



Health systems and long-term care for older people in Europe  
Modelling the interfaces and links between  
prevention, rehabilitation, quality of services and informal care

## The role of informal care in long-term care

### National Report Italy

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# 1 Introduction and Background

## 1.1 What is understood by “informal care” and “formal care” in Italy? What are the main definitions used to distinguish between the informal and formal care sectors?

We can define “formal care” all services and financial support mechanisms which are fully or partially provided and somehow also controlled by the public authority as for their target and/or their standards of quality. Assistance is provided by paid experts, who are specifically trained and coordinated by highly qualified professionals. With respect to social and healthcare services, management is often in the hands of private subjects according to a public-private partnership. Long term care to aged people are structured in residential services (residential nursing homes and residential care homes), semi-residential services (day care centres), domiciliary services (Social Home Care, SHC and Integrated Home Care, IHC), cash benefits (family allowance and attendance allowance), and support to private care work (tax reduction, targeted subsidy, training courses, registers, matching supply with demand information centres). National, regional and local competences interweave in long-term care policies: attendance allowances and tax reductions are under the responsibility of the State, Regions are responsible for social and health services and Municipalities for social services.

The boundaries between formal and informal care are hard to define. For instance in the Veneto Region, regional benefits to support the needs of people with LTC needs are mainly granted to families who pay for a (mostly migrant) family assistant.

## 1.2 Cultural and current political context: How are issues of informal/family care and LTC services discussed?

In 2006 a special Fund has been set up for people in need of LTC, with € 300 million per year for three years (2007-2009). Under the budget for 2008 a further amount of € 200 million was guaranteed for 2008 and 2009, but for 2010 the Fund risks to be cut down. The Fund is proportionally distributed to the Regions, allowing them to improve initiatives of long-term assistance, outreach services, residential services and support the network management. Some regions have used the fund to carry on out-and-out reforms of the system, aimed at re-outlining and strengthening all services for older people (e.g. Emilia-Romagna, Lombardia, Liguria). The Fund aims at ensuring the same system of social protection and care for people in need of LTC all over the country by means of:

- a) providing or strengthening one-stop services,
- b) activating ways of care towards the not person in need of care through an individual action plan, which includes social and health care interventions,
- c) activating or strengthening social and health care services, with home-care as a priority.

Apart from the Fund for people in need of LTC, today there is a general consent in considering the offer of publicly funded long-term care as insufficient. The key issue discussed in Italy is thus about the funding of LTC services for older people. Some believe that targeted public expense must be increased,

also considering comparisons with other European countries; others (a minority of the Italian experts) believe that the necessary improvement of care is to be obtained by means of private insurance.

The second crucial issue is the relationship between public services, older people in need of assistance and their families. Those who support a public system of care for older people and their families, point out their demand of more accurate information to face their needs by developing more coordinated interventions and services provided by the currently fragmented local welfare systems. As of today, users' choice between services is limited as well as continuity of services across the 'chain of care' from assessment to a continuous monitoring and review of care provision. Currently, some experiences are made in order to introduce one-stop services, while multiple access is the rule for the older users (GP, hospital, voluntary organizations, parish and so on). In many areas there are long waiting lists to access a geriatric assessment unit in order to set up a personal action plan. Case management to help the user in getting access to services is completely missing although, in theory, this function should be fulfilled by the GP.

A last issue relates to the debate about cash benefits. The attendance allowance and family allowances absorb almost half of all public expenditures for long-term care. Reform options include the transformation of cash benefits to more benefits in kind with a strong role of social and health professionals in initial assessment and individual care planning. In addition, more control on the use of cash-benefits has been claimed to ensure that cash benefits are used buy services. Today, those who receive a cash benefit and their families are mostly left alone, with no suggestions on how to use it and no help in their relationship with local services.

### 1.3 Legal aspects of care

In Italy everyone (old person or not) who is in need, can ask those having a legal obligation<sup>1</sup> to pay for alimony, that is either an economic support to face the situation or a request to go and live together with a member of the household.<sup>2</sup>

In Italy up to 331 hours a month and 420,000 hours a year are presumably spent by one or the other family member helping an older relative. Between 1983 and 1998, the number of people involved in taking care of a relative, is estimated to have grown by 21%.

According to some surveys made by INRCA on primary carers, care work is on average 92 hours a week, but in more than one third of the cases, care work spreads out over the day; the average number of hours spent in care activities varies also according to the professional condition. In fact, while women working as public officers spend 7.7 hours on average, women working in the private sector spend 8.5 against 12.8 hours of pensioners and 15.4 of housewives. When older people are affected by dementia, the average number of hours for their care can raise up to 22 hours a day in case of acute dementia.

Carers have to do with all the supporting activities necessary to the cared person. Among the tasks performed by the family carers, there are personal care and hygiene, cooking and serving meals,

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<sup>1</sup> In order: the partner, sons and daughters, sons and daughters in law, mother and father in law, brothers and sisters.

<sup>2</sup> Articles 433, 438, 443 of the Civil Code.

keeping company, going shopping and housekeeping. Always the family members are those who have the task of taking control of formal and informal helps available.

## 1.4 Main components of services in the national LTC systems (public, private, NGO)

In Italy, most of the care provided to older people in need of care is by the family, as informal help, and only as second resort comes the network of private and public services. Besides, it is crucial the role played by private assistants at home, usually coming from other countries and women, privately hired by the old people's family in order to face the needs of support and care of the not-self-sufficient person. The contribution provided by the private assistants overcomes, and sometimes by far, the contribution of "formal" care supplied by public or private organizations, in all the fields of action except the field of healthcare.

Public services of long-term assistance for older people are structured in residential services (residential nursing homes and residential care homes), semi-residential services (day care centres), domiciliary services (Social Home Care, SHC and Integrated Home Care, IHC), cash benefits (family allowance and attendance allowance), and support to private care work (tax reduction, targeted subsidy, training courses, registers, matching supply with demand information centres). Attendance allowances and tax reductions are under the responsibility of the State, social and health care services are under the responsibility of the Regions and social services of the Municipalities.

**Table 1 Public long-term care for older people in Italy**

<i>Areas</i>	<i>Services</i>
Home care	Integrated home care assistance (Assistenza domiciliare integrata - Adi) Social Home care assistance (Assistenza domiciliare sociale -Sad)
Residential services	Health, health-social structures (Nursing homes) Social structures (Old-age homes)
Semi-residential services	Integrated day centre Day centre
Cash benefits	Attendance allowance (Indennità di accompagnamento - € 472/month) Family allowance (Assegni di cura - variable)
Support for private home care (migrant private assistance)	Tax reduction, family allowance, training course, register, job help desk

Source: adapted by Studio Come, Rapporto non autosufficienza, 2009.

