Caring for non self-sufficient elderly people: contributions to the Tuscan welfare system from a strategic alliance between voluntary associations and public institutions. Findings and comments from an empirical study.

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Introduction

Long-term care for non self-sufficient elderly people is a key issue in most European countries, and its weight is becoming difficult to bear especially for those countries, like Italy, which are facing deep modifications in the traditional family structure and in the labor market, a growth in the call for services whilst funds to sustain the welfare system decrease. A deep understanding of the phenomenon is therefore crucial for institutional care providers, in order to know how to properly direct their planning and activity as well as how to set up the functional coordination of all available resources. It is within this framework that the empirical study on non self-sufficient elderly people with disabilities described here finds its place. The study was co-promoted and co-funded by Cesvot (Support Center for Voluntary Organizations of Tuscany) and the Tuscan Regional Administration and carried out by Qubica and the Volunteering and Participation Foundation.

Caring for non self-sufficient elderly people in Italy and Tuscany

Talking about care for NSS elderly people in a traditionally “family driven” welfare system such as the Italian one means first and foremost having to take into consideration the changes that are occurring in family structure. Among the most relevant ones we can refer to the reduction in birthrate while the age of parents increases, or to the raise in life expectancy which generates a higher care-related workload (mainly concentrated on women who are less numerous and going forward in their age\(^1\)) while solidarity networks occurring between generations (the “widened families” so traditional in Italy) are put under pressure by new forms of living together and make it less likely, for elderly people, to live close to their relatives and to receive effective support with limited costs. Moreover, work-life balance is complicated by job insecurity, which tends to deny any stability and certainty to workers, especially younger ones. This complex group of factors, summed with a lack of clear-cut definition of the phenomenon\(^2\) makes the loss of self-sufficiency (for elderly people especially) both a new “state of need” and a “structural problem” that socio-sanitary systems

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1 See also F. Tosi (2009).

2 The Non Self-sufficiency Network proposed to refresh a definition by De Ruggeri, thus “defining non self-sufficiency as the bio-psycho-social condition that comes from a disability – be it mental or cognitive, physical or motor and/or sensorial – which induces a permanent state of dependency on third parties in the undertaking of one or more functions, essential and recurring, of daily life, a dependency that is not influenced by either prosthetics or other external support tools” (N.N.A., 2010, p.10), but social workers well know how relevant also environmental factors like material living conditions (housing, for example) or availability of economic resources, presence of adequate support networks, etc. can be in defining individual conditions.
are trying to tackle through scores of organizational and economic difficulties. Non Self-sufficiency Funds (NSF) are examples of the strategies adopted both at national and regional level. The national NSF, created with Act n.296/06, was born to guarantee the implementation of base levels of care for non self-sufficient people but was funded only from 2007 to 2010, thus forcing the Italian system to make a great step back in 2011, given the rise in need of intervention³. Regional administrations were able to cope with it only partially, and some of them, like Tuscany, created autonomous projects directed to non self-sufficient people (Regional NSF) thus economically supporting service productions and integrating local resources. Tuscany's NSF was created in 2008 and distributed - from 2008 to 2010 - almost 197 million Euros to District Zones and Local Sanitary Firms for at-home care and to shorten waiting lists⁴. Local centers have been activated to strengthen access to services, and some of its first results were an increment in at-home care and a drop of admissions in nursing homes.

The value of collaboration with voluntary associations in the creation of services for non self-sufficient elderly people

Given the uncertainty and scarcity of local public resources while needs are growing and becoming more complex, looking at other actors who could implement the system seems not only a logical move, but a strategic one as well. Therefore why not look at some of the most precious resources Italy - and Tuscany especially – possesses? Why not explore how and to what extent local resources that are embodied in the third sector and in voluntary associations contribute to the process of caregiving for non self-sufficient elderly people? Why not evaluate what kind of impact can this contribution have upon the system? These are the main questions that sparked the present research, and they sprung from the consideration that voluntary associations are both traditionally numerous and well-distributed in Tuscany, and that, due to their distinguishing features and modes of action⁵, they seem to be more than able to strengthen the strategic framework of private and public services directed to non self-

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³ Data from the Second report on non self-sufficiency in Italy (2011), available at www.lavoro.gov.it, puts the number of disabled people in our country, because of aging and of chronic and degenerative diseases, at 4.1 millions, a number that is predicted to rise to 4.8 millions in 2020.


⁵ The capacity to recognize the needs of a territory before they are made evident, a higher quickness of action and the ability to work on the fringe and by experimenting are only some of the main characteristics of the identity and of the action of Italian non-profit actors – and particularly of voluntary associations – that were reviewed in recent studies, and through which a greater focus on Social Added Value (SAV) in the Third Sector in Italy was achieved. For a more detailed overview, see Volterrani, Bilotti, Tola, 2009.
sufficient elderly people.

**Research structure and methodology**

A mix of quantitative and qualitative techniques was used in the research, since there was more than one objective. During the first phase, which was primarily explorative, a survey of all regional, provincial and local organizations (for municipalities above 10,000 residents) that stated to be working on non-self sufficiency was made. The aim was to create – for the first time in Tuscany - a census of all active partnerships taking place between local institutions and voluntary associations. To do so, the database of the National Center of Voluntary Associations (NCVA) in Lucca was queried, since it integrates the updates coming from the institutional records of voluntary associations and those coming from the records of associations that are part of Cesvot, the Tuscan Center for Services to Voluntary Associations. Additionally, a further set of semi-structured interviews was conducted, targeted to some key witnesses coming from both voluntary associations and from Cesvot’s local committees, in order to bring to light case studies and experiments realized outside the perimeter of usual private/public partnerships. The main characteristics and contents of every project were also outlined, either directed to NSS elderly people or to supporting caregivers. The interviews outlined the characteristics and general dynamics at play, but also pinpointed specific cases to be selected as case studies for a subsequent and more detailed analysis. In this second phase of the research, 10 experiences put in place by 10 different Tuscan voluntary associations were examined, and the activities included guidance and advocacy, light support services or experiences of day care centers directly managed by the associations. Semi-structured interviews were targeted towards all subjects (i.e. voluntary associations, local institutions, local health authorities) who had a role in planning and/or managing services. Whenever possible, recipients of services were also interviewed, but only when physical or mental conditions, or confidentiality obligations, allowed it.

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6 In Italy there is still no official record regarding projects and services directed non self-sufficient elderly people or to family caregivers. Therefore, the nature of the census realized by this research has to be considered preliminary and exploratory, since only the sectors of activity of associations that were self-declared, and registered in the databases examined, were available.

7 Coordinators of regional committees of voluntary organizations that are particularly active in the sector of non self-sufficiency (in accordance with the query of the NCVA's databases) were also interviewed, such as Anpas, Anteas, Auser, Avo, Misericordia, Arci-solidarietà.
Results of the research

Survey outcomes

The analysis of available data paints a heterogeneous picture regarding partnerships between local health authorities and voluntary associations. Even though structured, strong and continuous relations are present in 75% of instances, their onsets are extremely variegated. Partnerships are unevenly distributed on the regional territory, painting a picture where areas in which partnerships are absent (25% of local health authorities say they have no relationship with local voluntary associations on the matter) right next to others where local health authorities have up to 21 active partnerships at the same time. Relationships are almost always official (pict.1) and conventions and agreements are the preferred sources of financing.

Pict. 1 – Type of relationships (percentage)

Voluntary associations are, in the majority of occurrences, part of a wider regional structure (second-level associations) and have a long time experience in health, social and socio-sanitary sectors. They are also the most widespread on the territory, and, as such, they can network and multiply their range of action. Sometimes their activity is so intense that more than one partnership with the same institution can be active simultaneously. There are occurrences, however, of purely local organizations, historically active in the area and strongly present among the local population or sector-specific (or disease-specific) organizations like Alzheimer's disease that undertake actions. The activities detected (pict. 2) are, on one hand, those that can be more “easily” managed by voluntary associations (i.e. light home care - LHC -, active surveillance or social transportation) and on the other hand those

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8 The "Misericordia" and “Pubblica assistenza” associations, mainly involved in socio-sanitary activities, are widely spread throughout the region (with about 470 associations) and the vast majority of them have been active for decades.
that – given the diversity of their practical implementations - are more likely to give a ready, effective and sustainable answer to the needs of a territory, oftentimes integrating with public institutions and other actors of the third sector, like social cooperatives.

