

**Long-term care for non self-sufficient elderly people:  
a social challenge for institutions and voluntary associations**

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**Abstract**

The paper focuses on the efforts that Italy's voluntary associations are putting into action at present in the field of long-term care for non self-sufficient elderly people. The study aims to give local administration(s) a deeper knowledge framework to be used for the monitoring, qualification and development of the Tuscan regional fund for long-term care for non self-sufficient elderly people and to highlight all distinctive elements within the Tuscan welfare system. Moreover, it aims to contribute to the growth in attention and qualification of Tuscan third sector organizations, and especially voluntary associations, regarding the theme of care for non self-sufficient elderly people. Using a mix of research techniques, all events where official collaborations take place locally between public institutions and voluntary associations regarding care for non self-sufficient elderly people – or support directed to carers<sup>1</sup> – were at first pointed out. Afterwards, by going in depth into 10 case studies, the needs have been analysed more thoroughly, as well as the planning and management of activities and services, while the main outcomes and obstacles encountered have been described. The different issues which have emerged will be analysed granularly within this paper, with the hope of giving a small but innovative contribution to the discussion of the matter at hand and also on the discussion on Social Added Value (SAV).

**Key words:** voluntary association(s), third sector, long-term care for non self-sufficient elderly people, Italy, welfare system, Social Added Value (SAV).

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<sup>1</sup> The authors used the word loosely to describe young women coming from abroad to care for elderly people, often without any professional qualification. This phenomenon is widespread in Italy, mainly involving young women coming from eastern Europe.

## **Introduction**

Long-term care for non self-sufficient elderly people is a core issue in most European countries, and its relevance is progressively increasing. Its weight on both public and private welfare systems is becoming heavier and heavier in Italy, due to present and well known concurrent phenomena, such as the increase in life expectancy for the general population, a progressive reduction in funds against a growing call for services, and ongoing modifications in both family structure and in the labour market. A deep understanding of the phenomenon is therefore crucial for all 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 long-term care for non self-sufficient elderly people described here finds its place. The study has been co-promoted and co-funded by Cesvot (Support Centre for Voluntary Organizations of Tuscany) and the Tuscan Regional Administration, and has been carried out by Qubica and the Volontariato e Partecipazione Foundation.

### **Long term care for non self-sufficient elderly people in Italy and in Tuscany**

Working on lack of self-sufficiency of elderly people is a complicated matter, and for many reasons. The first is the lack of a clear-cut definition of the phenomenon<sup>2</sup>. There are many different occurrences that can add up to form a diagnosis of non self-sufficiency, and a state of need can indeed be traced back to one or more psychical or physical problems, but the role of “socio-environmental” factors – like material living conditions (housing conditions, for example), the availability of economic resources, the presence of adequate support networks – must be taken into account as well. The second factor refers to the specificity of the Italian context, where a prevailing “family-driven” welfare system makes all changes in the structure of families – their increasing fragility during these past years first and foremost – and in the structure of social networks relevant elements for an appropriate consideration of new needs and requests for support. Furthermore, in Italy families are becoming more fragile because less and less children are born and from increasingly older mothers, two elements that, paired

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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).

with increased life expectancies, generate a higher care-related workload which is concentrated mainly on women who are less numerous and ageing<sup>3</sup>. At the same time, new forms of living together, such as common-law marriages, are increasingly putting the traditional solidarity networks that occur between generations (the so-called “widened families”) under pressure – which in turn makes it less likely, for elderly people, to live close to their relatives, and therefore to be able to receive an effective support with limited costs. Moreover, the job market has increasingly introduced more and more people to the condition of being temporarily employed for long periods of time, if not forever, thus making work-life balance even harder. This complex group of factors, which has here been described only in brief, makes the lack of self-sufficiency (particularly for elderly people) both a new “state of need” and a “structural problem”, an issue that socio-sanitary systems are trying to deal with, even if through scores of organizational and economic difficulties. An example of this situation can be seen with the creation, both nationally and regionally, of the experimental Non Self-sufficiency Fund (NSF), which was prematurely stopped for lack of resources at the national level. Created with National Law n.296/06, the national NSF, which was born to guarantee the implementation of base levels of care for non self-sufficient people, has received funding only for the years 2007-2010. The lack of funds for 2011 has been a great step back for our country, given the rise in need of intervention<sup>4</sup>, and regional administrations have been able to cope with it only partially. Some of those, like the Tuscan one, have been creating their own NSF, with which to both support economically the giving of services and to integrate local resources – which have been increasingly substituting national funds, like it has to all intents and purposes been since 2011. Tuscany's NSF was created in 2008, and from 2008 to 2010 it has distributed almost 197 million Euros to local health authorities for at-home care and to shorten waiting lists. Local centres have been activated to strengthen access to services, and some of the first results were an increment in at-home care and a drop of admissions in nursing homes.

