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Salute e Società

Citizens'
health services

edited by

Leonardo Altieri
Maria Augusta Nicoli
Vittoria Sturlese



FrancoAngeli

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EDITORIAL

Giovanni Moro*

The relationship between citizenship and health seems so obvious that it would actually not require any attention. At the very end, indeed, the Marshallian-based systematization puts the access to health services among the main contents of social citizenship, though leaving open the question of the degree of implementation of this entitlement in an age of financial constraints in Italy as well as in the other “European Social Model” countries.

This view, however, is less and less able to interpret and explain what is going on in the relation between citizens and health services, not only in Italy. As this volume of *Salute and società* shows through essays, articles and interventions, nowadays the question goes well beyond the Marshallian *vulgata*, according to which citizenship means that the state delivers services and the citizens benefit from them on an equal footing, financially contributing in proportion to their income.

The renewal of citizenship studies – the “return of citizenship”, according to the Bryan Turner’s wording – that took place in the last decades for a number of reasons, not least the institution of European citizenship, in 1992-93, allows us to grasp the link between citizenship and health services in a richer and wider way.

There is, first of all, a new vision of Marshall’s contribution in dynamic and non trivially evolutionary terms. As Richard Bellamy has recently clarified, the core of the English sociologist’s contribution is that citizenship is essentially the “right to have rights”, thus a base of an

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unending political struggle. The fact that the rights presently at stake are different both in terms of content and way of use, claimed by actors different from those that lead the 20th century welfare policy and regarding, so to say, unexpected forms of citizenship, sheds light on this feature that emerges from a non-scholastic reading of Marshall.

Just the observation of citizens-health services relationship shows a dynamic that consists not only in the claim of new rights regarding health assistance or in the struggle for enlarging their field of application (it is the big issue of welfare provisions for immigrants in Europe). It consists also in the definition of a catalogue of rights that concerns the way of delivering and using services and that raises operational but not less relevant questions as those focused in the 2002 European Charter of Patients' Rights: right to preventive measures, to access, to information, to consent, to free choice, to privacy, to respect of patients' time, to the fulfillment of quality standards, to safety, to innovation, to avoid unnecessary pain, to a personalized treatment, to complaint, to compensation.

It must also be mentioned the trend of overcoming the controversial elements that divide the liberal, communitarian and neo-republican approaches to citizenship. These approaches, usually dealt with in the theoretical debate as reciprocally alternative, are increasingly recognized as thematizations reflecting essential components of citizenship: namely, the dimensions of rights, of belonging and of participation.

This step forward allows to better grasp what amount of contemporary citizenship is at stake in the relationship between citizens and health services. Beside the already mentioned dimension of rights, the access to health services and their quality degree clearly divide "who is in" and "who is out" the community, that is, the base of belonging. Moreover, the access to services, especially in the EU territory, is linked to collective identity, which is an essential part of belonging to political community.

As for participation, the third dimension of citizenship, what is new is the enlargement of the participative dimension from voting to the definition and implementation of public programs and services.

This new participative dimension is thematized by various literatures: from the one on political participation to the one of interest groups, from the one on governance to the one on co-production of services; from the one on participatory and deliberative democracy to policy analysis, from the one on civil society to the one on social movements, from the one on stakeholder engagement to the one on territory planning and management. Though with different shades and stresses, these approaches emphasize the common element of an active role of citizens, between one election and the

other, to face public issues that directly affect them, in forms and ways that are different from representative democracy standards. The reflection and discourse on this phenomenon are fed by scholars, experts, activists and practitioners, often in a rich mix of roles.

Not all is clear, however, in this phenomenon, which is in a sense the most important in the present age. In order to fully catch it, it is necessary to overcome reductive approaches and theoretical as well as empirical confusions, and even put under discussion elements taken for granted but no longer relevant.

