both rights and responsibilities in a balanced way: it entails the recognition that in a society all individuals are mutually dependent and that by making a positive contribution towards the society by participating in its life, they are helping themselves as well as others. Active citizenship is the glue that helps to keep

society together, since it allows people to focus beyond their own self-interest. It implies a responsibility to ensure that no one is socially excluded, especially the weakest, disabled and ill people; and is oriented towards the full implementation of their social rights.

In fact, the predominant purpose of self-help/mutual aid groups is specifically geared to the promotion, protection or rehabilitation of health and well-being of their members as specific social rights. However, in the real world, these groups are often part and parcel of wider organizations providing benefits or services of altruistic type (voluntary organizations, charities, etc.) or of associations aimed to safeguard the respect of rights of the most vulnerable citizens (advocacy associations). All these active citizenship associations have as a common denominator the desire to promote, take care and represent the rights, needs, interests and expectations of citizens, especially the most vulnerable ones such as the disabled and the chronically ill, as users, patients, caregivers, or simply sufferers in the context of health and social systems and of the wider societal arena. However, both organizations of volunteers and associations of advocacy do not necessarily share a common problem or predicament, which remains the hallmark of self-help/mutual aid and the social basis for the establishment of the ‘circle of sharing’.

Even though practically the boundaries among self-help/mutual aid, volunteering and advocacy are often blurred in the same organization, from a theoretical point of view it is appropriate to distinguish them at least as ideal types of different activities, since the sharing of a common problem involves a different prevailing purpose and foundational principle. In fact, the main purpose of voluntary organizations is to deliver services of altruistic and solidarity type, whereas associations of advocacy are aimed to provide information and support to the observance of the social rights of the weakest citizens, especially when they become users/patients of social and health care services. Thus, we could define the ‘gift’ (on the meaning of the gift in non-Western societies, see Mauss, 1923–24) as the foundational principle of volunteering based on altruistic action; whereas empowerment of the weakest citizens is the foundational principle of advocacy associations, centred on the action supporting the exercise of their rights from the perspective of a substantive equality (for a specific perspective on ‘empowerment’ in the social and health care context, see Starkey, 2003).

Instead, self-help/mutual aid is geared towards the promotion of what Riessman defines as ‘the helper principle’, that is “You alone can do it, but you cannot do it alone” (Riessman, 1965). On one hand, the direct taking of personal responsibility, on the other, the mutual aid: their conjunction implies a situation of interdependence, in which the person agrees to assume her/his responsibility, but within a context of mutual aid.

It “consists in benefit, through the testimony of the personal experience, from the obstacles and the skills acquired over time. Helping others has a strong value of aid for themselves” (Focardi et al., 2006:23). It is probably this junction of proactivity and of reciprocal solidarity the basic element and the fundamental pivot around which rotate all the other possible characteristics of self-help/mutual aid.

2. A new civil society and public space

The active citizenship approach is grounded on two other fundamental concepts, discussed at length in the social sciences: civil society and public sphere. The concept of civil society is of problematic definition and has undergone a significant historical evolution in contemporary Western societies (Cohen and Arato, 1992). In the context of the European philosophical-political thought of the sixteenth and seventeenth centuries, for Locke, Kant and Rousseau the meaning of the concept coincided with the

متن کامل مقاله

دریافت فوری ←

ISIArticles

مرجع مقالات تخصصی ایران

- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان دانلود رایگان ۲ صفحه اول هر مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات