

**Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage**

EUROFAMCARE

**National Background Report
for Italy**



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Introduction – An Overview on Family Care

Due to the very rapid ageing process occurring over the last few decades, Italy is considered today the country with the highest percentage of over 65-year-olds in the world, this segment making up over 18 % of the total population (Golini 2000, Kinsella and Velkoff 2001; United Nations 2003). This is due to the lengthening of life expectancy on the one hand, but also to a particularly accentuated drop in birth rates on the other, which has reduced the consistency of the younger generational cohorts.

As in most West-European countries, although this process has been accompanied by an overall improvement in the health status of the elderly population, the absolute number of older persons suffering from disabilities and chronic diseases is also increasing, especially in the over 75 year old age group, with a trend which is expected to continue over the coming decades. Current estimates indicate that about 5 % of the Italian elderly are severely disabled, that 2.3 % are bed-ridden or unable to leave their homes due to their disabilities, and that these figures are expected to increase by at least 50 % in the next ten years (Presidenza del Consiglio 2000: 85 & 103; Ranci 2001:27).

While the demand of care by the elderly population is increasing, the same cannot be said with regard to the care-supply side, i.e. to the number of adult persons potentially available to provide this care. Estimates indicate that the potential support ratio – i.e. the ratio between the number of adults aged 15-64 and the numbers of over 65-year-olds – is expected to drop from 3.8 to 1.5 between 2000 and 2050, following a trend which will be particularly strong in all Mediterranean countries (United Nations 2000). This decreased availability to provide care depends however not only upon demographic reasons, but also upon economic ones, such as the increasing female participation to the labour market – women's activity rate rising from 22 % in 1970 to over 36 % today – which prevents many women from ensuring informal care as traditionally done in the past. In the future this trend is expected to continue also because of the effects deriving from the probable upward shift in the minimum retirement age limit, which will keep Italians in the labour market longer. A further phenomenon affecting caregiving availability is the change in living arrangement patterns, which shows an increasing number of households made up of older adults only – many of which are elderly persons (especially women) living alone – and complementarily a decreasing number of multigenerational households (elderly persons living with their children). This phenomenon, which on the one hand reflects a growing preference of Italian families towards "intimacy at distance" rather than cohabitation, might on the other hand make family care logistically more difficult and complex. Finally, a slow increase in the number of elderly living in residential facilities should also be mentioned, albeit still on a much lower level than in Central and North-European countries.

All the above-mentioned phenomena can be summarized in the following bullet points:

- In the last few decades Italy has been affected by an intensive ageing process, so that today it is considered the **oldest country in the world**, its over 65 year old population making up 18.6 % of the total. Although this phenomenon is an effect of an overall improvement in the health status of the elderly population, it has as a consequence also **an increase in the number of elderly persons suffering from disabilities and chronic diseases**, which is expected to exert a growing pressure on the demand of elderly care in the future. On the other hand, the number of potential carers is expected to decrease, for several reasons:
 - a reduction in the **potential support ratio** – i.e. the ratio between the number of adults aged 15-64 and the numbers of over 65-year-olds – especially in the Mediterranean countries;
 - an **increasing female participation to the labour market**;
 - a probable **upward shift in the minimum retirement age limit**, which will keep Italians in the labour market longer;
 - a **change in living arrangement patterns**, with an increasing number of households made up of older adults only and a decreasing number of multigenerational households, making family care logistically more difficult.

The care of dependent elderly in Italy: main regulations regarding health and social care

- In Italy, elderly persons requiring care can count on **free health care** from the National Health System (NHS), **means-tested social care from Municipalities**, and **monetary transfers from the State** – in the shape of (means-tested) disability pensions and (non-means-tested) care allowances – **as well as from local authorities** (Regions and Municipalities, generally means-tested). According to this system, which is undergoing a process of devolution of competences to the Regions, free health care is actually limited today to primary care by GPs (who virtually reach the whole population) and to hospital acute care, while long term care costs in residential and nursing homes are covered only partially (the patient having to pay for the “social part” of them, since the NHS covers only the “health component” of costs).
- Furthermore, a fact that has to be taken into account is that in Italy any person who is unable to live independently has the **constitutional right to receive public support**, but at the same time **the legal right to ask for alimony from relatives** (up to the second degree, such as grand-children, children-in-law etc.). The first right is creating an increasing financial problem to Municipalities, which are obliged to cover the difference between fees for residential care and the incomes of the increasing

number of elderly people who are resorting to it. So that, albeit the right to alimony can be asserted officially only by the interested person, many Municipalities are currently trying to exert “undue” pressure so that families will intervene financially to cover the residential care costs of their elderly members.

Italian family carers: what are their main needs?

- Not many in-depth studies are available in Italy on the difficulties faced by Italian families in providing care to their family members. This is probably due to the fact that it is still a deeply rooted value of the Italian society that elderly care should be accomplished by the family, so that it is almost “socially unacceptable” to admit that families are not able to organise themselves so as to accomplish this task. However, the steady ageing of the Italian population is quite rapidly changing the traditional attitudes towards the issue, so that the request for a higher social recognition not only of the needs, but also of the rights of caregivers, is becoming louder and louder, especially by part of the younger generations (Colombo 2002). These needs / rights can be schematically synthesized as follows:
 - **accessibility to respite care** measures and services, such as for instance day care centers, temporary residential care and / or substitutive home care services;
 - appropriate **counselling** and **information** about existing support services, measures and networks, including self-help groups;
 - **integrated and timely support** from health and social care services, to be achieved also through a **higher care continuity** between the different services and measures, including **early assessment of cases at risk**;
 - **participation** in the decisional processes involved in the implementation and assessment of the care services, through a better partnership;
 - **training** on characteristics of relevant diseases, on most appropriate caregiving responses to them and in general on how best to organize elderly care informally and in partnership with existing services;
 - **opportunity to conciliate working responsibilities with caregiving tasks**, through flexible working times, paid and / or unpaid care leaves, part-time, service vouchers etc.;
 - **recognition** of the care work provided, in terms of social visibility.
- It should also be mentioned that some categories of carers are faced with particularly burdensome tasks, such as in particular those deriving from the care of elderly persons affected by dementia (especially if accompanied by aggressive behaviours), with psychological problems (such as for instance depression), or with chronic diseases which require frequent

hospitalization, transportation or technical help in basic activities of daily living such as feeding, dressing, bathing, etc.

Elderly care between the family network, the public care service provision, the private care market and other informal care providers

- Currently, a trend towards an **increased involvement of market oriented care services** can be observed in Italy. One effect of this phenomenon is that service users (i.e. elderly and their families) play more and more often the role of “buyers” of care services which are provided by private suppliers, but paid by public institutions through vouchers and care allowances. This reduces the “counselling” role of the public authority, which ends up in many cases by playing only the limited role of service “financer”, without checking whether the elderly and their families are actually capable of using them appropriately.
- Under such circumstances, it cannot therefore be surprising that more and more Italian families are resorting to the help of **foreign immigrants to provide home care** to their dependent elderly relatives. Traditionally, the care of the elderly in Italy is a task which has been mainly accomplished by the family, and within this, principally by its female members, such as wives, daughters and daughters-in-law. However, the fact that a growing number of women are no longer available to provide care, has led many families to pay foreign immigrants, who are a cheaper workforce than autochthons, to accomplish these tasks. In most cases, this has taken place on an undeclared basis, although in 2002 a major legalization campaign has allowed the regularisation of the position of over 700,000 immigrants, of which more than half has been estimated to be represented by home helpers providing care to the elderly. The relevance of foreign immigrants within the Italian elderly care system is such, that in some areas they are employed not only at home, but also to **ensure night care in hospitals** (i.e. families pay them privately in order to help their elderly relatives during the hospital stay), often requested more or less explicitly to do so by the hospital staff itself, with obvious negative consequences upon the families’ budgets.
- These considerations allow stating that, on the whole, the role of the family in the care of the dependent elderly remains central in Italian society. Due to the too slow improvement of the formal (public and private) care sector in terms of quality, typology and quantity of care services provided, a growing number of families is relying on undeclared and therefore cheaper support from foreign immigrants, which currently represent one of the “main pillars” of the Italian care system.