The most important step to be done, from this point of view, is in my opinion avoiding the reduction of participatory dimension to an institutions' program. According to this view, institutions do decide if and when including the citizenry in the delivery of administrative acts, addressing more the individuals than the organizations, deciding in advance what can be discussed and what cannot, managing the process and influencing its conclusions.

What is at risk, in this reduction of the field, are precisely the distinctive elements of the new participatory phenomena, first of all the fact that the definition of citizenship does not come only from institutions' decisions, but also from citizens' "practices" (Antje Wiener).

In the field of health services, civic participation is a consolidated phenomenon, deeply established and wide, if it is considered not under the principle of representation but rather the one of intervention (Ulrich Beck). It's a matter of citizens existing in a variety of organizational forms, raising from their autonomous initiative in those public situations that affect them and not from an institutions' invitation; that participate not at the end of producing outputs (such as an administrative act) but outcomes, that is, impacts on reality; that do operate mainly in the implementation phase of public policies and not only in the decision one (the dimension that is often considered the only place of citizens' inclusion); that are present as groups, organizations and networks rather than as individuals; that tend to affirm their own agendas rather than simply accepting those coming from others; that often act more effectively as autonomous political interlocutors or as watchdogs rather than as participants in the deliberative arenas (or so supposed).

Nothing to say against participatory democracy programs, of course: they are a relevant changing factor for institutions, as long as they produce results that are relevant and different from the initial purposes (and it does not always happen). The point is that the issue of participation cannot be reduced to a "laboratory experiment", especially if it implies to ignore the

“field experiments” that citizens themselves, organized in groups, movements and associations produce and that would be, if taken seriously, sources of information of crucial importance. Not all the literature on participatory democracy shows these problems, especially the North-American scientific production on this topic (see for example the work of Archon Fung). The European one, however, is often characterized by a mistaken normative approach, according to which is the reality that must conform to theories and not theories that must try to describe and interpret reality; and, extensively, that citizens must conform to institutions’ policies and never vice versa.

The risk to be taken into account and to beware is (to paraphrase the title of a Paul Ginsborg’s book) to be concerned of the “citizenship that does not exist”, instead of studying and taking seriously the one actually existing.

INTRODUCTION

Maria Augusta Nicoli, Vittoria Sturlese, Leonardo Altieri*

Now that the book is over, the contributions can be read as a sole “body of text”.

Guidelines appear as manifold, but only on the facade. There are points of convergence given by the cultural tensions that the authors capture, narrate, process and outline, and they merge into a common theme which can be summarized as "chronicles of meetings".

In these chronicles the authors highlight motivations and strategies to turn the “places of care” into a space for the daily interaction between the social actors populating the scene of caring. Such actors cannot be easily included in unique and exclusive categories, since they could be seen as users or operators, and simultaneously as citizens, men, women, disabled people, and so on. The authors point out that this stalemate brings up the need to actively seek ways, places and times to generate collective awareness and shared practices of care. Care emerges clearly as a social object whose boundaries are becoming increasingly uncertain, and not spatially related to the traditional sites. The authors, as analysts of these “meeting processes”, explain the different options we have to get closer to

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understanding reality around us, which in turn acquires meaning only in so far as we realize that we must pay attention to what we observe.

Thus, we can place a greater emphasis on the contribution of each author/observer proposing a list of his/her own subjects.

The categories used to identify the subjects we are dealing with – demanding and vulnerable citizens, inexperienced users, immigrants, targets of stigma, family members, volunteers – build a floating constellation clarifying what these subjects are collectively staging.

Sometimes, in this taxonomic process, an interlocutor emerges, as if in the above mentioned “meetings” somebody actually interacts with such a multitude of subjects.

Most of the times interlocutors are represented in institutional roles (coordinators, facilitators, technical operators), or defined as institutions (regions, regional and national agencies) making the scene to promote, organize, support or manage the paths of participation.

A question spontaneously arises when we pay attention to professionals and operators, whose positions and problems often mirror the dynamics found in the "citizens": to what extent is this an inclusive approach? When we are talking about citizens, are we including professionals and operators, too?