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3 See also F. Tosi (2009)

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

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

How can the local resources that third sector and voluntary associations embody contribute to the process of care giving for non self-sufficient elderly people? This is the main question that sparked this research, and this is because voluntary associations are both traditionally numerous and well distributed in Tuscany, and also because, due to their characteristics and modes of action<sup>5</sup>, they appear to be able to significantly enrich the set of private and public services for non self-sufficient elderly people. But even if some of the case studies have reached excellent results, the number of associations that make activities for non self-sufficient elderly people an integral part of their identity is still quite small<sup>6</sup>, and this in turns speaks volumes about just how much this process of integration – and in some cases even of mere mutual acknowledgement – between public sector and non-profit organizations still needs work. Maybe, on this front, the present study could also give some input, since it highlights some of the defining traits of voluntary work in this specific sector and stresses how some of the associations are indeed a precious resource for their territories, as well as the number of issues that have been brought to light.

### **Methodology of the research**

A mix of quantitative and qualitative techniques were used in the research, since there was more than one objective. During the first phase, which was primarily exploratory, a census of all regional, provincial and municipal organizations (for municipalities above 10.000 residents) that declared their activity in the sector of non-self sufficiency<sup>7</sup> was made. To do so, the database of the National Centre of Voluntary Associations (NCVA) in Lucca was queried, since it integrates the updates coming from the institutional records of voluntary

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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.

6 As previously stated, the number of registered voluntary associations working in the field in 2003, according to Italy's National Institute of Statistics, ISTAT, is no higher than 2.2% of the grand total (Istat, 2005).

7 There is still no official record regarding actions and services directed to non self-sufficient elderly people or to family caregivers in Italy. Therefore, the census realized in this research was of a preliminary and exploratory nature, since only the sectors of activity of associations that were self-declared, and that were registered in the databases examined, were available.

associations and those coming from the records of voluntary associations that are part of Cesvot, the Tuscan Centre for Services to voluntary associations. Then, a specific inquiry, targeted to local representatives of non self-sufficiency public services, was made, with the aim to create – for the first time in Tuscany – a census of all active partnerships between local institutions and voluntary associations. The main characteristics and contents of all projects were also outlined, both for actions supporting elderly people and for those supporting caregivers. A further set of semi-structured interviews was conducted at the same time, targeted to some key witnesses coming from both voluntary associations<sup>8</sup> and from Cesvot's local offices, in order to outline the general level of involvement of voluntary associations regarding the subject at hand, and to bring to light case studies and experiments that were put into action outside of the perimeter of the usual private/public partnerships. The interviews allowed to outline the characteristics and the general dynamics at play for the subject, but also to pinpoint specific cases, on the territory, that were worth keeping in mind for the following stages. The second phase of the research, whose results and critical analysis will be described in more detail here, was mainly focused on the in-depth reconstruction of 10 case studies of voluntary associations that carry out actions for non self-sufficient elderly people. Semi-structured interviews were conducted as well, targeted towards all subjects (i.e. voluntary associations, local institutions, local health authorities and so on) that had a role in the creation and implementation of the actions: whenever possible, the recipients of such actions were also interviewed, even if this has been possible only in a limited number of cases.