Current debate on the possible introduction of a long-term care insurance in Italy

In the last few years a strong push towards the introduction of a long-term care insurance can be observed within the Italian political debate, so that a **bill**

proposal has been drawn up during 2003, aiming at instituting a “national fund” finalised to finance long term care costs (Progetto di Legge 2166, 2003). This proposal aims principally at:

- an improved **coordination of existing measures**, such as the care allowance;
- the provision of **more personalised services** by means of individual care plans through health districts and municipal social services;
- the provision of **financial support to cover the costs of residential or other form of care** which are not paid for through the health care system.
- The most controversial aspect regarding the proposed “funding” is how this should be financed. First estimations of costs, based on a set of services similar to those provided by the German long term care insurance (i.e. 3 levels of dependency, 80 % of recipients receiving cash, 20 % receiving direct services, in-kind services valued double as much as cash transfers, residential care rates at 5 % of all recipients) reach an amount of over 11 million Euros.

In the following pages, an overall picture of the Italian situation with regard to the support services available for family carers of older people will be provided. This description will detail the main characteristics of Italian family carers, the role played by care policies and services in supporting them as well as the core financial issues related to costs and funding, identifying main trends and future perspectives and providing - in the Appendix – major statistical data and most relevant examples of good practices recently developed in this field in Italy.

1 Profile of family carers of older people

The most important studies on caregiving in Italy refer to three main categories of family carers: **primary carers of dependent elderly people**, that is “those members of the family mainly involved in caregiving” (Tarabelli 2001; Melchiorre 2000 / a; 2000 / b)¹; **all carers** (both primary and other family carers) **of elderly people** (Quattrini et al. 2003)², and **carers in general**, i.e. not only carers of older people, but also of children, disabled people etc. (Istat 2000 / a, 2001; Sabbadini 2003)³. However, the inclusion of the latter category can be misleading, in that reference is made to informal care provided by persons over 14 years old to **non co-habiting** individuals, while most care recipients are cohabiting older adults (Lamura et al. 2003 / a), thus making it necessary to extrapolate only data referring to the subcategories of our specific interest (cf. § 1.7) and to interpret them with caution. In the following paragraphs we will refer to the first source on information on **primary carers of older people** as the “INRCA survey” (from the name of the research institute which carried it out), to the study on **all carers of older people** as the “ESAW survey”, and to the investigation on “all carers” as the “ISTAT survey” (ISTAT being the national statistical institute carrying it out).

1.1 Number of carers

Family carers represent by far the most numerous group of - both informal and formal - carers in Italy (Polverini and Lamura 2004: 8). The ESAW survey (see footnote 2) has estimated that about 11 % of the over 50-year-old population provides care to a dependent older relative, i.e. about 2,350,000 persons (Quattrini et al 2003). Since about 25 % of the whole disabled population (i.e. 700,000)⁴ is less than 65 year old (Istat 2001a: 63), and many carers of

¹ This study has been carried out between 1999 and 2001 by the Department of Gerontological Research of the Italian National Research Centre on Ageing (INRCA) in 6 Health Districts in Central Italy, involving 424 dyads of dependent elderly (randomly extracted from the list of local service users) and their most involved family carers (Lamura et al 2003/a).

² This research is based on the European Study on Adult Well-being (ESAW), carried out in 5 European countries in nationally representative samples of the 50-90 year old population (<http://www.bangor.ac.uk/esaw>). Differently from the other national samples, the Italian sample was requested to answer to a supplementary set of questions on elderly care, which allowed for inferences on the epidemiology of caregiving in Italy. The Italian sample, stratified according to age, gender, geographical position (North-West, North-East, Centre and South with Islands) and kind of area (rural, urban and metropolitan), is made of 2,018 subjects, of which 11% are carers of elderly relatives (Quattrini et al 2003).

³ These findings refer to the national survey carried out by ISTAT on about 60.000 households, which asks respondents, among other things, whether they provided “unpaid help to not cohabiting persons in the last four weeks” (Sabbadini 2003: 73). This definition of “help” excludes cohabiting care recipients, but includes any kind of support, i.e. also activities which cannot be strictly considered “care”, and finally also includes support to independent persons.

⁴ This figure is derived as a sum of the 25,3% of total disabled population (2.615.000 persons) who is younger than 64, i.e. 664.000 persons, and about 36.000 less than 6 year old dependent chil-

younger disabled persons are themselves over 50 (as parents or other adult relatives of the dependent cared-for child or adult), from these figures it can be reasonably estimated that about 3,000,000-3,500,000 Italians provide care to a dependent relative. Many of them are involved quite heavily in this care, especially in those areas - mainly concentrated in the “familist” regions of the South and of rural-mountain districts - where formal service availability is lower.

The high amount of care provided by family carers is confirmed by the ISTAT survey, which reports that in 1998 over 11.2 million persons – i.e. 22.5 % of the over 14 year old population – provided “unpaid help to not cohabiting persons in the last four weeks”, a number which has remained relatively stable over time (Istat 2001; Sabbadini 2001: 22; Sabbadini 2003: 73). It has to be underlined that this definition of “help” cannot be compared to the one used by the INRCA survey, since on the one hand excludes cohabiting persons from the recipients (i.e. mainly other family members), on the other hand includes any kind of support, i.e. also activities which cannot be strictly considered as “care” in the sense used for this report, such as for instance baby-sitting, financial support etc.; furthermore, it also includes support to persons who are not “dependent”, but simply recipients of any kind of unpaid help. According to this survey, it can be estimated that about 6.3 million persons (i.e. 56 % of the total 11.2 millions) provides help to other (non cohabiting) family members.

1.2 Age of carers

The ESAW survey points out that in the sample investigated by this study the average carer is 61 years old (± 8.4) and that carers are usually younger than non carers, whose age range is 65.5 (ds ± 9.9) (Quattrini 2003), women carers being on average slightly younger (60.8 years of age) than men (61.7 years of age) (Polverini 2003).

The INRCA survey on primary carers highlights a remarkable 10 % of very old caregivers who are, in certain cases, even over 80 (Melchiorre et al. 2000 / a; Melchiorre et al. 2000 / b; Lamura et al. 2001 / a: 25-26; Tarabelli et al. 2001: 244-252; Mengani et al. 1999).

1.3 Gender of carers

Although an increase in the number of sons looking after seriously disabled old parents has recently been reported (Taccani 2001: 258), caregiving remains a task traditionally performed mainly by women, as shown by the fact that one fifth of men and one fourth of women are involved in this kind of activity (Sabbadini 2003), two thirds of the total amount of informal care being in Italy pro-

dren, who are excluded from national figures (which include only over 6 year old disabled persons) (Istat 2001a).

vided by women (Istat 2001).

This is particularly true when we come to more heavy care tasks, as in the specific case of care to older people. Available studies on primary carers indicate that women are the family members more heavily engaged in this role, with a ratio of 4 women to 1 man (Lamura et al. 2001 / a: 25; Quattrini et al. 2001: 165). This female prevalence is confirmed also by the ESAW study, where the comparison between carers and non-carers indicates that women represent 65 % of the former versus 54 % of the latter (Quattrini et al. 2003).

It is also interesting to observe that, according to a recent nation-wide survey on a sample of 802 caregivers of non institutionalized elderly affected by the Alzheimer disease, the percentage of women carers increases as the disability degree and illness severity of the cared for persons raises, reaching 81.2 % in the case of very seriously disabled people (Vaccaro 2000; Censis 1999).

1.4 Carers' income

An analysis of the carers' economic conditions is of basic importance in order to understand their living standards, but this information is often difficult to obtain, given the rather confidential nature attributed to income issues by most Italians (Lamura et al. 2001 / a: 46-49).

Despite the relatively high number of missing answers reported by the ESAW study on this issue (about 30 % of respondents), the comparison between carers and non carers allowed by this investigation show that both family and per capita incomes are higher in the case of carers, personal income reaching an average of 13,813 euros per year in the case of carers and 11,954 euros for non carers (Quattrini et al. 2003). This is confirmed by the statistically significant fact that fewer cases of carers belong to the lower income group compared to non carers (28 % vs 36 %), and correspondingly more cases are found in the high income group (41 % vs 31 %).