**Table 2 Coverage of services**

<i>Services</i>	<i>% of older people covered</i>
Integrated home care	4.9%
Residential services	3.0%
Attendance allowance	9.5%

Source: adapted by Studio Come srl, Rapporto non autosufficienza, 2009.

At national level, in 2008, Integrated Home Care only reached 4.9% of older people. However, it covers on average only 24 hours per year for each individual user. From 2000 to 2005, the number of older people in residential structures (nursing homes) increased from 318,203 to 345,093 (3%). A similar trend could also be observed in the offer of places in old-age homes (care homes with reduced nursing). In 2005, older people admitted to residential facilities were distributed as follows: 38.3% in nursing homes, 33.1% in old-age homes with some nursing provided, 24.3% in 'traditional' old-age homes (social care only), and finally 4.3% in other facilities. The offer of residential facilities for older people is extremely different from region to region, and it increasingly decreases the further South of Italy a region is situated. During the past few years there has been a relevant increase in the offer of places in nursing homes that, from 2000 to 2005, have increased up to 24,400<sup>3</sup> places, while traditional residential care homes have seen an absolute decrease, as autonomous older people tend to prefer staying at home instead of moving to a residential facility. Those who are in need of LTC, however, increasingly ask for admission to residential facilities; this is why many old-age homes are inadequate and have started a conversion to meet the requirements of people with both social and health care needs.

Among the measures available for LTC in Italy, the attendance allowance is the most relevant measure not only for the high number of beneficiaries but also for the amount of public resources involved. In 2008 there were 1,131,710 people above the age of 75 entitled to this benefit, representing 9.5% of the population in this age group for a total amount of € 6.3 billion.

This benefit thus absorbs more than half of public expenditures for disability and older people in need of LTC, thus overcoming by far the beneficiaries of home care and residential care ((Ministry of Health, 2008).

About 70% of entitled persons are female and about 59% of all women receiving the allowance are now over eighty years old. On average, the allowance is paid for about 7 years per beneficiary (Ministry of Health, 2008).

Apart from the attendance allowance, family allowances for LTC needs are granted by the regions. In Northern and Central Italy reaches this benefit is granted to at least 1% of the older population, with a sharp increase in Bolzano-Alto Adige, Veneto, Emilia-Romagna and Liguria. The situation in the South is not well documented, but the number of entitled families is negligible. Regions – though investing increasing resources on this measure – progressively decrease the average amount of the allowance, since policy-makers prefer to extend the number of beneficiaries to the detriment of the individual amount granted.

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<sup>3</sup> In Italy the offer of services has an average of 2.3 beds every 100 older people, but there are huge differences between Northern and Southern regions, with the Province of Trento at the top of the ranking (5 places per 100 inhabitants 65+) and the Basilicata at the bottom with only 0.5 places per 100 inhabitants 65+.

**Table 3 Regional LTC for older people, 2005-2007**

Regions	Users in % (older people)	Older people in residential structures in %	Percentage of places in old-age homes	Older people in integrated home care (ADI)	Hours for ADI (average per user per year)	Expenditure for ADI as a percentage of total health expenditures
Friuli-Venezia Giulia	17.4	7.6	20	7.2	17	3.15
Emilia-Romagna	12.0	4.4	30	5.7	23	1.94
Veneto	11.8	4.6	19	6.4	14	1.11
Molise	10.2	2.5	22	3.7	12	0.70
Liguria	9.6	5.2	6	3.2	25	0.93
Lombardia	9.1	3.8	3	3.6	18	0.82
Piemonte	8.5	5.2	55	1.8	25	1.13
Abruzzo	8.1	1.9	30	3.6	33	0.86
Marche	7.9	3.1	43	3.9	28	1.66
Umbria	6.5	1.6	28	4.3	17	2.23
Lazio	6.4	1.4	60	3.8	21	-
Basilicata	5.9	0.6	61	4.3	44	1.37
Toscana	5.6	2.3	20	2.1	25	1.46
Sardegna	5.4	1.7	50	1.2	71	0.70
Sicilia	4.9	1.1	42	1.0	37	1.44
Calabria	4.8	0.6	29	2.7	17	0.37
Campania	3.7	0.6	70	1.6	59	0.38
Puglia	3.5	1.1	57	1.6	52	0.35
ITALY	7.9	3.0	28	3.2	24	1.08

Source: Rapporto non autosufficienza, 2009.

Though never declared, attendance allowances and family allowances are often aimed at providing a salary to the family assistants. Some Regions have decided to provide economic support mainly to those older people who are hiring a family assistant; this is a different measure from the usual non-earmarked family allowance that was mentioned before. In particular, Abruzzo, Emilia-Romagna, Veneto, Valle d'Aosta, Friuli-Venezia Giulia and Sardegna have linked this benefit to the existence of a regular contract between the family and a family assistant. The benefit is thus not only aimed at supporting the families but also legal contracts to turn irregular into regular employment. This economic support is usually spent to cover the social security contributions.

The extent to which families take advantage of these measures seems to be a problem: the real users are much less than the potential ones because the families, with limited economic resources, prefer to recur to the irregular market, thus giving up their right to an economic support. From this point of view, the quantity of contributions is a key element on which take action at regional level.

There are tax reductions for those who employ a family assistant. Those having an income below € 40,000 can benefit from a reduction of 19% of the total contributions paid up to a maximum amount of € 2,100 (i.e. a maximum of € 399). Employers may also claim a tax deduction within a limit of € 1,549.

**Table 4 Coverage and amount of regional attendance allowances**

<i>Regions</i>	<i>Denomination and year</i>	<i>% of older people 65+</i>	<i>Average amount par month</i>
Provincia di Bolzano	Attendance allowance "Assegno di cura" (2007)	about 3%	515€
Veneto	Attendance allowance "Assegno di cura" (2007)	2.2	200€
Emilia-Romagna	Attendance allowance "Assegno di cura anziani" (2006)	1.9	246€
Liguria	Attendance allowance – Regional fund for older people in need of care "Misura economica del Fondo regionale per la non autosufficienza" (2008)	1.6	330€
Friuli-Venezia Giulia	Attendance allowance "Assegno per l'autonomia (APA)" (2007)	1.0	375€
Lombardia	Attendance allowance "Buono sociale" (2006)	0.9	-
Provincia di Trento	Attendance allowance "Sussidio per la cura domiciliare di un anziano non autosufficiente" (2006)	0.6	354€
Umbria	Attendance allowance "Assegno di cura" (2005)	0.4	418€
Toscana	Attendance allowance "ADI indiretta" (2006)	0.3	-
Piemonte	Attendance allowance Assegno di cura (2006)	0.2	-
Abruzzo Calabria Sicilia	Attendance allowance since 2003 (Sicilia e Calabria), 2006 (Abruzzo) (estimate)	< 0.3	-
Puglia Sardegna	Since 2007 (Puglia) o 2008 (Sardegna)	n/a	n/a

Source: Rapporto non autosufficienza, 2009.