**Pict. 2 – Activities**

Furthermore, actions are everything but occasional in their occurrence and in the majority of cases are almost day-to-day. They are mainly carried out by volunteers, sometimes (roughly 30%) supported by paid and trained personnel. Networking and the adoption of a collaborative perspective in managing services are present in more than 64% of occurrences and are mainly referred to other voluntary associations or other third sector organizations. For-profit actors are almost never considered. When public institutions are the main partners of voluntary associations, the latter are asked to play a key role in the planning stage of actions only in 50% of cases. This is, by all means, a limitation, since by not including voluntary associations in this fundamental stage – even when the smaller skillset and lower decree of professionalism that are sometimes intrinsic to voluntary action are taken into account – a meaningful and important point of view, not to mention a precious first-hand experience, is kept out of the loop and out of the system.

The relationship between public institutions and non-profit actors also appears to be weak regarding monitoring and evaluating the quality of services given: even when present, it is likely to be a mere standard account of completed tasks, or a simple evaluation through questionnaires and reports. This keeps participation and engagement of users too much in the background, preventing them from appropriately developing and deploying their potential.

A closing note needs to be dedicated to services provided to caregivers by voluntary associations, since this is another theme that the research focused on. The survey paints a poor
picture: active projects are few (only 13), far-between and relationships are equally distributed between formal and informal ones. Public financial support through conventions is less widespread. Activities are mainly training-related (8 out of 13), reception-related (4) or related to pairing job offers with job seekers. Voluntary associations are actively engaged in the planning stage of actions, a fact that could indicate a greater degree of freedom in proposing projects within a sector that, at the moment, appears not to be central in the activities of local health authorities.

Qualitative examination and case studies: activities and procedures
The ten case studies, with their micro-oriented perspective and by intersecting the viewpoints of all actors allowed dynamics at play and internal mechanisms of the relationship between public institutions and voluntary associations to emerge. They then offered a chance to examine in depth some of the themes mentioned above, as well as:
- participation;
- relationship with structures and other actors in the territory;
- organizational identity and the nature of voluntary action;
- training and monitoring;
- evaluation.

In the following paragraphs, the observations regarding these themes will be described at length. The authors consider them to be – regardless of the case studies that prompted them – food for thought not only for voluntary associations who want to try their hand at planning and performing support actions directed to NSS elderly people, but also for all actors who might help them in doing so, particularly public institutions and other third sector actors. Maybe they could also function as a support to further stimulate qualification of actions and services on territories, and give a small contribution to the definition of third sector and voluntary associations' social added value (SAV).

Participation
Participation appears to be a good starting point, since it is the first that has to be faced when the case studies at hand are examined. Participation is, in fact, tied with the planning stage of interventions, is highly diversified in its instances and highly correlated with the particular
type of relationship that voluntary associations and public institutions tend to build. Some experiences “have seen a lot of winters”, and evolved in time due to the ability of public institutions and voluntary associations to work together and to merge different skillsets and expertise, to create new means to participate and share and to create an effective and concrete subsidiarity which resulted in effective socio-sanitary actions. There are experiences, instead – and sadly they are not a minority – that lack it altogether. It is indeed not uncommon, in the cases that were analyzed, for the relationship between public institutions and voluntary organization to be almost “on demand”: the former is faced with specific needs and this generates an ad-hoc need for actors who can provide support (the latter). When this happens, projects are primarily managed by the public institution, who defines the characteristics of the service needed on a case-by-case basis and appoints voluntary associations to have that need serviced. This process can have at least partly negative consequences on the activities that are put into action, and this risk is related to two main factors:

- the danger of a growing frustration of the voluntary personnel, or of an incomplete or inadequate usage of resources, both human and social (knowledge of local society, organizational skills, etc.) that voluntary associations can provide if they are not “boxed in” by action parameters that are too strict;
- a sort of “dependency” that voluntary associations can develop from public institutions when faced with the practical implementation of activities and services, thus dampening their need to face new challenges and their potential growth.