## **Results of the research**

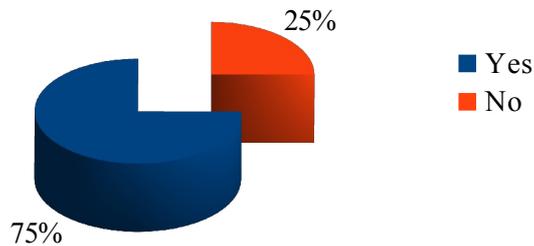
### **Types of activity and modes of implementation – the data of the survey**

The analysis of databases available on the territory paints a heterogeneous picture regarding the partnership between local health authorities and voluntary associations on services for non self-sufficiency in elderly people. Even though structured, strong and continuous relations are present in 75% of instances, their onsets are extremely variegated (see picture 1 below).

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<sup>8</sup> Coordinators of regional voluntary associations that are particularly active in the sector of non self-sufficiency (in accordance with the query of the NCVA's databases) were also interviewed.

**Picture 1 - Does the local health authority have any ongoing relationship with voluntary associations on projects directed to non self- sufficient elderly people at present?**



The territorial distribution of these partnerships appears to be in a haphazard fashion: there are areas without partnerships (25% of the local health authorities say they have no relationship with local voluntary associations on the matter) right next to areas with lots of activities (some local health authorities can have something like 21 active partnerships at a time). Relationships are almost always official (see picture 2 below) and mainly financed through conventions and agreements.

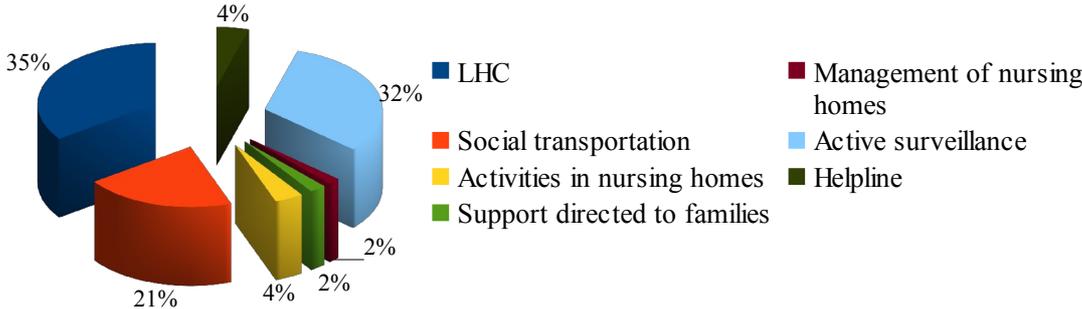
**Picture 2 - Type of relationships (percentage)**



Voluntary associations are mainly part of a wider regional structure (second-level associations) and with a greater history of intervention in the health, social and socio-sanitary sectors. They are also the most widely distributed 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 at any given time. On the other hand, there are also cases where actions are undertaken by purely local associations – that are historically active in the area or strongly present among the local population – or by sector-specific (or disease-specific) associations, like those that specifically deal with patients suffering from Alzheimer's disease. The activities (see picture 3 below) detected are, on one

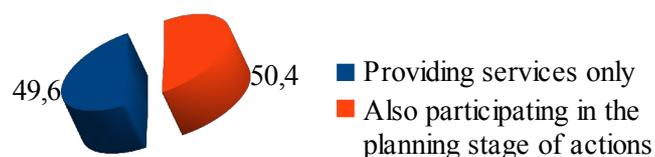
hand, those that can be more “easily” managed by voluntary associations, like light home care (LHC), active surveillance or social transportation, and on the other hand those that – given the diversity of their practical implementations – are more likely to give a ready, effective and sustainable answer to the needs of a territory, oftentimes integrating a complex and structured system of actions coming from public institutions and from other actors of the third sector, like social cooperatives.

**Picture 3 - Activities**



Actions are furthermore everything but occasional in their occurrence and in the majority of cases are almost day-to-day. They are mainly carried out thanks to the efforts of voluntaries, and are integrated in a noteworthy percentages of instances (roughly 30%) by the support of paid personnel. The process of networking and the ability to go beyond partnerships with public institutions only characterize more than 64% of collaborations and it mainly refers to other voluntary associations or other forms of third sector actors. For-profit actors, on the other hand, are almost never considered. When public institutions are the main partners of voluntary associations, the associations are asked to be active participants in the planning stage of actions only in 50% of cases (see picture 4 below). This is without a doubt a limitation of the system, since not including voluntary associations in the planning stage – even when the smaller skillset and degree of professionalism that are sometimes intrinsic to voluntary action are taken into account – means keeping a meaningful and important point of view, and a precious first-hand experience, out of the loop and out of the system.

