



**Multidisciplinary call for contributions on:**

“The place of lay carers in social policy, between free choice, recruitment, and protests”.

**For the January-March 2019 issue**

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This call for papers is addressed to researchers in sociology, economics and management, law, philosophy, political science, as well as statisticians and actors in the field of social protection.

**Articles are expected before Monday 8 October 2018.**

Lay carers are non-professionals in social protection, care, and health services. They are most often family members, more or less distant relatives, spouses, cohabitants, neighbours, friends or other relations who are increasingly solicited or even “recruited” in tasks of institutionalized solidarity. Over several decades, a series of decisions in the health care field have been taken in France, as well as in other European countries, in support of those elderly who are disabled or suffer a loss of autonomy. These decisions encourage people to remain at home. Hospitalisation at home and deinstitutionalisation are both formulas which imply not only the mobilisation of the “home” but also that of the relatives of these different types of vulnerable persons, whether or not they are cohabitants with these persons, or simply have neighbourhood or kinship links with them. In addition, even in the context of persons registered in institutions, relatives are asked to develop certain activities that provide for their well-being (entertainment, reading, outdoor outings, etc.). More broadly speaking, there is a similar movement in other fields of social intervention, such as in the process of integration or of legal protection (guardianship, trusteeship). Of course, the forms taken by this involvement-solicitation of relatives differ according to the populations concerned (elderly people, people with disabilities, people on the path to integration, etc.), in particular because of the role of relatives’ associations. The underlying logic of these movements oscillates between two extremes: the veiled intentions of limiting public spending and the encouragement of people's ability to choose. However, this question of “free choice” formulated in relation to vulnerable persons does not always include the question of the choice of relatives who find themselves grappling with more or less heavy caregiving tasks that could severely affect their own ability to formulate life choices.

Moreover, the concepts/notions of “free choice” and “recruitment” highlight certain tensions and ambiguities in public action in this field: the provisions concerning child carers relating to their

training, to the possibilities of professional leave, or even to their compensation can be interpreted both as recognition and support for their involvement as well as institutional modalities for their recruitment.

Beyond the renewal in philanthropic aid concerning social protection in its financial aspects, the new moral and political economies of solidarity, in different national contexts and branches of social policies, are leading to the mobilisation, or even in specific ways to the recruitment, of lay carers in fixed tasks. In a parallel movement, there are people from the voluntary sector who in some cases demand recognition for their specific expertise in the field of *care* or support. The place of caregivers is thus in a state of tension between choice and assignment, demand and constraint, occasionally revealing contradictory cases of personal commitment. These contradictions and ambivalences are reflected in the instability of the categories that official texts mobilize to designate caregivers, sometimes calling them “natural”, “family”, or “close relations”. The question of boundaries and areas of friction between professionals and lay caregivers raises the question of respective knowledge and “good care”. The resulting forms of competition or collaboration can be read not only in interindividual relations, but also in the established forms of accompaniment. Thus, “assistance plans” - implementation of the public care schemes for disabled children or adults or frail elderly – logically see their content vary according to the concrete possibilities of intervention of these lay caregivers. Moreover, the difficulties that social or medical sector professionals find in responding to declarations by caregivers concerning, for example, the quality of service or of intimate care is undoubtedly indicative of this ambivalence. This reveals the confrontation between the legitimacy of expertise based on training and recognized professional qualifications on the one hand, and the more intimate knowledge of social and family trajectory, of tastes and phobias, etc. of the person being

helped, on the other. In certain circumstances that should be described and analysed, the lay caregiver can play a mediating role between the person and professionals, thus facilitating support and improving its quality.

The signs of a tendency to incorporate relatives into social protection schemes include the forms of remuneration paid to disabled person's carers, the more or less urgent requests made to relatives to participate in collective tasks (social life) in certain EHPADs, and the increase in training for relatives who work with frail or sick persons. Moreover, public actors support these forms of recruitment of lay social protection workers through the granting of certain social rights, for example as regards employment (right to rest breaks or special leave), various statuses, and active financial support for training provided by associations or parastatals. Beyond the medico-social field, particularly that of disability and loss of autonomy in which “assistance” plays a central role, the challenges of supporting people in difficulty show the importance of this phenomenon in the social field in general. The question of the professionalization of this lay personnel is never made explicit: At best, it is only part of a longer-term goal.