**Table 5 Attendance allowances for migrant private care**

<i>Regions</i>	<i>Access criteria</i>	<i>Amount</i>
Abruzzo	assessed LTC needs Isee (social-economic situation of the older person) Contract for private assistant	max € 300/month
Emilia-Romagna	assessed LTC needs Isee (social-economic situation of the older person) max. € 10.000/year Contract for private assistant	€ 160/month*
Friuli-Venezia Giulia	assessed LTC needs Isee (social-economic situation of the older person) max. € 35.000 Contract for private assistant at least 25 h/week	From 25 to 39 h/week: € 120/month; more than 40 h/week: € 200/month
Veneto	assessed LTC needs Isee (social-economic situation of the older person) max. € 14.992 Contract for private assistant at least 24 h/week	max € 260/month on the basis of the amount of care assistance (hours)*
Sardegna	Disability assessed Isee (social-economic situation of the older person) max. € 32.000/year Contract for private assistant at least 6 h/day and 6 days/week Private care assistant registered Training for private care assistant	€ 3.000/year
Valle d'Aosta	assessed LTC needs residence in the Region Private care assistant registered In the future: private care assistant registered	max € 1.800/month, on the basis of the amount of care assistance (hours), the co-habitation, the number of assistants.

Source: elaboration of IRS, 2008. Note: \*) "Private care allowance" is paid as a supplement to the attendance allowance.

## 1.5 Data on informal family carers and other informal unpaid carers

National data referring to 1998 show that a number of caregivers equal to 20.5% of the population aged 14 and over, while the number of households taking advantage of informal care has decreased. According to ISTAT, we can say that about 6.3 million people (56% of a total of 11.2 million) provide help to other family members who are not living together. Care work is particularly intense in those areas where formal services are scarcely available (especially in the "familist" regions of the South and in the rural and alpine areas).

National data highlight that care to older people is most frequently provided by sons and daughters (68%), the partner or other relatives living in the same house (48%), or other relatives living away (26%). 70% of the carers are women, most of them temporary working in the field of services, which is typical for its greater flexibility. The percentage of women who provide care increases according to the extent of care needs, ranging from 73.8% to 81.2% in case of severely ill patients. In most cases, it is the daughter (37%), the wife (10.6%) or the daughter-in-law of the old person; in fact it seems that daughters and daughters-in-law are involved in care activities for more than 13 hours a day.

A survey carried out by INRCA pointed out that almost half of the carers (both primary and not) live in the same home as the cared person (42%) or within short distance (32%). According to other national surveys, the percentage of carers sharing the same house as the cared person can reach 65-75%, in case of severe disease (Vaccaro, 2000).

As pointed out by the results of the national survey ESAW, the carers' average age is 61 (ds  $\pm$  8,4 ), being lower for women (60.8 years against 61.7 of the men). The survey carried out by INRCA on the primary carers above mentioned, detects a not negligible 10% who provide care although old and sometimes even aged well over 80.

## **2 Main links and interfaces between informal carers and the health and long-term care systems**

### **2.1 Policies for informal/family carers of older people in need of LTC**

Traditionally in Italy there hasn't been a specific policy for informal care, since care in the family has always been considered as granted (as a family duty). Undoubtedly a well-known support now is money transfers. At national level there is attendance allowance. At regional and local level, economic support to the families providing home care to an old member being no longer self-sufficient is essentially in the form of family allowances. These are economic helps, based on need and income, that Municipalities and Local Health Authorities provide to the families of older people in need of care to support them in their effort of care: they have been largely introduced at local level recently. Family allowances are quite common, particularly in Northern and Central Italy. The value of these allowances varies significantly from one local context to another. Rules define these contributions as instruments to help the families, but often they are used in order to buy assistance from private assistants irregularly employed. Without coordination and monitoring measures, these allowances can end to be just money to buy private care through irregular employment.

Another support for the carers is the possibility of getting paid for the hours used as time off work to assist the needy family member. In Italy, under the law 104 of 1992, the worker who provides care to a family member with care needs – whose status is officially recognized as severely handicapped – has the right to take three days off every month during all his/her life's work.

Besides, carers have the right to get a paid permit of three working days every year for documented acute illnesses of the partner or relatives up to second degree (husband and wife, sons and daughters, parents, brothers and sisters, grand-parents and nephews or nieces) or the co-habiting partner (Law 53/2000). In addition, public and private employees, in case of serious and well-documented family reasons, can ask for up to two years – all together or in fractioned periods - of family leave which is not paid, so as to provide care to a family member with care needs. During that period, the employee keeps his/her job, gets no pay and cannot perform any other activity. Law also regulates working time flexibility with measures in support of it such as contributions to enterprises implementing contracts with positive actions of flexibility and training programmes towards reintegration contracts after a period of leave (Law 53/2000).

## **2.2 Links and/or gaps between informal carers of older people and their use of formal care services**

In Italy as well as in other countries, professional care and family care are not considered as alternatives any longer, they are instead complementary activities to be connected and integrated through measures of support to family care. Therefore, in many regional and local areas (the most advanced) family care is explicitly taken as an important element to assess care cases and suitable measures to put into action.

However, the continuum between formal and informal care is usually very difficult to implement because it is hard to make formal and informal carers cooperate together, especially for two reasons:

- First, formal and informal carers differ for the amount of time they can dedicate to care activities. While professionals supply a service under determined expectations and certain time, family members have no start and no end in the care they provide.
- The second reason is the fact that a formal carer has got specific skills and specialized information, while informal carers act according to their personal information, based on previous experience coming from their own environment. This difference makes the professional carers feel superior and this is actually a limit to cooperation (often just seen as a supervision of the public on the private service). All that generates a sense of closure and isolation in the informal carer who is actually set apart from the network established in support of the older person with care needs; so the informal carer is let alone to cope with critical situations deriving from the old person's worsening conditions.