If we don't lose sight of the distinctive features by means of which the authors/observers articulate their analyses, we have no risk of assuming that we are referring to “citizens” as part of a relational vacuum, ignoring any reciprocity and increasing the distance between "us" (included in the system of care services) and "them" (outside the system of care services) or vice versa, "them" (included in the system) and "us" (outside the system). The authors/observers investigate how relational contexts are expanding and becoming more and more complicated (e.g., the citizens/volunteers/services triad; the dynamics between senior management, intermediate management executives, operators and users; the focus on active volunteers, volunteers, volunteers as a community resource, integrating volunteers, etc.).

We are called to take into account the relational contexts characterizing the "places of care", and to act on such contexts in order to radically transform the conditions that lead, mark, and define relations – as paternalistic, or condescending, or ceaselessly defending against an impending siege. We are invited to turn these contexts into opportunities for interaction and to replace monologues with dialogues.

The oscillation between the demand for theoretical definitions (in scientific literature and WHO documents) and the need to prove an actual

efficiency on topical issues such as participation, empowerment, civil rights, citizenship, expresses once again the convergence of the contributions included in this monograph.

We cannot trace the paths to follow by simply arranging the basic concepts, and we cannot force the world of care services to understand something that is still perceived as alien. We have to deal with the cynicism of those who see participation as a loss of precious time and the “it can’t hurt” approach of those who promote participation even though they do not believe in it. Maybe we need to revert to the awareness of our being both observers *and* actors (in our working and living contexts) in order to escape this trap. Citing one of the authors, it’s the feeling of helplessness experienced felt in the encounter with “the other”, no matter who he/she is, that leads us to move on without fear.

As we said, the question running through this book is about how to turn the “places of care” into meeting space, indeed. This brings to our active debate about “doing by thinking” – or “thinking with one’s hands”, as Sennett would say (appropriate tools, methodologies and/or techniques, organizing paths of participation, and so on). We are invited not to postpone action until better times or to expect that this should happen somewhere else, but rather to think and act here and now.

This monograph should be read following what the authors highlight in terms of their peculiar points of view. Social worlds come to the surface, in opposition to the fact that usually they are not perceived as part of the same cultural compound – even though they are important to understand the scenario in which we stand. Health care, in its broadest sense, has to be taken seriously because today “caring” is the area where playing out our social life structures our relationships and worldview, and the repercussions do not inform only health policies and welfare systems. As Nunes points out in the final essay: “The realization of one’s right to health appears, then, as a challenge (...). The most fruitful way to respond to this challenge shall go through a deeper and more accurate exploration of the processes of co-production or heterogeneous construction of health as knowledge, experience, collective action and right, of the ontologies and epistemologies associated with different practices and of the ontological policies configuring such practices”.

THEORY

Citizenship rights, participation, public health

Leonardo Altieri*

Are users of health services “consumers” or “citizens”? What does citizen participation really mean? Why are citizenship and participation so strictly bonded? This essay attempts to answer these questions. An effective participation guarantees the rights’ respect. There are several important and creative participation experiences in the health services. Participation, though, is not always “citizens activism”. It is often ambiguous and useful to the aims of “management activism”.

Key-words: citizenship rights, citizens participation, common health, health services, experiences of participation, citizens activism.

1. A defence of public health as “common good” for citizens

It is a remarkable coincidence that we are going to end this monographic edition of *Salute & Società (Health & Society)* dedicated to “citizenship and health” precisely while, in Italy, people are starting to consider the meaning of the surprising results of 4 referenda that took place in June, 2011¹. What link should exist between such different issues? Let’s ponder it!

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¹ Actually, this coincidence is not so strange if one considers that the participation and citizenship themes have been being pondered for years by the writer, and that the undersigned last year worked actively during the weekends to collect signs for the referenda about water. He did not act as a professor, but as a sociologist in a “participant observation” who studied the heterogeneous social