This growing recruitment of lay persons reveals a three-fold resizing of the perimeter of social protection. It concerns the actors, the fields of intervention, and the aims of social protection.

**First, there is the question of the actors. Who are these lay persons?** Are they close relatives, children, family members, neighbours, co-workers, friends or simple relations? What are their personal and professional trajectories? What are the moral duties, legal obligations, experiences, personal commitments and beliefs, skills, training or incentives/interests that animate or guide them? What effects do the statutes, social rights, forms of remuneration or compensation proposed by the institutions have on them? Are there “traps” that close in on individuals who

move away from the labour market to take part in these tasks? What recognition do businesses give to employed caregivers and what measures do they put in place to meet their needs? Are there professionalization paths other than that in the childcare sector? Above all, while the available studies show the predominant weight of women amongst those involved in helping vulnerable relatives, do the different mechanisms mentioned here apply differently according to gender? Are there also differences according to economic resources and cultures?

**Second, the place of lay caregivers raises questions concerning the separation between public and private.** We note that their recruitment is partly linked to the incorporation of activities in the field of social protection traditionally associated with the “private” or even the intimate sphere. This aspect refers to the ambivalence that separates private and public issues in social protection. The regular extension of the field of public problems in the health and social fields leads almost mechanically to the multiplication of interactions between public and private tasks, or to a repositioning of the relations between these logics, within the framework of public action.

**Third and finally, lay carers raise the question of the purpose of social protection.** Caregivers are often called upon on the basis of their “qualities”, which are supposed to be better able to meet people's needs. Professionals are considered to be “operating technicians” in a profession which has been organized in a way which is too rigid to be able to meet the diversity of needs and situations. The question of fine-tuning to people's needs, the effective recognition of the principles of autonomy, of well-being, etc., find a particular echo here. On the level of domotics (home automation), there is a tendency to change the conditions of intervention of

professionals and laymen. In addition to the technical characteristics and the aims of autonomy and security generally attached to the corresponding objects by their promoters, it is interesting to question the point of view of lay carers on the perceptions and uses they have of them. Are their “qualities” even more solicited as compensation for a technical intrusion which also signifies the user’s situation of dependence and whose use imposes a form of autonomy on him likely to lead to his isolation? More generally, the results of international comparisons have clearly shown the importance of the interdependency between professional services and the place of carers (Naiditch, 2012). The question of the articulation between professionals and lay carers is a rather acute one, not only because of their respective skills, but also because of more underlying elements (professional legitimacy; rights and obligations of relatives). Is this a broadening of the range of interventions for vulnerable relatives with reference to new principles of public action (autonomy, dignity)? Is it rather a trend towards the outsourcing of medico-social support functions undermined by a process of rationalisation of the management of health care services or *care* (retreat limiting care to hygienic conditions) which can result either in the subcontracting of certain services (merchandising/privatisation) or by the involvement of close relatives in carrying out these tasks?

An opposite perspective justifying the recruitment of laypersons as actors in these public policies is given by the developing struggle of caregivers who seek to increase their weight in the field of social policies, and contest the pre-eminence of “scholarly experts” in health policies in the broad sense. As “experience experts” with a unique knowledge of the constraints of the situation and support needs, they demand a greater role in care from policy design to involvement in care pathways. More or less radical and involving diverse organizational structures according to sectors, the defence of “experiential knowledge” or “knowledge of close relatives”, as counter

posed to the professionalization in the field of care, is widely diffused in the public debate. It calls for citizen participation in the definition of “good health” and in the organization of social solidarity. It also stresses that therapeutic education, as part of long-term support for people with disabilities or chronic illnesses, is not sufficient. The experiential knowledge of carers and the interactions between accompanied persons and carers implemented in particular within the framework of peer help experiments testify to the interest of this perspective.

Our dossier therefore wishes to include articles showing the existing tensions between the different possible forms of involvement of lay carers in social protection and the demands of individuals and collectives, often associations, in different branches of social protection, in France and abroad.

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before 8 October 2018