## **2.3 Positive and negative aspects of care-giving**

Assistance by a family member allows the old person to keep on staying in his/her own house. Therefore family ties are preserved, as well as inter-generational relationship (sons-nephews) and social network, thus positively affecting life expectations. However, providing care to a family member involves (sometimes very radical) changes in everyday life also affecting the carer's working life and health conditions. Family care to older people in Italy is in fact characterized by the parallel issues of "continuity" in time (long periods of assistance) and pervasiveness – intensive care tasks are determining a dangerous mix in terms of high risk of stress and work overload both for the family members and many family assistants. In order to face the situation, assiduous effort and long-term care can gradually wear the carers out, either physically or psychologically, with a negative impact on the

personal and relational balance for the caregivers involved. As a matter of fact, on the one hand family plays a protective role for the older person, on the other hand family carers are presumably in need of protection and help themselves. Indeed, family carers (if not the entire family) are forced to change their way of living when older family members start needing heavy care. At the same time, the great majority of carers are un-experienced and, at the outbreak of a disease, they suddenly feel unable to play that role as it is shown by the overwhelming gap often perceived between the quantity of requests and needs of the person in need of care and the personal needs and resources available.

It is thus possible that caring leads to stress, anxiety and different forms of depression; loneliness due to lack of time to dedicate to oneself and to social relationships; contradictory feelings of anger, fault, and excessive involvement (in particular as a reaction to the patient's behavioural troubles); a feeling of disappointment and emotional emptiness, pain and impotence, usually leading to a low level of life satisfaction.

With respect to carers in paid employment this situation produces 'interference' particularly in terms of reduced working time, more part-time work (if such options are at all possible), and in some extreme cases even dismissal and early retirement. Once more it must be underlined that most caregivers are women; women's employment level in Italy is well below the average European level and far from the Lisbon's objectives also due to the lack of care services for older people and children.

## **2.4 Support for family carers and its impact on the care process**

Information and "training" services on how to provide care to an old person give the family members a major awareness on their own capability and knowledge of the service system, thus facilitating their task and helping them to improve care quality. Care Education and tutoring are particularly useful in the first period of care and whenever facing critical phases in the care work (cared person's worsening health conditions, emergencies, admission to or discharge from hospital, absence of the family assistant etc.).

Relief services allows the family member to "recharge batteries" in order to preserve his/her own personal and family life, his/her physical and psychical health and again to avoid any full immersion in the care process, ending with a feeling of isolation. For this reason, in addition to relief services, it's important to structure listening groups, family care associations, free time activities helping the family member not to feel alone in the most difficult situations. These groups have as an objective to talk about common problems about the care provided to older people with care needs, trying – whenever possible – to find out common solutions and mutually supporting each other through information and solidarity.

Economic contributions give the old person more opportunities to stay home, thus preserving family and social ties. A steady economic, social and relational situation improves life quality, not only for the cared person but also for the family assistant.

## 3 Description of the ‘good practice discourse’

### 3.1 How and by whom is good practice defined?

Many Regions have promoted measures to support family members taking care of older people with care needs.

- In Trieste, the local health authority has a project in support of informal carers dealing with older people affected by Alzheimer’s disease. The objective is to reduce the consequences of the illness, by means of a service network. The project aims at identifying and activate some little but precious tools for caregivers, so as to help them to positively face the everyday problems, supporting their hope and trust by combating loneliness. The project includes a training course for caregivers. This course has as an objective to soothe the pain suffered when a family member is affected by Alzheimer’s disease, and to help people become more efficient, also by exchanging and sharing similar experiences between carers.
- In Regione Lazio, the LHA RMC in cooperation with the association “Alzheimer Uniti Roma” has promoted a series of actions to support people suffering of Alzheimer’s disease and their relatives. Courses are regularly offered to the families of people suffering of Alzheimer’s disease. In those courses, medical and behavioral aspects are explained so as connected to the disease, including cognitive deficiencies and behavioral attitudes. Psychological aspects are focused on the issues of family care, patient’s management, and all the emotional aspects of assistance.
- In some hospitals in Rome, there are supporting groups open to the family members of Alzheimer’s disease patients, or other forms of dementia. In the group, families share experience, talk about their difficulties and find out important solutions on how to treat the disease and how to relate to the ill person. From the shared experience between family members, some indications on paths and strategies to face critical situations come out. This is a way to help understanding, acceptance and embrace solidarity between participants.
- Lombardia Region has adopted the tool of social and healthcare vouchers for its users. It is about home care provided by the local health authorities. Vouchers can be of 362, 464 or 619 Euros a month and they must be spent, by the families who apply for them, in accredited facilities. Everybody can have access to the voucher, with no limits about income and age, being the only condition that the person is actually fragile and in need of home care at that moment in time.
- Veneto Region has started a pilot project to offer economic support to the families recurring to regularly employed family assistants in order to take care of their family members with care needs. The project, in its first phase, had a budget of € 5,467,500 to be given to the families in form of vouchers paid by the Municipalities.
- Valle d’Aosta Region has provided for the supply of economic contributions aimed at the payment of fees in residential homes, as well as private care services alternative to institutionalization (usually this task is up to the Municipalities and not to Regions).
- Friuli Venezia Giulia Region has established a special fund to convert some properties owned by the Province of Trieste into social gathering centres in order to develop interpersonal and group relationships between family members and old people affected by Alzheimer’s disease or senile dementia. All the regions are gradually stressing the importance of providing social and health care on a regular basis, monitoring the quality of the services etc.
- Emilia-Romagna Region has introduced, together with family allowances, the new position of case manager (usually a social worker) in order to ensure steady care to the older person with care needs,

thus providing a unique and clear reference point for the cared person and his/her family members. In the same region, there's a project for senile dementia. In every LHA there must be a consulting office as a support to the services, tasks of which include guidance, monitoring, coordination between medical staff and family, and between hospital departments and care services. Concerning the support to the families, every health district keeps a certain number of beds available to temporary hospitalizations of people affected by dementia, and organizes training courses for family assistants, thus offering a deep knowledge of medical, psychological and behavioural aspects relating to progression of disease.

## 4 Family carers' private solutions to care and their links with the formal health and long-term care systems

### 4.1 The use of migrant workers in the field of LTC at home

Recently, a new term has been introduced in order to define the work made by a private assistant in a home environment. Overcoming the Italian word "badante" (that we might translate as "caretaker", a person working as a sort of custodian taking care of older people), we now use "family assistant". And this is not only to better describe the work of care made by plenty of foreign women (sometimes men too) in the Italian households with older people in need of care ...The new term also shows how public institutions in Italy have eventually become aware of the issue.