Other studies seem to show however less positive findings. From the INRCA survey there emerges in fact that about 60 % of the respondents are dissatisfied with their economic situations (Lamura et al. 2001 / a: 46-48), and that, generally speaking, stressed and overburdened carers experience worse economic conditions in terms of both available income and dissatisfaction with their economic conditions (Lamura et al. 2001 / b: 34). As for their income sources, this survey reveals that a substantial percentage of caregivers (31 %) declare not to have any economic resource, a result which probably reflects the high number of housewives caregivers. The remaining 60 % enjoy incomes from present or past working activities (28 % work earnings, 26 % old age pensions) while a lower percentage enjoys social pensions (7 %) and disability pensions (2 %) (Lamura et al. 2001 / a: 46).

1.5 Hours of caring and caring tasks, caring for more than one person

With regard to the **amount of time** dedicated to caregiving, the findings of the INRCA survey on primary carers show that these provide, on average, 92 hours a week of care-related tasks, but in more than one third of cases their engagement is extended to the whole day (Tarabelli et al. 2001: 244). The average number of hours devoted to caregiving varies depending on the carer's professional condition, working women devoting to caregiving the lowest amount of time (an average of 7.7 hours for public employees and 8.5 for private ones), while retired people (12.8 hours) and housewives (15.4 hours) reach the highest amounts (Quattrini et al. 2001: 168).

It should be stressed that these differences might partly reflect the tendency to include all domestic activities – also those addressed to other, independent family members - under the “care” category. On the other hand, however, the fact that even 10-12 % of working carers declare they provide assistance during the whole day - as if the time devoted to their professional working activity did not exist – seems to reflect the situation of “mental involvement” characterising many carers, who “feel” responsible for the cared-for person even when they are at work (Quattrini et al. 2001: 168-169).

In the case of demented older people, the number of hours devoted to care is likely to increase and, as indicated in different studies conducted on the relatives of patients with Alzheimer's disease cared for at home, caregiving can often last 15 or more hours per day, due to the high need of surveillance requested by such patients: almost one fourth (24 %) of the 802 carers interviewed for a national survey carried out by CENSIS (1999) are in this condition, but one smaller and more focused study on 81 more severely demented patients reveal that 82 % of their primary carers are engaged 22 hours a day (Gambina et al.: 2001).

Much lower amounts of care are recorded when we focus on non primary caregivers, as shown by the ESAW data, according to which all kinds of carers devote, on average, “only” 23.8 hours of assistance per week (Quattrini et al. 2003).

As far as the **caring tasks** are concerned, the majority of carers (about 60 %) declare to be engaged **in all activities** necessary to meet the caring needs of the assisted person (Sabbadini 2003; Lamura et al. 2001 / a: 30). Among the caring activities most frequently offered by family carers, there are “personal care and hygiene”, “the preparation and administration of meals”, “company”, “errands and shopping” and “housework”. While women generally perform all activities, men appear to be mostly involved in specific activities such as management of financial matters, repairs and transportation (Melchiorre et al. 2000 / a: 2; Facchini 1994) as well as the settlement of bureaucratic matters (Sabbadini 2003; Istat 1999 / a).

There are also many cases of “multiple” care. According to the results of the INRCA survey, although only 6 % of the respondents declare they are currently providing care to more than one elderly person at the same time, on the whole there results to be a percentage of 20 % who declare they have cared for some other elderly person in the past (Lamura et al. 2001 / a: 32).

These and other not presented data show that family care of the elderly in Italy is often characterised by a parallel phenomenon of “continuity” over time (i.e. long duration) and of “pervasivity”, i.e. of intensity of the caring tasks to be performed, which represent a dangerous “cocktail” in terms of high risk for stress and overburden for many carers (Lamura et al 2004).

1.6 Level of education and occupational status of family carers

Carers seem to have a higher education level if compared to non-carers; as a matter of fact 34 % of the former group has a high school diploma (compared to 27 % of the latter) and 16 % have a degree; besides, 39 % of non-carers have only an elementary school certificate (compared to 26 % of carers) (Polverini et al. 2003).

As for their professional status, several surveys show that housewives and pensioners make up about 60 % of caregivers (Vaccaro 2000), though the quota of privately paid carers (about 25 %) cannot absolutely be considered residual (Lamura et al. 2001 / a: 28; Tarabelli et al. 2001:248).

However, the ESAW nation-wide survey shows that retired people and housewives are less numerous among carers than among non-carers (48 % compared to 61 % and 17.8 % compared to 18.2 %), while full time workers are more numerous (26 % vs 23 %) (Polverini et al 2003) and women carers are more active on the labour market if compared to non-carers (with a percentage of 37 % vs 29 %) (Quattrini et al. 2003), but this seems to be explained mainly by the fact that, on average, they result to be younger and in better health condition.

1.7 Generation and relationship of carers to cared-for older person

National data indicate that the categories of persons more frequently involved in caring for older people in case of need are their children (68 %), their spouse or other relatives living with the family (48 %) and other relatives who do not live with the family (26 %) (Censis 2002 / b).

Several studies seem to confirm that in the vast majority of cases, these relatives are the old man’s daughter (37 %), his wife (10.6 %) (Quattrini et al. 2003) or his daughter-in-law, daughters and daughters-in-law apparently being engaged in the caregiving task for over 13 hours a week (Sabbadini 2003; Istat 2001).

1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc.)

Family size

The most frequent household pattern in Italy is the nuclear family composed by two people (about 40 % of caregivers), but 3 or 4-members households also appears to be quite common (17 % and 26 % respectively), families with more than 4 members being much rarer even in the case of co-residence of several generations (Lamura et al. 2001 / a: 27-28).

Residence patterns

The INRCA study reports that, in almost half of cases, carers (primary carers and non primary carers) live in the same house as the person to whom they are providing assistance (42 %), or they live very close to their house (32 %) (Quattrini et al. 2003). Other studies, referring to carers of older people suffering from dementia, report higher percentages of cohabitation (65-75 %), mainly as a consequence of the more severe health status characterising the cared-for person (Vaccaro 2000).

1.9 Working and caring

Several surveys have tackled the problem of the often very heavy consequences of caregiving on the daily life, professional activity and health status of caregivers themselves (Tarabelli 2001; Quattrini et al. 2001: 166; Mengani et al. 2003: 35).

It seems, however, that consequences as far as the outer working activity is concerned, vary noticeably according to different professional situations. As a matter of fact, in the case of women, at least 17 % of housewives and 13 % of retired women complain about a major negative impact of caregiving on their professional status, the main consequences being either the impossibility of working, the need to quit their job, or to retire before retirement age. Conversely, working women apparently face serious problems in the attempt to conciliate their caring tasks with their professional activity: more than half of them declare they were forced to work less hours and take on part time jobs which, on the other hand, are wished for by one out of four non-working women carers - probably because they are considered a possibility of access to the labour market - and by 23 % of women working in the private sector (Quattrini et al. 2001: 166-172; Mengani et al. 2003:35).

Among the measures which are most strongly advocated on the part of caregivers, the following play a central role: economic provisions (38 %), help from other family members (21 %), part-time jobs (17 %), and a period of paid (15 %) or also unpaid leave (8 %) (Tarabelli et al. 2001: 248). This shows that, in order to grant adequate assistance to dependent older people and at the same time maintain an acceptable level of quality of life for those mostly in-

volved in their assistance, the preferred measures are those that make care-giving possible without giving up one's working activity (Quattrini et al. 2001: 175).

1.10 Employment rates by age

For Italy there are neither national data on carers and employment nor general disaggregated data regarding employment rates for women aged 45 and over, since the age bands considered by ISTAT data are 35-54 and 55-64 (see Table 1 below), which show that female employment rates drop drastically from 50.4 % to 15.3 %.

Table 1: Employment rates by sex and age band. Year 2000

Age bands	Total	Male	Female
15-24	25.9	29.6	22.1
25-35	65.0	77.7	52.0
35-54	69.6	88.8	50.4
55-64	27.7	40.9	15.3
65+	3.2	5.8	1.5
Total	4.1	5.6	30.6

Source: Istat 2000

Although there are no available national data concerning age and employment category or job type (part-time, full-time, etc), a number of studies have highlighted the fact that 70 % of carers are women, mostly employed in temporary jobs in the service sector, characterized by higher flexibility (Melchiorre et al. 2001 / a; Facchini 1999; Istat 2000).

One concluding remark concerns the increase in the female employment rates, which not only in the long run (Lamura et al 2001 / c: 116), but also in the last few years keeps uninterrupted: between 2000 and 2003, the percentage of active women in working age moved up from 39.6 % to 43.1 %, showing an almost double increase as compared to men (see Table 2).