Obviously the points of view and goals of the two entities we are considering are very different, and the pressure on the public system by growing needs and scarcity of resources has to be kept in mind. But the heavier the needs become, the more important an effective collaboration of all available resources gets, since it is only then that the abilities and skills of every actor are allowed to work at their full potential. In other words, participation needs to be seen as a means to ensure that the associations become a main character in the process of service provisioning, avoiding the risk of limiting volunteers to a frustrating role of performers, and of losing the natural tendency of associations to answer creatively to the needs of territories. This can be translated into the necessity to go “back to the drawing board”, in a way, with the analysis of local needs and the plan of interventions, in such a way that all actors, both institutional and voluntary, are allowed to suggest, experiment and share

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9 In some cases, the lack of this optimal usage of resources has a negative impact on what can be defined “networks of collaboration” in projects. There have been cases where the presence of more than one association as service provider becomes a way to better “cover” vast and non-homogeneous areas, rather than a chance to use all available resources.
different experiences.

**The relationship with other actors in the area**

The second point regards integration with other actors – welfare officers and general practitioners, for example - which should start by building and implementing an effective communication and a mutual exchange in expertise. This could maximize the impact of interventions on territories and prevent the risk of wasting energies and other valuable resources. Ongoing relationships between welfare officers, volunteers and their associations – given that everyone's area of competence is respected, and that the privacy rights of every single patient are fully protected – becomes indeed fundamental in providing effective services to non self-sufficient elderly people, and the contexts in which this happens (or does not happen) can be very different from each other, as the case studies show. When, for instance, relationships are even too strong, but rather than being geared towards a true interaction they express a sort of a “call for help” that welfare officers direct to voluntary associations, the latter are gladly given a monitoring and surveillance function, but oftentimes without a strong activity of coordination and mutual relationship. This custom can generate frustration among volunteers, since it somehow tells them they are mere appendages of the system - resources to be activated promptly, but not a true part of the system. And this is not only a matter of safeguarding the well-being of human resources - which is of course fundamental - but rather a matter of proper allocation and management of resources, energies and experiences that, by not being properly linked together, are most probably not being used at their best.

**Managing services: organizational identity and nature of voluntary action**

How do voluntary associations manage services directed to NSS elderly people? Our case studies appear to say that they do so in two main ways: either referring to volunteers as core in service provisioning and – according to National Law 266/91 – supported by paid personnel only to guarantee a continuous service or to deal with specific functions, or either by referring to professional - and paid - care providers who work for the association. The difference lays primarily in the type of services the single organization is due to provide, either them being services that need highly specialized professional skillsets or else services
which could be defined as “lighter”, and could therefore be provided by actors with a lower level of expertise, that have only been trained with some basic courses made available to everyone, regardless of their professional status or qualification. In this latter case we face what we could call a more “pure” voluntary activity, but - given the growing complexity in services which are asked for, and in spite of its being a way to guarantee a qualitative difference between professional providers and volunteer providers - it could also turn out to be a risk for voluntary associations and their action. Reference is made to situations in which the single volunteer, in his or her “willingness to help” might be ready to do things that he or she must not, because he or she lacks the skills which are considered to be necessary. Together with these modes of intervention, there are services that are indeed organized and coordinated by voluntary associations, but that are de facto provided by paid personnel working for hire.

The difference between these two ways of carrying out services is sensible, since the fact that a service is provided by voluntary associations is a defining feature: volunteers have a very different attitude towards both the service and the person it is provided to. “One must do what must be done and what can be done” becomes the mantra of the action (with all the possible negative consequences described above), and the focus is shifted from the service to a need that becomes global, that involves the entire family and that creates new connections and networks wherever a volunteer cannot reach by himself or through the association. This ultimately strives towards prevention through the use of community networks.