The increasing number of private workers taking care of people and the fragility of both involved (the old person and the immigrant) stimulated a lot of Italian authorities (particularly Regions and Local Authorities) to take action in support to and to face the problem of private assistance in a home environment (matching demand with job supply, training initiatives, economic support etc.). Notwithstanding the growing pressure of issue there has not been any coordination in the Government's policies nor uniformity at local level. At regional level too, in the new rules and regulations for the services, it seems that this type of care still does not exist. Apart from the scarce attention paid by national and regional laws – except for some good examples<sup>4</sup> – indications to public care services' workers are scarce, e.g. on how they should relate to and deal with the private care workers. The following example is emblematic: in the Integrated Home Care service much effort is to find tools and resources to support coordination between social and health workers, whereas finding out suitable ways to develop coordination between public and private workers seems to be of little interest.

In Italy, local authorities – urged by the growing needs of older people – are particularly those choosing home services as a social policy strategy within the new models of welfare including private care.

Without private home care, in fact, two targets of the Italian society – the older people at home and their daughters/daughters-in-law who work – are thrown into crisis. No professional service is able to

<sup>4</sup> Friuli Venezia Giulia, Sardegna, Emilia-Romagna.

cover, at sustainable costs, the assistance needed by older people in need of care at home. And without 24-hours care services, the burden of care is completely on the family.

There are no indications at national level also referring to another crucial issue: how to consider the presence of private assistance in the public service access? The question is particularly relevant in many cases, when the demand is larger than the offer of services. In several local areas, a scarce attention by the policy makers has brought about a limited action by the social and healthcare services towards private assistance. Anyway, if in the previous years the approach of the public body towards private assistance was mainly about contributions to cover the costs without showing any interest in how the service was supplied, a lot of local authorities have started to introduce measures aimed at ensuring and improving quality in the area of private assistance (private workers' training, a register of family assistants, information support, match of supply and demand, tutoring etc.).

## **4.2 A rough estimate of the proportion of directly paid migrants providing care at home**

Taking care of people with care needs is largely tackled by families (wives, daughters, daughters-in law) who, in the absence of any other support, often ask for private assistance, mainly private migrant care workers. According to the latest official data, between 2000 and 2007, mainly due to the regularization in 2002 (Bossi-Fini Law) in Italy foreign private assistants have more than doubled, raising from 134,000 to more than 464,000. If in the year 2000 the foreigners were a little more than half the total of caregivers registered with the INPS (Italy's Social Security Institute) that means with a regular contract, in 2007 they were more than 77%. Adding the irregulars, we believe that the presence of private migrant care workers, involving men and women, is today included between 400,000 at lowest up to 900,000<sup>5</sup> at the highest level. It follows that general housekeeping work and particularly care work in a home environment mainly involve foreign workers (coming from outside the European Community).

Between December 2007 and February 2008, there were more than 400,000 applications to recruit personal and home care aides, connected to get a residence permit, that were received by the Ministry of the Interior (corresponding to more than half the total applications). The flows decree 2007 has set a limit of 65,000 units to the foreign workers who can be hired for family assistance. In addition to them, other 47,100 units could be considered, according to some international cooperation agreements (but there is no specified number of incoming workers). Taking the best case, that is considering that all these incoming workers are personal and home care aides, we can say that the admissible applications for this category of workers will be 112,100 altogether. That means at least 287,900 families have no chance to regularize the status of the immigrants whom they will keep on giving work to.

The highest quota of recruitment applications exceeding the available places is detected in Lombardia (99,000), followed by Veneto (43,800) and Emilia Romagna (42,000). The incoming quotas are larger than the applications only in the Autonomous Province of Bolzano, Molise and Basilicata. It is difficult to hide the fact that most of the workers who could not take advantage of the regularization are already in Italy as irregular migrants, also as personal and home care aides.

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<sup>5</sup> Appraisals coming from Sole-24Ore, Cgil and Censis.

In the flows decree 2008 other 257,781 applications were re-encluded<sup>6</sup> with 105,400 additional places for private assistant. Many of them are still waiting for an answer about their regularization.

The need of private assistance from Italian families arises so as to make the Government choose since September 2009 a regularization of tax and social security contributions for those private assistants working without a regular employment contract<sup>7</sup> (the employers – older people or their families – have to submit an application asking for regularization and pay a flat amount of € 500). Each household can regularize up to two private assistants. According to the estimated figures of the Ministry of Interior, the applications on regularization will range from 300,000 to 500,000 at maximum.

### 4.3 Profile of migrant care and domestic workers (legal and illegal)

The absolute majority of private care workers is female (a sort of “specialization of gender”) but whereas among the Italians, men are almost absent, among migrant carers, men are increasingly relevant.<sup>8</sup>

60% of foreign women working as private assistants come from East Europe: Ukraine, Russia, Moldova, Bulgaria and Romania. They have middle-high level of education, with 25% of women with a degree and 46% with a high-school diploma and according to a survey carried out on local contexts, about 12% has even got a post-degree qualification; besides more than half of them is on average 40 years old (38% is between 30 and 40 and about 28% is between 40 and 50 of age).

Nearly all of them come to Italy with a tourist visa, invited by a friend or a relative, and start work in a family. New private assistants are different from the first migrant workers who came to Italy in the middle of the '90s: they are more oriented to provide hourly assistance instead of living in the same house and only one out of four declares she would like to live in Italy in the future. Most of them wish to come back to their home country or move somewhere as soon as possible (28%) or as soon as they finish work (47%), provided that it won't be longer than some years in any case (60%). Cohabitation is extremely nerve-racking, both for the families and the migrant workers, for they are mutually dependent and often forced to downward agreements. Private migrant assistants tend to be more than ever focused on short periods of work before coming back home, and it seems that nobody can ensure their replacement in the medium and long term. The situation in their countries of origin is in evolution; there are new job markets opening there or in other countries in Europe which are more convenient for them.

The assistance market is still submerged: the Ministry of the Interior believes<sup>9</sup> that the irregular private assistants are at least 600,000 and, on the basis of the information collected by IRS, only one out of three has a regular employment contract. More than half of foreign family assistants (57%) completely or partially work without a contract, but among the regular workers there is an increasing trend to “grey work” that is working more than the declared hours. According to an IREF survey this choice is influenced by the need of obtaining a higher salary, but also the awareness of how irrelevant social

<sup>6</sup> Applications rejected in 2007.