Table 2: Employment rates by sex. Age band 15-64. Years 2001-2003

Year	Male	Female
2000	67.5	39.6
2001	68.1	41.1
2002	68.8	42.0
2003*	69.7	43.1

* Data referred to the month of July 2003.

Source: Istat 2000; 2003

1.11 Positive and negative aspects of care-giving

Carers' needs, motivations and emotional characteristics

The INRCA survey on primary carers highlights, through an analysis of the main predictive factors of psychological difficulties, that over 25 % of caregivers show high levels of dissatisfaction in terms of assistance burden, stress, anxiety, depression and a general feeling of existential dissatisfaction (Balducci et al. 2002). From the point of view both of consequences on health conditions and in particular on mental health, the most endangered seems to be non working women - above all older, retired women - who suffer from moderate-severe anxiety in 20 % of cases and from depression in 30 % of cases, while among working women, those working in the private sector appear to be in a less risky situation as to their psychological health (Quattrini 2001: 11).

The ESAW survey on primary and non-primary carers, investigating, among other things, quality of life levels (measured by calculation of a synthetic 'satisfaction with life' index, on a scale from 0 to 22), highlights relevant differences between **carers and non-carers** (the former being slightly more satisfied than the latter), **geographical areas** (carers living in central Italy being the least satisfied), **rural, urban and metropolitan areas** (those living in the latter area appearing to be slightly more satisfied), in correlation to the **disability degree of the older person** (the higher the disability, the worse the carer's quality of life) and, finally, in correlation to kinship (lower life satisfaction being felt mainly by wives, husbands and daughters) (Lamura et al. 2003 / a).

Among the reasons and motivations that primarily lead to provide care to one's elderly relatives, the most relevant is – according to the previous INRCA study - the spontaneous wish to help them, but not seldom the decision is also due to the fact that "there is nobody else to give them support and care", so that, also owing to the pressure of powerful "social rules", the caregiving relatives feel in the "irreplaceable" position of being the only person that can help them (Lamura et al. 2001 / a: 32).

As for the analysis of needs, it is important to remember that it is not always easy to make a sharp distinction between the needs of carers and those of the elderly person in need of care. In fact, apart from some specific services clearly aimed at meeting the needs of both the elderly (such as for instance residential care, home care services for hygiene and rehabilitation) and the caregivers (such as for instance training courses), it can be stated that what can relieve the sufferings of the former, often contributes to relieve the latter as well. In any case, from the comparison carried out within the same INRCA study between the needs of carers and those of the cared for elderly, there emerges in the case of carers a stronger need for more frequent and better contacts with GPs and for economic provisions in the form of care allowances (Lamura et al. 2001 / a: 59).

Information on carers' needs can be inferred also indirectly through an analysis of their preferences regarding services. Among the **health services** that are considered most useful by the older adults in need of care and their families are above all the hospital (28 %) and laboratory tests at home (26 %), followed by physiotherapy and nursing assistance at home (19 % and 15 % respectively), while among **social care** services, the most useful services are home care assistance (22 %), economic provisions (8 %), companionship service / transports (6 %) and temporary stays in hospital (5 %), a solution which is considered even more useful, if applied to short periods such as a few days or weeks (Lamura et al. 2001 / a: 56-58). These findings are confirmed by the results of a local survey (FAI 2003), which has shown that family carers require the strengthening of first aid services, the creation of family counselling and a greater number of structures for temporary stays.

Elderly abuse

According to international data, **elderly victims of abuse** are often female, over-80, non self-sufficient and with scanty economic resources, abuses often taking the form of negligence, psychological abuse and economic exploitation. However, there are no precise national data available about the diffusion of this phenomenon in Italy (Pasqualini, Salvioli 2001; www.geriatria.unimo.it/abuso.htm). ISTAT does not tap data referring to elderly abuse, in terms of violence and ill treatment, since the only available information from ISTAT refers to the 14-59 age range and mainly to cases of abandonment, neglect and poor service - although an investigation focussing upon abuse to women over-70 is currently in progress.

The few associations that can be found in some metropolitan contexts such as Turin, Rome, Milan and Genoa to support elderly victims of abuse have been set up thanks to a successful collaboration between Municipal Authorities and local voluntary agencies, and the most important are: the association for the "Help to elderly victims of abuse" located in Turin (website in <http://www.intrage.it/attualita/2002/05/10/notizia4337.shtml>), the "Silver Wire", a telephone based help-line organised by the older people's organisation AUSER, including the possibility to denounce violence and abuses (website in <http://www.auser.it/>) and the office of the Municipality of Rome dedicated to elderly victims of criminality (website in www.comune.roma.it/sicurezza/anziani_vittime_reato.htm). Despite the pioneer work performed by these local programmes, a discrepancy can be observed between the wide diffusion of the phenomenon and the scant national relevance attributed to it. The existing initiatives report, in fact, that the figures for phone calls received, denouncing cases of family violence against older adults, are very high, but the relevant data are limited to the metropolitan area concerning each association. For this reason a number of projects have been initiated in order to shed further light upon the issue – some of them on a national basis, others with European extension, such as the DAPHNE project (focussing upon abuse against older women), in which the Genoa Municipality (Safety for Older Adults Unit) was

the Italian partner contributing to the final Report on the main outcomes of the project (www.centromaderna.it/visual.asp?num=1056).

Some comparative, "indirect data" are however available, albeit more referring to "passive" neglect behaviour – contributing to solitude – rather than "active" abuse. According to a recent survey conducted by the "**Psicologi volontari Help Me**", **association**, that monitored 2,500 people aged over 60 all over Europe, the Italian elderly are the ones who most suffer from loneliness and neglect and they most harshly accuse their children. In actual fact, 76 % of the Italian sample accuses them of cruelty, 72 % complain because their children have too many engagements, 56 % think they are ungrateful and 44 % would like greater involvement on the part of their children, especially during the summer (Cairola 2002).

The phenomenon of solitude of older people is considered by many as their worst enemy, often responsible for their death. In Milan, out of 270,000 elderly persons living in this city, one third live alone and among them one third are at risk of being found dead in their homes or of being rescued in extremis dehydrated, ulcerated, or in situations of severe degradation and neglect. What makes things even worse is the circumstance that those risks are not due to situations of poverty or marginality, but rather to sheer solitude (Cremonese 2002). This phenomenon had in summer 2003 as a consequence an increase of 21 % in the mortality rate of over 75 year old population in the most urbanised areas of the country, as one of the worst heat waves of the century hit Italy (Ministero della Salute 2003), against which in 2004 many municipalities, regions as well as the Ministry of Health have tried to organise themselves organising monitoring and support services to older people more at risk (Ministero della Salute 2004, Comune di Brescia 2004, Bubbolieri 2004).

1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand

According to different estimates and a recent national survey, in Italy there are about 600-700,000 people engaged in home help care as personal assistants hired by Italian families, mainly foreign immigrants employed to provide care to dependent older people (Sarno 2001: 26; Caritas 2002; Polverini and Lamura 2004: 7-8). The only socio-demographic data available on privately paid carers refer to carers regularly registered with INPS, i.e. the Italian "National Institute for Social Welfare" (INPS 2002). Although these are partial data, since INPS workers are only a part of privately paid carers, they can however reveal interesting trends.

During the last ten years the number of INPS workers has not increased much, but a meaningful change has taken place in the distribution between Italian and foreign paid carers since during the nineties the percentage of the latter increased from 20 % to 50 % of the total (INPS 2002). This confirms that most workers employed as privately paid carers are foreigners (mostly coming from

Eastern European countries), even if a significant number of Italian workers is still employed in caring (Gori 2002: 20).

As for the gender aspect of the phenomenon, women are the absolute majority among INPS regularly registered paid carers, but while among the Italians very few men provide care, among foreign care workers men are relatively more numerous and on the whole their number is increasing (Socci et al. 2001). However, also in this case there emerges a clear centrality of women in the activity of personal care and assistance, following the traditional “gender specialization” (Melchiorre 1997; Ziglio 1990).

From a recent national survey (Giustiniani 2003)⁵, there emerges that foreign carers – of whom only 70-80 % work with a regular contract, the rest being employing on an undeclared basis (Caritas 2002) - have in most cases a medium-high level of education, with 25 % of people holding a degree and 46 % with a secondary school diploma, while according to a survey conducted in the Region of Marche, about 12 % can even boast a Bachelor of Arts or a Bachelor of Science, half of them being younger than 40 (Lucchetti et al. 2003:11).