**Picture 4 - Actions carried out by voluntary associations when in partnership with public institutions (percentage)**



The relationship between public institutions and non-profit actors also appears to be weak regarding the monitoring and evaluation system regarding the quality of services given: even when present, it is likely to be no more than a standard account of completed activities, or an evaluation through questionnaires and reports. This particular detail keeps the entire process of participation and engagement of users – a factor that could greatly improve the growth of the entire system – in the background.

A closing note must be dedicated to services given to caregivers by voluntary associations, which is another theme that the research focused on in this phase. The survey paints a poor picture: active projects are few (only 13) and 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), reception-related (4) or related to pairing job offers with job seekers. Unlike the previous observations, voluntary associations are actively engaged in the planning stage of these actions, a fact that could indicate a greater degree of freedom in the proposing of projects within a sector that, at the moment, does not appear to be central in the activities of the local health authorities.

### **Case studies: activities and procedures**

By using a micro-oriented perspective, which analysed the dynamics at play and the internal mechanisms of the relationship between public institutions and voluntary associations and described the viewpoints of all actors, the case studies offered a chance to examine in depth some of the themes that were previously enunciated, as well as further remarks on:

- the theme of participation;
- the theme of relationship with institutions and other actors in the territory;

- the theme of organizational identity and the nature of voluntary action;
- the theme of training and monitoring;
- the theme of evaluation.

In the following paragraphs, the observations regarding these themes will be described at length. The authors consider them to be – regardless of the single case studies that prompted them – food for thought not only for voluntary associations that want to try their hand at planning and performing support actions for non self-sufficient elderly people, but also for all the actors that might help them in the matter, particularly public institutions and other third sector actors. The authors are also of the opinion that, in accordance with what has been previously stated regarding the matter at hand and with the goal of making a contribution to the definition of third sector's and voluntary associations' Social Added Value, these same considerations can function as a support and as a boost to further qualify the actions that will take place in the territories, mainly for voluntary organizations and public institutions.

### **Participation between voluntary associations and public institutions**

The theme of participation represents a good starting point because it is the first that has to be faced when the case studies at hand are examined. It is a participation that is tied with the planning stage of the project, 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 have been evolving in time due to the ability of working together of volunteers on projects and initiatives, putting different skillsets and expertises in synergy and creating new ways of participation and sharing. Alongside these accounts of a subsidiarity that is seen as necessary for the realization of effective socio-sanitary actions, however, there are experiences – and sadly they are not a minority – that lack this altogether. It is indeed not uncommon, among the case studies, for the relationship between public institutions and voluntary organization to be almost “on demand” when the local health authority is faced with specific requests and in need of ad-hoc actors that can provide support and help. When this happens, projects are mainly managed by the public institution, which to all intents and purposes defines the characteristics of the service needed on a case-by-case basis and contacts voluntary associations to have that need serviced only

after that. This process can represent a stimulus for the voluntary associations of the area, since it faces them with problems, activities and needs that force their collective hand towards openness, learning and ultimately developing new skills. In other cases, however, this process can have at least partly negative consequences on the activities that are put into action, and this is related to two main factors:

- the risk of a growing frustration in the voluntary personnel or of an incomplete or inadequate usage of the various resources, both human and social (knowledge of the local society, organizational skills and so on) 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 therefore their potential growth.

Obviously we are examining two entities, public institutions and voluntary associations, that have very different point of views and goals, and the ever more pressing needs that the public service must address with progressively more limited or insufficient resources must be taken into account. But when needs becomes heavier, it becomes even more important – and some of the case studies demonstrate this – that local resources work together, and that the abilities and skills of every actor are allowed to work at their full potential<sup>9</sup>. This can translate into the necessity to go “back to the drawing board”, in a way, with the phase that analyses the needs of a territory and to plan interventions in such a way that all actors, both institutional and voluntary, are allowed to suggest, experiment and share different project experiences.