<sup>7</sup> The worker must have been employed for at least three months and before 30th April 2009.

<sup>8</sup> Women are 87% of foreign workers, 96% of Italians.

<sup>9</sup> La Repubblica, 19 July 2009.



contributions are in order to get a pension, knowing that it's impossible to cumulate or buy them back once in their country of origin.

#### **4.4 Intensity and type of tasks provided by migrant care workers**

Family assistants take care of everything: personal care and hygiene, cooking, housekeeping, washing clothes, shopping, going out with the old person for doing something or just for a walk, providing little health care and, though it should not be their task, they also make injections and give treatments. The incidence of migrants within the Italian social and health care system is so that sometimes they not only work at home, where the old person lives, but they also provide night assistance in hospital. Workload and the activities required to a private assistant increase as much as the age of the older person.

#### **4.5 How many and which kind of families use this kind of assistance?**

The demographic transformation, the ageing process of the population, the changes occurring in the household structure and gender roles, together with an inadequate public system of welfare, have relevantly influenced an explosion of the demand for private assistants from the families, given that 14% of the Italian population are older than 75 years of age and a large part of them are in need of full or part-time assistance.

According to the information provided by Cittadinanza Attiva, in Italy only 1.9% of patients aged over 75 can actually get some Integrated Home Care. Although it has increased in the period included between 1997 and 2003, its volume of activity is essentially inadequate.

ISTAT provides official figures on Integrated Home Care, saying that in 2006 the service is active in 173 Local Health Authorities out of 180; in the previous years there was a fluctuation: in 2004 there were 181 LHAs having an active service out of 195 and in 2005 they were 184 out of 195. In the last year available as concerns official figures, most of the Regions (17 out of 21) have that active service in all the LHAs. The patients receiving care at home have increased across the years: from 396 thousand in 2005 to 414 thousand in 2006. This piece of information is absolutely not sufficient compared to the need. If in fact we consider the data in the SDO Report 2008, we can see that only 0.2% of the population is discharged from hospital while activating Integrated Home Care, 0.9% when transferred to other rehabilitation facilities, 0.2% when there is a hospitalization at home (sheltered discharge), 0.5% in relation to a transfer to a Nursing Home, whereas 98.2% of patients are simply discharged and sent home. This information clearly points out a scarce implementation of the integration by the National Health Service between hospital and territory and therefore of the principle of care continuity.

As for the offer of residential and semi-residential care we report here the official data provided by ISTAT (Annuario Statistico Italiano, 2008), which illustrates the various percentage of beds available from Region to Region. There is a great unevenness with a concentration of facilities in the Regions Lombardia, Emilia Romagna and Veneto (Puglia has only got two, Sardinia one and Sicily seven).

**Table 6 Residential and semi-residential care in the Regions – 2006**

<i>Regions</i>	<i>Places in residential structures per 10,000 inhabitants</i>	<i>Places in semi-residential structures per 10,000 inhabitants</i>	<i>Places in residential structures (rehabilitation) per 10,000 inhabitants</i>	<i>Places in semi-residential structures (rehabilitation) per 10.000 inhabitants</i>
Piemonte	46,8	7,7	0,4	0,1
Valle d'Aosta	6,4	1,0	0,0	0,0
Lombardia	63,4	13,0	4,6	1,7
Trentino-Alto Adige	65,6	0,8	2,1	0,2
Bolzano/Bozen	43,1	0,6	2,7	0,1
Trento	87,2	1,1	1,5	0,2
Veneto	63,3	15,9	0,4	0,9
Friuli-Venezia Giulia	57,0	4,3	0,7	2,9
Liguria	18,9	3,4	2,7	2,1
Emilia-Romagna	46,3	15,6	0,4	0,1
Toscana	30,1	6,2	2,9	2,6
Umbria	21,6	8,6	2,2	2,1
Marche	12,1	2,6	4,4	1,1
Lazio	10,8	2,3	3,2	4,2
Abruzzo	19,2	1,0	6,5	5,7
Molise	1,9	0,6	8,5	0,6
Campania	3,4	1,6	2,3	5,6
Puglia	6,6	1,4	2,3	1,6
Basilicata	8,9	1,0	11,2	2,1
Calabria	8,7	1,5	3,4	0,8
Sicilia	4,8	1,1	1,4	3,3
Sardegna	9,2	1,9	4,3	5,3
Nord	54,8	11,6	2,1	1,1
North-West	53,7	10,4	3,2	1,3
North-East	56,4	13,2	0,6	0,7
Centre	17,9	4,1	3,2	3,1
South	6,7	1,4	3,4	3,5
Islands	5,9	1,3	2,1	3,8
Italy	30,6	6,5	2,6	2,4

Source: "Coordinamento nazionale Associazione Malati Cronici, ISTAT/Annuario statistico italiano".

The request of care work by the private workers is directly linked to the need of help of older people and their families. Public services can only provide a small part of the services needed by the older population who is no longer self-sufficient and their families. In most of the cases, two thirds of the families help themselves. Even in the most difficult conditions, only 43.3% of the families can rely on an external aide, which means that more than half of these families potentially need private migrant care workers.

If in the past, mainly the middle class families used to hire private assistants, today private care at home is an issue involving all the social classes. Plenty of old people can afford a private assistant thanks to the contribution of their sons who often play a role of coordination with the private assistant (including the management of the contract and substitutions).

According to a Iref-Acli survey of 2006, on migrant men and women working as housekeepers in Italy, more than half of the interviewees (57%) work in houses where live over-75 people: 29% of them provides care to only people, 20% to couples of old people, 7% to families with at least an old person in charge.

#### 4.6 Which kind of employment contract is used?

The contract used for private caregivers is the same as for housekeepers ("Colf" in Italian). It's a national contract which has been existing for more than thirty years and that was adapted to include the cohabitation home care service. The contract considers four different positions, according to activity required and minimum salary.

**Table 7 Minimum pay 2009 for a private assistant at home (Level CS)**

<i>Cohabiting workers (per month)</i>	<i>Non cohabiting workers (per hour)</i>	<i>Assistance at night (per month)</i>
880.17 €	6.10 €	1,012.20 €

Source: adapted by Studio Come srl, Ministry of Labour, 2009.

**Table 8 Average costs par month 2009 for private assistant at home (Level CS)**

	<i>Cohabiting (54 h/week)</i>	<i>25 h/week</i>
With contract "COLF*"	1,350 €	850 €
Without contract (average)	850-1,000 €	700 €

Source: Rapporto non autosufficienza, 2009. Note: \*) The cost refers to a private assistant for an older person with LTC needs. It includes third party and costs for managing the contract, and substitution of the worker during holidays.