With regard to irregular work - which is not an exclusive prerogative of foreigners (Gori 2002: 47) and which refers to a great part of the sector offering personal care - since demand is only partially satisfied by regular workers (Ambrosini 2001), there is not much quantitative information available, although several surveys conducted in differing cultural contexts seem to confirm the strong presence of foreign workers (Piva 2002; Castegnaro 2002) (Cfr. also § 6.2 about the recent legalisation concerning foreign immigrants).

Caregiving to older people (and domestic work in general) appears to be a mainly individual activity and it tends not to assume organized forms. The strong prevalence of individual providers compared to more organized structures is not a specific feature of the Italian and Mediterranean labour market in this sector, but it is common to other European countries (Weinkopf 2000).

As for comments and opinions of relatives about the possible employment of foreign personnel, one family out of 10 uses or has already used this form of assistance, one out of four is absolutely against it and 40 % are uncertain. The tasks usually entrusted to the assistant are the most tiring and the least emotionally demanding (Socci et al: 2001:14; Lamura et al. 1999).

⁵ This study has been carried out by the Italian National Council of Economy and work (CNEL) on a sample of 400 foreign women employed as home helpers in Italy.

2 Care policies for family carers and the older person needing care

2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people

2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important? Do minority groups have different ideologies?

Concerning the problem of caring for dependent older people in Italy, family care, which is traditionally felt to be a “social duty” in this country, is often ideologically seen as the best solution by the elderly, the family as well as by the policy makers. Traditionally, in fact, the problem of dependence in old age has always been addressed through the intergenerational support provided by family members, who feel morally bound to provide the necessary care to their elder relatives, beyond the more or less constraining legal issues involved. This is especially true of women (Paoletti, 2001:293), in connection to a deeply rooted type of mentality, which partly explains also the limited recourse made to residential facilities. When institutionalisation eventually becomes necessary, as is sometimes the case because of the excessive, no longer sustainable caregiving burden, it becomes not seldom a source of severe guilt feelings for the family caregivers. Although home care services are generally considered to be the best of all possible solutions, the State and the local bodies (Regions and Municipalities) has so far not being able to widespread adequately this kind of services on their own (Melchiorre et al. 2000: 4). On the contrary, it is generally accepted as normal and legitimate that the community and institutions should become involved in caring for elderly family members only after the family resources – often interpreted in a very extended sense (up to the third degree of kinship) have run out (AUSER 2001a: 1). In Italy, the subject is tackled by the common use of public monetary transfers. Now, even if the latter are important in helping support families that are often faced with high costs, often for long periods, they are undoubtedly insufficient as compared to the existing needs. In fact, the debate on how to obtain further economic resources is of growing importance (Da Roit-Gori 2002: 132-133). As a consequence of these policies aimed at the family rather than at the services, in Italy about 75-80 % of elderly care is carried out in the informal network of an extended family (Mengani et al. 2003: 32). Caring for a disabled and ill OP requires a constant physical and emotional commitment from the family carers. The tasks and duties that range from economic support to physical help are often difficult and complex. Therefore, if on the one hand the family protects and defends the disabled OP, on the other hand it underlines the strong need

for help and protection, in order to prevent possible pathologies connected with caregiving such as stress, anxiety and depression. These are all symptoms of a heavy caring burden, due also in part to the conflicts between the needs of the OP and the personal aspirations of the caregiver (Melchiorre et al. 2000: 2, Lamura et al. 2001c:126-127). For these reasons, but also following the demographic transformations taking place in Italy, the ideological system on the family is changing. If caring in the family is considered as the best solution, it is evident that new public implementations and rules are needed to tackle this situation in terms of more rational monetary transfers (through personalized schemes instead of standard and inadequate sums), availability and accessibility of care services. The problem, far from being solved due to the presumed excessive costs of the Italian health system, should also be traced back to an incorrect allocation of the resources (Melchiorre et al. 2000: 3). A further suggestion for tackling this problem is the development of a private care system, provided this is also regulated by more adequate rules (Gori 2002: 24).

As to caregiving patterns of ethnic minorities, it is difficult, as yet, to give a precise picture, due to the scanty numbers of older members of migrant populations present within the Italian community. The number of foreigners regularly registered in Italy amounted to 1,708,062 in 2002, of whom only 5.7 % were over 60 (with a noteworthy drop from 7.6 % in 1992). Generally speaking, the immigrant population is quite young, with 54.8 % ranging between 18 and 39 years of age and 19.2 % aged 18 or less (Istat 2003 / a).

2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?

In Italy, a whole, clear picture on the subject does not exist. Various regulations that have been developed over time have led to several definitions and entitlements, and therefore to different services, as reported below (further benefits provided at the local level being presented also in § 2.3).

1) “**Severe disability**”: the national law defines as “severely disabled” people those who have been recognized as such by the Health Commission instituted according to art. 4 Law 104 / 1992.

Definition: if a person’s impairment, single or multiple, has reduced his / her independency, so that **permanent, continuous and overall assistance is required**, both at the individual level and in relationships with others, then the situation is described as “**severe**”. This assessment, which controls for the person’s difficulties, need for permanent assistance and total residual capacity, are carried out by the local health authorities through medical committees according to art. 1, Law n° 295, 15th October 1990, with the help of a social worker and an expert in the case under question, all working for the local health boards.

Entitlements: the working father, mother, relative or a kin within the third degree (spouses, children, parents, brothers, grandfather-grandson, uncle-nephew) who show that they are involved in caring for the disabled person, have the right to **three paid days of leave per month** throughout their working career. Furthermore, this status is necessary for having access to the various social-health services at the district level. The national regulation does not fix age limits to this definition, but in enforcing this law, some regions have introduced the age barrier of 65 for some specific programmes addressing the needs of disabled persons.

2) “**Civil disability**”: civil invalidity is dealt with in art. 2, Law n°118, 30th March 1971, and modified by the legislative decree 509 / 88, that introduces the definition of civil disability for citizens over 65.

Definition: “Disabled civilians” are those that suffer from psycho-physical disability whose causes do not depend on war, services nor work. The disability may be congenital or acquired and, according to the degree of disability, there can be partially or totally disabled civilians. Blind and deaf and dumb civilians must also be added to this group and, because of the special nature of their disablement, they are dealt with separately from other disabled civilians, also because they are entitled to specific economic benefits, regulated by special laws.

Civil disability is “measured” according to the working capacity of the applicant. At present, three “classes” of disability exist: up to 73 %, from 74 to 99 %, 100 %. Even the over 65 year olds who have persistent difficulties in carrying out tasks and functions in accordance with their age may be considered disabled civilians in order to benefit from the social health services and to be entitled to a care allowance (www.ital-uil.it/guide/invalidi/invalidi/inv_civili.htm).

Entitlements (see table 3): for those with a disability up to 73 %, no additional pension benefits are provided, but one has priority over others for being engaged in public bodies; for those with a disability between 74 and 99 %, a means-tested monthly **invalidity allowance** of 223.90 Euros is provided; for those with a 100 % disability, a **disability pension** of the same amount is provided, which is also means-tested, but allowing for higher levels of extra income. The 100 % disability is assigned to people with severe and persistent difficulties in carrying out tasks and functions according to their age.

Disabled civilians with 100 % disability (similarly to totally blind persons) can further apply to benefit from the State **care allowance** (Law n°18, 11th February 1980). It should be pointed out that not all persons with 100 % disability are entitled to receive this allowance, which is granted only to those who are “unable to walk without the permanent help of other persons or need continuous assistance due to the impossibility of carrying out the basic activities of daily living” (ADL). The aim of this allowance is that of contributing to the extra costs that have arisen due to the need of care. This is the highest monetary allowance granted to disabled civilians. It is not means-tested and aimed at

maintaining the old person in the family context. It is very common, being granted to about 6 % of people with at least 65 years of age. The users are not subjected to any restriction or to any statement of expenses regarding this allowance. It should be pointed out, however, that especially in the past and in some areas, it has been used to supplement low-income families or more commonly to buy care work in undeclared form (Gori 2002: 131-132). Up to the end of 2002, 756,446 care allowances were granted to Italian citizens of over 65 years of age, for a total cost of 3,622,322,940 Euro (Da Roit-Gori 2002: 133).