### **The relationship with structures and other actors in the area**

The aforementioned topic is partly tied to the relationship between voluntary associations and the other structures and actors in the area, particularly welfare officers and general practitioners. Regarding these two actors, an ongoing relationship with volunteers and their organizations – given that everyone's area of competence is respected, and that the privacy rights of every single patient are fully protected – becomes fundamental for the providing of

<sup>9</sup> 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 the resources that every association can bring to the table at their best.

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. There are cases in which this relationship is even too strong, not geared towards a true interaction, but rather towards a sort of a “cry for help” that welfare officers direct to voluntary associations, which are gladly given a monitoring and surveillance function but oftentimes without a strong coordination power and mutual relationship. These attitudes, even if they are well understood by volunteering personnel, can generate frustration in their ranks, since they can feel like mere appendages of a system, rather than a true part of it. And this is not only a problem of safeguarding the well-being of human resources – which is of course fundamental – but rather a problem of proper management of resources, energies and experiences that, by not being properly linked together, are more likely to not be used at their best.

### **Organizational identity and the nature of voluntary action**

The authors defined in this way the relationship that, in the case studies, is evident between the role that voluntary associations have in projects as organizations and as aggregators of volunteers.

Even if only formalized collaborations between public institutions and voluntary associations – with a single exception to this norm – were taken into account, there is a substantial difference between those voluntary associations that provide services with both voluntary and non-voluntary personnel and those that deploy voluntary personnel only, in some cases supported by paid personnel that – in accordance to National Law n.266/91 – contributes to the structure's activities and guarantees a continuous service, or deals with specific functions. This difference is strongly related to the type of service that the single association must provide, since while some of them need a highly specialized professional skillset others can be defined as “lighter”, and can therefore be provided by actors with a lower level of expertise, only trained with some basic course accessible to everyone, regardless of their profession or qualification. In this case we face something which could be called a more “pure” volunteer activity, but this condition, given the growing complexity of the services needed, is at the same time a way to guarantee a qualitative difference between professional providers and volunteer providers and a sort of constraint for voluntary associations that

oftentimes also face the risk that the single volunteer, in his “willingness to help”, might be ready to do things that he must not because he lacks the necessary skills. 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 being a service voluntary is a defining characteristic: volunteers have a very different attitude towards both the service provided 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, and that ultimately strives towards prevention also through the use of community networks.

### **Training**

Of course, as has been mentioned above, training and technical expertise deeply differentiate – among other factors – service providing in the field of care for non self-sufficient elderly people. Regarding this matter, volunteers and their associations 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. And associations are without a doubt capable of skilfully creating relationships networks that can keep the flow of informations 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 the network of actors in the area 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 theme of monitoring and evaluation of the interventions is key, and many of the examined associations do not seem to value these processes for what they are worth: they do not seem to have created ad-hoc evaluation systems for the services they provide, or systems that can be autonomous from those of the institution. The same can be said for public institutions as well, since in the majority of cases they simply monitor the number of complaints or purely quantitative accounts, based on number of accesses and services provided. In most cases, then, the evaluation 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, 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 the case studies only rarely change over time: generally speaking, they are projects and services that are born inside very strict boundaries and that are carried out year after year with few modifications, if any, whereas evaluation – and the use of the data that comes from it – 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, at the same time 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. They also have the collateral effect of continually re-motivating all actors in the process, avoiding routinization and stimulating learning and critical thinking.

## **Conclusions**

The involvement of all actors, recipients and volunteers/operators included, in the portrayal of the case studies has allowed for an in-depth analysis the qualitative dimension of services, and to describe in detail the complex system of relationships, expectations and needs that have an impact on the life conditions of the non self-sufficient elder person. The narrations allowed the authors to assess the added value that comes from the volunteers' activities

carried out within official partnership with public institutions, since 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 influence the strategies of monitoring and prevention of the transformation of the subject from frail/alone elder person to non self-sufficient person, in the cases where 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 the subjects that the 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 fabric 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 psychophysical stress of the caregiver – 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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