A formal employment contract is a binding condition to get a residence permit. However, there might be different irregularities in the performance of contractual obligations:

- Welfare contributions for a number of hours smaller than actually worked
- Monetisation of holidays (instead of benefitting from them, you get paid)
- Restrictions on time off, Sundays and bank holidays

- Evasion of Christmas bonus and end-of-service pay-out.

In some cases, the lady workers just agree, either because they are not much interested in welfare contributions if they won't be able to enjoy their benefits in their country of origin, or because they don't care to waive their time off, for they strongly need to quickly earn money as much as possible.

On average, the salary of a caregiver without a contract is about € 700-800 a month if she lives night and day with the old person. If she works four or five times a week her salary will be a little more than half, and so on. Decreasing amount of time proportionally makes her salary go down. According to a recent survey (Sgritta, 2008), almost three quarters of older people hire private immigrants without any legal employment contract.

## 4.7 Policies to promote the use of migrant care workers

### 4.7.1 Information

Families and old people are often obliged to rely on passing of information by word of mouth in order to employ a private migrant care worker, often incurring the risk of not getting them precisely, with added difficulties in reaching who can provide them correctly.

In lots of local areas, where it is common to hire private assistants, Municipalities are implementing the function of social secretariat in order to support the families facing difficult situations connected to the old and no longer self-sufficient person who needs care. Support includes information activities, guidance on local services able to meet the needs and the requests of the customers:

- Information on the whole range of social and health care services for people with care needs
- Information on how to employ private family assistants
- Referral to trade union offices in order to get information on the contracts and calculate the socio-economic situation (ISEE)

Additional information is provided to private workers who are about to start work in a family.

Finally in Italy, there are two professional associations – Api-colf and Acli-colf – to support household staff (“colf” in Italian), private workers (Italians and immigrants) and families who are about to employ a private worker. Associations offer information on:

- Procedures to follow in order to employ a private assistant (for personal and home care)
- How to make a regular contract to the private assistant already working in the family
- How to correctly manage the contract
- How to correctly fill in the national forms to pay for welfare contributions

### 4.7.2 Recruitment of the assistant

From both the point of view of the family and the caregiver, matching demand with job supply is a service that answers to different needs and should therefore support both of them, either dealing with care or with work. The responsibility to provide an answer to these needs is of different institutions: from the social side, Municipality carries responsibility; from the working side is the Province. That's

why the services to match the older person with the assistants are of two types: social care help desk and job help desk.

### **Social care help desk**

The social care help desk, promoted by the Municipality and usually managed within the services for families, older people or social secretariat, is aimed at providing information to both families and caregivers. In some local contexts (best practices) the social care help desk supports the care giver starting to work at an older person's home, offers a tutorship service made by professional tutors, helps to sort out the problem of substitutions either with its home care service or providing a temporary admission in a hospital (relief hospital admission). Those typical social functions come with information on training opportunities for the caregiver while she will be sent to other services as for the contract aspects.

### **Job help desk**

The job help desk was born within the SIP and officially carries out all the intermediation activities, including counselling to residence permit, migrant worker's skills balance, guidance to training system. On the other hand, any care counselling is sent back to the social and health services network. For example, the provinces of Ferrara and Parma have set up at the SPIs a dedicated pole to match families with carers, which offers:

- Information and guidance to carers' work and training
- Counselling on the work relationship with the hosting family
- Individual interviews and skills balance
- Intercultural mediation
- Free courses to become "family assistant" and inclusion into a specific register that certifies the achieved skills
- Group meetings to jointly elaborate opinions on the local job market and individual professional paths.

### **Trade Union offices ("Patronati")**

Together with those two solutions, both within the public services, there's a third possibility: the trade union offices ("patronati" in Italian), which have been recently reformed (L. 152/2001). Piedmont Region in its regional law 1/2004 promotes the trade union offices providing a service of social secretariat (information) and in Italy there are plenty of Municipalities and Local Health Authorities working in partnership with them in order to calculate ISEE (socio-economic situation) and do some bureaucratic papers in order to access to social and health care services. The Municipality of Arezzo has signed up a free-cost partnership to ensure a lighter bureaucratic burden to the families, and the same has done the Province of Siena. Other Municipalities, such as Venice, in occasion of the decree legitimizing migrants, have asked the trade unions offices to support the families and the care givers in order to make their work become legal.

Under the reform, it is possible for the trade union offices to play an extensive role towards families and migrant carers: information, guidance to the services network, support to get a residence permit, help with job contract and in case of controversy.

### **Private agencies**

Lately, several private agencies have been set up with the aim of linking families to private workers, asking for a contribution in terms of membership card and sometimes working as temporary employment agencies, thus directly making a contractual agreement with the family. Those solutions resulted to be well-accepted by the families in absence of structured public services, but they show some limits as for universality and free-of-charge access.

### **Weaknesses**

The different schemes implemented on the territories should not be taken as “exemplary cases”, that is to imitate or widespread. At this phase, it is difficult to identify what is the optimal solution, for three reasons which are to be reminded here. The integrated network of social services is not always provided with an “access entrance” equally open to all the citizens, able to provide guidance on issues out of social and social health care. In their turn, employment services are just trying to have an active role, providing counselling to the person seeking job while the families are not perceiving themselves as employers yet, and therefore do not turn to these services when they need to hire a family assistant. The mainstream practice has thus far followed other ways. Information has first been passed on by word of mouth between families and caregivers, and secondly through churches, associations, and non-profit organisations. On the very same territory one can observe a wide range of groups, both small and large, that only relate to each other occasionally, on the basis of cultural and political similarities, but with no common direction. To actually help older people, their families and caregivers it is important to link the information centres in a network including social and work aspects and give them the suitable tools to act homogeneously and tackle the difficulties faced by the people involved.

#### **4.7.3 Contract (incentives to legalization)**

Public funding, specifically aimed at stopping under-the-table work, provides partially refund to the family who pays for the caregiver’s social security contributions. In this case, the choice made is that one of supporting correct behaviours when a private assistant is to be hired. For this reason, funding is targeted at a wide range of people, its amount is usually lower and only related to the social security contributions and not to the whole cost supported for the worker.