In general: pensions granted to disabled civilians are monetary transfers for totally or partially disabled, blind, deaf or dumb persons with low or no income. Since 1st January 2001, the assessment of disability has been assigned to the Regions, which verify the health requirements through medical committees instructed by the Local Health Authorities (ASL). For awarding the pension to disabled civilians, only the personal income of the applicant is considered (see income limits in table 3 below).

Table 3: Amount and income limits for disability pensions and allowances to civilians in Italy (2003)

Eligible people	Type of pension or allowance	Limit of personal annual income	Monthly amount of allowance
Disabled civilians	Invalidity allowance	€ 3,846.05	€ 229.50
	Allowance for minors	€ 3,846.05	€ 229.50
	Disability pension (1) (*)	€ 13,103.20	€ 229.50*
	Care allowance (1)	No limit	€ 436.77
Deaf and dumb	Pension (2) (*)	€ 13,103.20	€ 229.50*
	Allowance for communication (2)	No limit	€ 220.18
Blind civilians	Pension for the totally blind (3) (4)	€ 13,103.20	€ 248.19
	Pension for partially blind: allowance for up to 1 / 10	€ 6,299.62	€ 170.30
	Allowance for 1 / 20	No limit	€ 157.69
	Care allowance (3)	No limit	€ 649.15

(1) These two provisions are cumutable.

(2) These two provisions are cumutable.

(3) These two provisions are cumutable.

(4) If the blind person is hospitalised, the pension is € 223.90. From: www.inps.it.

(*) These pensions after the age of 65 are transformed into the "social allowance" (see point 4 of this same paragraph), which amounts to € 358.99 per month for 13 months per year.

The total number of recipients of these benefits is the following (all data taken from INPS, and referred to 1st January 2002, cfr. http://banchestatistiche.inps.it/sas_stat/pensionitab18.html):

- **Disabled civilians:** total number of recipients: 1,310,733, of which: receiving only the pension: 368,073; receiving both pension and allowance: 222,820; receiving only the allowance: 719,840;
- **Blind civilians:** total number of recipients: 111,572, of which receiving only the pension: 647; receiving both pension and allowance: 83,162, receiving only the allowance: 27,763;
- **Deaf and dumb:** total number of recipients: 40,765, of which receiving only the pension: 64; receiving both pension and allowance: 14,320, receiving only the allowance: 26,381.

Concerning the pension treatments of the disability allowance and the disability pension for the disabled civilians, it is important to specify that, due to a past tendency to grant disability pensions even to people that did not have the prerequisites for obtaining them, there has been an increase over the last few years in the number of controls on the users in order to regularize the situation. As a consequence, two phenomena have taken place: a decrease in the number of payments for these pensions (in 2002 it was 6.5 % in line with the tendency of the last few years), and an increase in judicial controversies started off by those whose application was rejected (especially with regard to civil disability). Because of this, INPS, the disbursing institution, has lost about 50 % of all causes (P.C. 2003).

3) Other national measures: Amongst the other major monetary provisions existing in Italy, there is a "worker's disability allowance" and a "worker's disability pension".

Worker's disability allowance: This is an allowance granted by INPS to dependent and self-employed workers affected by a physical or mental infirmity which reduces their working ability to less than one third. These individuals can avail themselves of certain social-insurance tax pre-requirements, and precisely an old age insurance for 5 years, of which at least three years paid in the five years preceding the application for an ordinary disability allowance. The amount depends on the taxes deposited. If the allowance is very modest and the person concerned has a low income, the amount of the pension may be increased to a sum, which does not exceed the social allowance (358.99 Euro per month in 2003). In any case, the allowance cannot exceed the amount of the minimum pension (402.12 Euro per month in 2003). It is valid for three years and it can be confirmed, upon application of the user for three consecutive times, after which it becomes definitive. Whoever receives the disability allowance may continue to work. Upon reaching retirement age the allowance is transformed into an old-age pension.

Worker's disability pension: It's similar to the worker's disability allowance, regards workers who have become totally unable to work. The amount of the pension varies depending upon the taxes paid up to that moment, which are then supplemented with a contribution calculated up to the coming of retire-

ment age. The disability pension is not definitive, it can be subject to revision and it is not transformed into an old-age pension. Theoretically, this pension may be cumulative with the disability pension of the disabled civilians, which is in any case subject to a limit according to the personal annual income (see table 3).

4) “Social allowance”: it’s a monetary transfer granted to over 65 year old citizens with low income (in 2003 being considered “low” an income inferior to 4,666.87 Euros per year, or 9,333.74 Euros per year for married persons). The amount of this allowance, which is tax-exempted, is up-dated every year, reaching 359 Euros in 2003.

5) Vouchers: According to Law 328 / 2000, the town council must provide for the concession of “vouchers”, which are economic benefits for the purchase of social services aimed at guaranteeing the citizen an autonomous choice as to the services to acquire (art. 17) from the professional disbursing agencies (in competition with each other) accredited by the public body. The sum of the vouchers is ranked on the basis of economic resources and of the needs of the old person, analogously to the care allowance, but in this case there is a destination bond (Battistella 2002: 1). Some believe that this is the best instrument for guaranteeing the quality of the service (Da Roit-Gori 2002: 137), because by having to ‘intercept’ the vouchers that users can spend, the disbursers are stimulated to improve their capacity to offer precise responses according to the needs (Battistella 2002: 2). The down side of this provision is the short time of assistance received (limited to the length of the service) compared to the actual needs (Battistella 2002: 4).

6) Care: In Italy, some forms of assistance are officially guaranteed to all citizens through the Essential Levels of Assistance (LEAS, cfr. also 2.4) for care both in the hospital and at home (the latter being distinguished into “scheduled home care” and “integrated home care”, cfr. also 4.1.1). Furthermore, health and social-health activities are guaranteed to individuals with psychiatric problems and to their families, health rehabilitation and social-health activities to individuals with physical, mental and sensorial disabilities, residential and semi-residential territorial services such as health and social-health activities to dependent elderly people.

7) Chronic and disabling diseases: individuals with chronic and disabling diseases (cfr. “Regulation for individuation of chronic and disabling diseases” according to art. 5, comma 1, letter to D. Lgs. 29 April, 1998 n.124) have the right to be exempted (partially or totally depending on the case) from the “ticket” (cfr. 2.4), i.e. the fee to be paid to receive medications or treatments for these diseases, some of which are typical of ‘old age’, such as rheumatoid arthritis, dementia such as Alzheimer’s disease, Parkinson’s disease, etc.

2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psycho-social support etc.)?

In Italy, each person (elderly or not) who requires assistance, can ask for ‘alimony’ to the obliged people in his / her family⁶, who may chose to fulfil this obligation either by paying an amount of money each month or by accepting and supporting the person needing assistance in their own houses (articles 433, 438, 443 of the Civil Code). Alimony is a right of the person that cannot be asserted by anybody else, except in the case of the recognized total or partial incapability.

In defense of those persons who are incapable of taking care of their own interests, implementations exist, which have been introduced by the legislator, such as deprivation of civil rights (if the mental capacity has been totally excluded) or disqualification (if it is only limited), in order to limit the legal capacity (that is the suitability of the person to be entitled to rights and obligations) of these people to act. In these cases, the examining magistrate appoints a guardian whose main role is to look after the protected person. Usually, for the interdicted elderly people, guardianship is entrusted to the spouse or to a younger relative (Romeo 1999: 178-188, Lamura et al. 2001c: 102-103). It should be however be underlined that, while this report is being written, a new law is under approval by the Italian Parliament, according to which an improvement and simplification of the whole system is achieved through the introduction of a “support administrator” for persons in need, who can more easily intervene in support of older people than a guardian or a tutor (Cendon 2004).

With regard to obligations of institutions, according to article 38 of the Italian Constitution, any citizen incapable of working and not provided with the necessary means of subsistence, has a right to maintenance and social assistance which the State is obliged to provide. Apart from all good intentions, however, the right to social assistance decreed by the Constitution, remains as yet in many cases still unimplemented (see also next paragraph).

2.1.4 Is there any relevant case law on the rights and obligations of family carers?

As concerns judicial decisions, a picture of the most frequent facts in Italy which fall (even indirectly) within the area of the rights-obligations of family carers can be summarised as follows.