**Training**

Planning and carrying out an adequate training system and periodical refresher courses directed to volunteers - by “adequate” meaning that the training is not only based on technicalities related to the service (i.e. the handling or transportation of the elderly) but also on other knowledge, such as laws and the functioning of local health and welfare system - should be considered crucial to build an effective system of intervention. This is still too rare, as our case studies show, since only informal and unrecognized training is mostly carried out, preventing its important effects from becoming a common asset for organizations. Regarding this matter, though, volunteers and associations seem to have a two-fold and emblematic reaction. The opinion that “no special training is needed to become a volunteer”, or that some
informal training together with experienced volunteers is enough, when paired with motivation, is voiced by many. Associations are without a doubt capable of skillfully creating relationships networks that can keep the flow of information going. But sometimes it just is not enough, and the need for more structured and recurrent training and retraining becomes evident, since these courses can, without necessarily having to make a professional out of every volunteer, make them both more efficient and more safeguarded. Where this training is implemented – and especially in the cases where it is an occasion to relate with other actors on the field, like welfare officers and general practitioners – the aim is twofold: the operator and his service become more qualified, and the network of collaboration in the area is strengthened. The bottom line is not only an increased well-being of the human resources who provide services, but also, and more importantly, an improvement of energies, resources and knowledge pools that are not used at their best when not linked together.

**Monitoring and evaluation**

The analysis of case studies revealed a structural defect in setting up monitoring and evaluation actions which are able to go beyond simple reporting or sporadic checks on customer satisfaction. A proper assessment system appears instead to be fundamental, since it would enable associations to gather information upon which to plan and carry out their interventions, to redesign them and, in the end, to be able to respond more effectively to the needs of users, their families and the community in general. In most cases, instead, the evaluation system our case studies found is efficiency-oriented, while rather important issues like customer satisfaction and effectiveness of the actions given the starting needs are left to informal and non-continuous surveys. The kind of data which is regularly recorded is therefore far from irrelevant, then, but by no means comprehensive, given the wealth of information that could be useful both for the management of single projects and, more importantly, for a further implementation of the same project at a later date. This can be seen as one of the reasons why projects and services too seldom change over time: generally speaking, they are born inside very strict boundaries and are carried out year after year with few modifications, if any. Evaluation, and the use of the data that comes from it, instead, could be key for an improvement of services and of shared re-planning. So we are back to our starting theme: if projects can improve their effectiveness by networking more actors, re-planning and evolving a project is a necessary goal for not only a higher operative potential,
but also for an evolution of the service in the face of a change in needs, if not, in some cases, of their anticipation. The collateral effect is also that all actors are continuously re-motivated, routine is avoided and learning and critical thinking are stimulated.

**Conclusions**

Involvement of all actors, recipients and volunteers/operators included, in the portrayal of the case studies allowed for an in-depth analysis of the qualitative dimensions of services, and for a detailed description of the complex system of relationships, expectations and needs that have an impact on life conditions of non self-sufficient elder people. Narrations allowed to assess the added value that comes from the volunteers' activities, and the fact that their presence is seen as a key factor in the creation and in the preservation of relationships of trust with the elder person. But there's more than that. The stakeholders' words describe a voluntary action that can effectively influence monitoring strategies and prevent elders from falling from the condition of “frail/alone person” to the one of “non self-sufficient person” when qualified personnel is entrusted with the case. This is because the “fragility” we are facing here is not only physical, but mainly social and cultural, a “fragilization” of the relational systems of people that volunteers can somehow overcome, with an effective emotional support that is gratifying both for them and for the people they are giving care to. By comparing the narrations of the subjects, the complexity of the social needs related to non self-sufficiency strongly emerged: the themes of physical disability are tied to the vulnerability of the elder person, but also to the mutations of the social structure of the territories, and to the general role of third sector organizations. By involving associations in the planning phase of interventions, a significant contribution to the growth of the role of voluntary associations in terms of subsidiarity can be made, since they can - given their widespread presence in the areas and their deep knowledge of social distress - really help in better identifying the need, in monitoring cases more thoroughly and in maintaining higher qualitative standards in providing services. While by no means exhaustive, the ten cases brought to light perceptions and problems that are widespread, together with effective attempts to care for people and their families alongside areas where needs are still unmet. The lack of points of reference, of projects and of support services aimed towards a better work-life balance for relatives, or towards lessening the psycho-physical stress of caregivers – especially during the first phases of the non self-sufficiency – are still not a widely discussed
subject, and maybe represent one of the next challenges to be faced.

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