To this direction went the Municipality of Venice, Arezzo and the Province of Siena. In Venice, for instance, the Municipality adds resources of its own to the regional funding in order to provide a contribution of € 150-200 a month in support of the expenses of 530 households. In Arezzo the social area supplies a service bonus that can partially or completely cover the cost of a family for social security contributions ranging from a minimum of € 129.42 a month to a maximum of € 258.23. In Siena, the Province has launched the call “One euro, an hour” addressed to all the citizens who regularly hire a private worker.

### **4.8 Education and training programmes for private assistance**

Caregivers’ work performed at the looked-after person’s house is underestimating by most of the people, as if acting in an informal place could make this activity less professional. It seems normal to believe that all the necessary skills to correctly run these activities are easily acquirable by practice or even naturally owned, especially when to do them is a woman, who has always been a reference point

in the house and family care. On the contrary, in order to make a quality care service, specific skills are required, including human and technical expertise.

### Care giving skills

With the aim of correctly assess the care giving skills, the Region Liguria has promoted the project “*Lavoro doc. Buone prassi nel lavoro di cura*” (good practices in the care giving job), financed by ESF Axis E1 Ob.3. The skills so identified can be of three different levels:

- *basic*: knowing one’s own employment contract, and therefore the rights and duties included in it, those of the family and the looked-after person; knowing about the people involved in the old person’s care and the services to which he/she can refer to; knowing the Italian language
- *technical-professional*: handling bureaucratic papers, knowing how to make the looked-after person stand up and move around, being able to manage his/her diet and treatments, taking care of his/her personal and environmental hygiene, being able to cooperate with medical staff
- *multi-level*: capacity to listen, communicate, mediate and adapt themselves; to build up trusting relationships, manage intimacy and distance, have an attitude to flexibility; provide support to promote independence, be positive and able to face emergency; be able to combine private and working life.

Currently, the new professional profile of family caregiver is not officially recognized at national level. Nevertheless, at regional level, some Regions have formalized the profile, by certifying professional skills or creating a professional qualification (first level).

**Table 9 Regional profiles for private care assistants**

<i>Regione</i>	<i>Hours of training</i>	<i>Title/certification</i>	<i>Credits for OSS<sup>10</sup></i>	<i>Laws</i>
Abruzzo	400	Qualification		DGR 04-05-2009, NR 207
Campania	120	Certified competences		DGR 2843/2003
Emilia Romagna	120	Certified competences	x	DGR 924/2003
Friuli Venezia Giulia	200	Certified competences	x	LR 28-52 del 1 ottobre 2004 DGR 1232 dd. 14/05/2004
Lazio	120 300	Certified competences Qualification		DGR 31 luglio 2007
Liguria	200	Certified competences	x	DGR 287/2006
Marche	100	Certified competences		DGR 118/2009
Piemonte	200	Certified competences	x	DGR n. 46 – 5662 del 25 marzo 2002
Toscana	300	Qualification	x	DD 7/197 del 18/12/2002
Sardegna	200	Certified competences		DGR N. 45/24 DEL7.11.2006 Prot. N.5422 Cagliari, 04.07.2007

Source: elaboration of Studio Come srl on the basis of regional legislation.

<sup>10</sup> Operatore socio-sanitario (health and social care worker)

Training modules, having shorter or longer duration, are now available in different Italian areas (Modena, Parma, Piossasco, Reggio Emilia, Roma, etc.).

Among training actions, it is also to consider the action of doctors, nurses, or other operators who teach the caregiver the care techniques within a specific working context. It is called “in-site training” and it is the case of, for instance, a social and health care operator working in a RNH who shows the caregiver how to properly do her job. Another example is that one of a nurse who, while providing home service, gives suggestions and support in order to train the caregiver. The latter can actually learn how her work is carried out by a professional. Often, this transfer of know-how naturally occurs and is neither structured by the professional carer nor by the caregiver. It will be necessary to enhance and formalize these experiences. Some activities also include economic incentives in support of the caregiver’s training. This is the case of the Province of Siena that, in the project against under-the-table work “*Un euro all’ora*”, includes a bonus aimed at vocational training for family caregivers.

## 4.9 Guaranteeing the quality of the services

*Guarantee services* are called those services available to a core unit made up of the older person, the care giver and the family so as to share responsibility, integrate lacking aspects, improve the professional quality of care, coordinate private assistance within the network of help including: general practitioner, hospital, RNH, day care centre, home care giver as well as the other providers of social and health care services on the territory. There are mainly three different ways to put a guarantee service into practice: tutoring, ‘sheltered’ discharge and substitutions.

### 4.9.1 Tutoring

One of the weaknesses that occur to the caregivers at their first care experiences is to exclusively trust on their own capacity and self-learning. Usually, they haven’t attended any specific training course in their country of origin, though they have an intermediate level of education, and they used to do different jobs. What they know about care for older people mostly stems from previous experience in other Italian families.

*Home tutoring* is a service made by a professional worker, usually a home caregiver or social and health care worker, who is provided on demand of the family or the older person, and supports the private care giver when she starts to work in the family and in possible difficult situations occurring later on. The tutor helps the caregiver to make better plans, arrange and manage the care work that she has to do for the family. This function is regularly performed when the older person with care giver is also supported by the home care services and more and more often it is implemented by the general practitioners too, when they go and visit their patient at home.

Among the experiences of home tutoring in Italy we point out: *Madreperla* in the Province of Modena, the social tutor in the Province of Parma, *Premiata Fabbrica* of the Iris and Cissabo Consortia, *Casa Amica* of the Consorzio Cidis, *Agenzia solidale per il lavoro domestico* of Biella, the social caretaker of Arezzo.



#### **4.9.2 'Sheltered' discharge**

A common practice in some hospitals and particularly in some departments where the affluence of the older people is high (heart surgery and orthopedics) is to call the caregiver to the hospital before the patient's discharge in order to provide her with useful indications about the treatments to be followed at home, suggestions on diet, sleep schedule, mobility, as well as the little or big changes to be introduced into everyday life during the convalescence period.

In Italy there are different experiences. However no standard procedures and protocols have been defined yet, with indication of the interaction between hospital and general practitioner, the family member of reference and the caregiver.

#### **4.9.3 Substitutions**

For the family it is important to rely, in case of need, on an alternative offer during the periods when the caregiver is absent from work. Currently, the families cover these periods of leave with their own holidays, taking time off work, or hiring other caregivers as substitutes. Some home care services allow these families to get temporary access to: home care services, day care centres for frail older people, relief hospital admission. So dealing with the problem of substitution can turn out to be an opportunity for the families – who do not use the public services or do not have the necessary requirements to use them – in order to get temporary access to these facilities, thus experimenting new forms of care, by paying a fee as a contribution for the service received.

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