⁶ These persons, identified by law, are in the order: spouse; legitimate, legitimized, natural or adopted children, and, if they are lacking, to the closest descendants; parents and, if they are missing, the closest ancestors even natural, and adopters; sons and daughters-in-law; father- and mother-in-law; brothers and sisters, German or half with the former having precedence over the latter.

Whoever does not abide by the obligation to give **alimony** (cfr. 2.1.2) is punished according to article 570 of the Penal Code, which provides for the offence of “violation of the obligations of family assistance” for those who neglect subsistence to the relevant relatives, incapable of working, etc (Dogliotti et al. 1999: 89). Even if according to the law, the competent care services cannot ask the relatives responsible for the alimony to fulfil the care of the poor relative, it often happens that the authority by-passes this obstacle and obtains payment from the relative, sometimes even under the threat of non-admission or dismissal of the patient from the residential institution where he / she is hosted. If the relative refuses to pay the fee, refusal of admission to an old people’s home or dismissal may be considered as an illegal behaviour and as such, may be contestable in front of the administrative judge (Dogliotti et al. 1999: 90-94).

Treatment and dismissal from hospitals and old people’s homes: due to not always “legitimate” procedures, some of the provisions contained in the constitutional principles and in the ordinary legislature are in some cases far from being realised. During the admission into hospital, abuses are sometimes committed; in old people’s homes, sometimes free beds are not available, but these suddenly become available if the patient decides to pay; sometimes the services offered by hospital or residential institutions are so poor, that the patient or relatives are more or less directly “obliged” to hire people privately for cleaning, help, supervision purposes, etc. Once the acute phase has been overcome, the disabled old patient is dismissed, usually to home, but in some (rare) cases to a ‘sheltered house’, an institution which does not belong to the health system but to the social care services (Dogliotti et al. 1999: 80), this becoming a way of relieving the burden of the family, especially when chronic diseases are involved (Inglese et al. 2002: 24). Some Regions have also ‘invented’ a limited time for hospitalization in private institutes operating under the health national system, which is non-existent in public structures, and which makes it more difficult for the older person and his / her family to recover adequately after dismissal (Dogliotti et al. 1999: 79).

Deprivation of civil rights and disqualification: Guardianship is poorly suited to guarantee the rights of a person. In fact, according to the laws in force, the main preoccupation of the guardian should be the conservation and growth of the disabled person’s property, whereas what the disabled person actually needs is assurance and psychological support. There are problems also in the choice of the guardian. Usually, a relative is chosen, but sometimes the choice becomes dangerous and harmful for the disabled person, with cases of neglect and illegal possession of his goods / property (Dogliotti et al. 1999: 84-85). The recent law introducing the “support administrator” (see § 2.1.3) should however significantly improve this situation (Cendon 2004).

Appeal against the refusal of providing health care services: in case an elderly is denied the right to receive health care services (or even against an insufficient economic support), it is possible to appeal not only by the adminis-

trative way, but also to the administrative judge and to the ordinary judicial authorities. Another solution, already experimented by some carers, is that of use the service which has been previously refused by ordinary bodies, and then asking for refunding from the public health system under the form of compensation for the damage suffered (Dogliotti et al. 1999: 86).

2.1.5 What is the national legal definition of old age, which confers rights (e.g. pensions, benefits, etc.)?

In Italy, one can be considered to ‘enter old age’ at 65. This is in fact the usual age limit which establishes, in the majority of policies, the right to have access to certain types of economic contributions, such as an allowance for assistance (cfr. § 2.3) even if in this case there is a priority in admission when the age exceeds 75 years (Minguzzi 2003b: 201). This limit is also the one under which it is impossible to have access to other services which are instead reserved for the disabled, since disability is treated differently according to whether it appeared before 65 or after 65 years of age. After 65, it is also possible to enjoy certain concessions such as reduced price on entrance tickets or on subscriptions for public transport or to attend cultural-recreational-sporting events. Even the Italian national statistics institute (ISTAT) uses the 65-year age barrier for calculating most of the age related indices. As concerns the minimum retirement age, the main Italian social insurance institute (INPS), as from 1st January 2000, has fixed this at 65 years for men and at 60 for women, even if at present, due to pre-retirement ‘window-frames’, people usually retire earlier. After 65, one can also take advantage of exemptions from health costs (cfr. § 2.4), but this also depends on the level of the family income.

2.2 Currently existing national policies

2.2.1 Family carers?

In Italy, traditionally, specific policies for family carers have never existed, since family care has always been taken for granted, as a sort of compulsory duty. Things have partly begun to change in the last few years because there has been greater concern (but merely as a trend, since the attention has not taken the shape of specific norms) by politicians towards family care for dependent elderly people. Furthermore, this situation also leads to control over public expenditure, since it is an alternative to hospitalization (Da Roit 2001: 106). But meanwhile, especially among carers and older adult organizations (cfr. § 6.3), the debate on the rights of carers is growing, especially to undermine this “traditional” mentality and to take steps aimed at promoting assistance and support for family caregivers through social-institutional services (Colombo 2001: 15, Colombo 2002: 39-45).

With the drawing up of the Health Plan 1998-2000, one of the objectives was that of “adopting policies for supporting families with elderly people in need of care at home (especially to protect women’s health, since women usually take on the burden of caring)” (Health Plan 1998-2000). This objective is also included in the latest Health Plan 2003-2005: “The elderly person lives better at home and within the family network. However, the family often has economic or logistic difficulties in assisting the OP in need of care at home. It is therefore necessary to support the family in this task” (Health Plan 2003-2005: 18). But very rarely have these general guidelines been followed soundly, and if they have, through services not integrated with one another. Among the main measures taken in this sector, the following can be reminded:

- The law n°328 of year 2000 for the reform of social services is considered a turning point, aimed at governance of the problem of aging, but since this subject is not included in the priorities of the present government, it is in many ways an outline of a law whose contents run the risk of remaining on paper and the Regions are assimilating it by carrying out choices different from one another. Concerning care and assistance of the dependent OP, the law aims at promoting home care for keeping the OPs in the place in which they have always lived, wherever possible (Minguzzi 2003a: 80, 84). In 2001, according to art. 18, comma 2 of Law 328 / 2000, a National Plan of Interventions and Social Services was presented. One of the objectives of the plan is “supporting dependent people, in particular the OP and seriously disabled people through home services” thus increasing the value of family responsibilities. To pursue this goal, the policies must be directed to the Regions who should provide support and develop the supply of care services (i.e. temporary hospitality in residential care, entrustment to families) (NAP 2001-2003);
- The law n°342 of the same year, which states the possibility (art. 30, comma 1) of deducting from the taxable income (cfr. § 5.6.3) the costs relative to welfare contributions deposited for paying private carers up to a maximum amount of 1,550 Euro a year. These are fiscal benefits aimed at facilitating the increase in the demand for legal collaborators (Da Roit-Gori 2002: 117), but in Italy this benefit leads to a reduction in the cost of total work which has been estimated to be less than 5 %, therefore the savings are almost non-existent.

2.2.2 Disabled and / or dependent older people in need of care support?

In Italy policies are almost totally reflected in the normative aspects governing rights of access to the monetary transfers and benefits related to disability pensions and care allowances, as previously mentioned (please refer to § 2.1.2).

2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job sharing, part time work, etc)?

Legislation upon these matters in Italy is incomplete and fragmentary. The opportunities offered are often really accessible only to civil service employees, since people working in private employment are at risk of “jeopardizing their jobs” if they dare to apply for them (Tarabelli et al. 2001: 251). Following laws provide some relevant framework norms in this field:

- **Law n°335, 8th August 1995:** Article 40 states that for pension treatments determined exclusively according to the tax system, periods of figurative credit are recognized even for leave from work such as for assisting children from six years onwards, spouses and parents as long as they are cohabitants, when they resort to the conditions stated in article 3 of Law n° 104, February 5th 1992 (that is if the disabled person exists). These amount to a total of twenty-five days a year, with a maximum total limit of twenty-four months throughout the entire working career;
- **Law n°53, March 8th 2000:** This law promotes, among other things, equilibrium between working time and caring time through paid and unpaid leave. Any worker (art. 4) has the right to paid leave for three working days a year in case of death or documented severe disability of the spouse or a relative within the second degree (children, parents, brothers, grandparents-grandchildren) or the cohabitant. In addition, the employees of private or public companies can ask for up to two years of continuous or split unpaid leave for severe and documented family reasons (such as, for example, in the case of workers with a dependent person in the family who needs care and assistance). During this period, the employee keeps his job, but has no right to the salary and cannot be employed in any other job. This leave is not calculated in the length of service nor in the social-insurance scheme. The worker can ask for redemption, or proceed to pay the relative taxes, calculated according to the criteria of the voluntary prosecution. The law also includes measures in support of flexible times. For example, contributions to companies which favour positive actions are contemplated regarding flexibility and training programs for the reinstatement of workers after the period of leave;
- **Law n°104, February 5th 1992:** According to this law, the working father, mother, relative or akin, within the third degree (spouses, children, parents, brothers, grandparents-grandchildren, aunt/ uncle-nephew/ niece) involved in caring for another dependent family member recognized as being severely disabled (cfr. § 2.1.2), has the right to **three days of paid leave per month** throughout the entire working career.

Apart from these normative aspects, the whole debate upon time organization considering family-caring-work is becoming a matter of increasing interest in Italy. In 2001 for example, in the context of the European project “A New Or-

ganization of Time Throughout Working Life (OTWL), INRCA carried out a survey upon the topic in Italy, aimed at a data comparison between European countries. Objective of the research was the improvement of conditions influencing time management for workers involved in a caregiving situation with a dependent elderly relative, and / or for the up-bringing of children (Lamura-Principi, 2002).

2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people?

In the last few years, in addition to the monetary transfers granted by the State, there have been contributions by many Regions and Municipalities (Melchiorre et al. 2000: 2). At the local level, the economic contributions for families that care for dependent older people at home are mainly substantiated in the form of care allowances (Da Roit 2002: 41). These are monetary transfers based on need and income (while the State **care allowance** is granted only on the basis of necessity, being non-means-tested) that Municipalities and Regions grant to families of dependent elderly people to support the burden of caring (see also § 5.7.1). This has become very popular in the last few years at the local level, especially in the Central and Northern areas of the country, reaching amounts which strongly vary in the different local contexts (Da Roit-Gori 2002: 131-133) (Cfr. § 5.7.2).

The legislation describes these contributions as measures to help families, but often they are used to purchase private care from the illegal care market. In this way, the allowances end up as an aid for purchasing private care illegally (Gori 2002: 28, Battistella 2002: 2). Besides, these allowances are not sufficient to cover entirely the remuneration of the carers, which is guaranteed through funds from the family of the beneficiary or from the beneficiaries themselves, this meaning that those families in a better financial situation are mostly inclined to get help from the private care market (Gori 2002: 25, Lamura et al. 2003). In the case of the regularization campaign carried out in 2002 for private assistants previously hired illegally by the family (this foresees the recovery of a minimum percentage of the cost by deduction from taxes, cfr. 5.7.3), the procedure involved an application which costed 330 Euro to the “employer”, i.e. the older person or his / her family (Da Roit-Gori 2002: 125). A further risk associated with this phenomenon concerns the possible poor professional skills of carers, which could lead to inadequate care (Battistella 2002: 4).

One of the recurrent subjects in the regional legislative measures deals with the promotion and exploitation of the role of the family and social network which the elderly person is part of. The main aim consists in supporting and allowing care work without penalizing the female family members and in a way also of reducing “the negotiations for resorting to old people’s homes of weak, dependent individuals to only extreme cases”. In the following, some examples

of how different local institutions have tried to implement this kind of policies are reported:

- in **Triest** the local Health Authority has created a project for the support of family caregivers of older adults with Alzheimer’s disease. The goal is to reduce the consequences of Alzheimer’s by means of a network of services focusing upon caregiver support. The project aims at identifying and making available to caregivers a series of small but precious tools helping them to address daily living problems with greater optimism, hope and trust, and to overcome their loneliness. Within the project a free course will be held involving family caregivers. Course objectives include reduction of grief generated by presence of family member with Alzheimer’s disease, help in becoming more efficient, thanks also to the sharing and exchange of experiences with other carers in the same situation (http://www.triestesalutementale.it/guida/guida_frame.htm);
- The **Lombardy** region has arranged social-health vouchers for its users, not to be confused with the social vouchers provided for by Law 328 / 2000 (cfr. § 2.2.2). These are home care services offered by the ASL, based on vouchers of 362, 464 or 619 Euro per month given to families who request them (and fulfil the need and income requirements), to be spent in accredited structures. Everybody can make use of them without limits of income or age. The only condition is that at the moment of request, the person be frail and assisted at home (Fondazione Manuli 2003, Polverini and Lamura 2004);
- the **Milan** Municipal Authority has introduced a social-health voucher, in lieu of the care allowance. This service contemplates the distribution to primary caregivers of one of two standard amounts according to whether the dependent elderly person is cared for by a family member or by a paid carer (cfr. § 5.7.2).

Other regions have focused their attention on continuing the social-care and social-health services, by monitoring the quality of the services. In this respect, probably the **Emilia Romagna** region deserves special mention, as it has adopted certain measures in this area, which have often anticipated and in fact stimulated national policies. By way of the L.R. 57 / 1994 “Protection and exploitation of elderly people, interventions in favour of dependent elderly people” care allowances were introduced already in 1995. According to this regional law, the person in charge of the case (usually a social worker) was responsible for ensuring continuous care to the dependent elderly person, thus guaranteeing the person and their family a clear and univocal reference point. Instead L.R. 2 / 2003 takes into account the law 328 / 2000, its main objective being to organize a system of services able to accompany the person along the whole life span, therefore not only in times of proclaimed difficulty. But on the whole, the law is a kind of “outline of a law of an outline of a law”, which still greatly remains to be implemented (Minguzzi 2003a: 97-105).

In the same region, a project for senile dementia has also been set up (<http://www.emiliaromagnasociale.it/wcm/emiliaromagnasociale/home/anziani/demenze.htm>). The regional plan, enforced in 1999, establishes that in each Local Health Unit (ASL) an advisory bureau, be created offering support services together with orientation, monitoring and co-ordination between family doctors, hospital units and Elderly Care Services. Concerning support to families, each health care district reserves a number of beds for temporary hospitality to subjects with dementia, and organizes educational meetings for family caregivers, offering a more in-depth knowledge about the medical, psychological, behavioural aspects related to disease progression, besides advice as to adaptation of the home to the dementia patient's needs, and to legal and welfare issues deriving from the disease. During the project, for a restricted period of time (from 2001 up to the present) a limited selection of operative units offered the opportunity of in-depth exploration of a number of aspects of Alzheimer's Disease, thanks to the Project for the "Qualification of day centres, residential institutions and support actions for family carers", eventually leading to the production of a manual for caregivers of subjects with dementia (http://www.emiliaromagnasociale.it/wcm/emiliaromagnasociale/home/anziani/demenze/Manuale_Demenze_II_Edizione.pdf).

Furthermore, an important panorama exists but is hardly accessible at the information level (if not only partially), concerning the services of the local authorities, in particular municipalities. In some local realities – such as for instance some municipalities of the provinces of Modena and Parma (www.regione.emilia-romagna.it/web_gest/notizie/1999/gen/anziani3.htm) and the municipalities of Genova (<http://www.comune.genova.it/sociale/anziani/>), Ancona (http://www.comune.ancona.it/ancona/no_menu/UrpScheda_urp_29-3-2001_43097.htm) and Fasano (<http://www.comune.fasano.br.it/Regolamenti/Affidoanziani.pdf>) - a service exists which entrusts families willing to give their help to older people who are alone, and for possible relief the families providing care must turn to residential care facilities for temporary admission. However, this re-enforces more and more the deeply rooted culture of family care in Italy in the attempt of finding a family for those who do not have one, rather than making a better use of residential or home care.

2.4 Are there differences between local authority areas in policy for family carers and / or older people?

As previous paragraph makes quite clear, local policies do exist, and may also be quite different from one another, the most commonly recurring instance being the care allowance, which is not contemplated in all regions. Public services, in fact, inevitably reflect the existing policies, and whilst Italy is faced with a wide and growing demand for care, little reaction is provided in terms of direct provision of public care services, which are also strongly diversified in the various territorial contexts (for example, among the better equipped regions there are Emilia Romagna and Lombardy, whereas the averagely

equipped ones are Marche, Umbria and Lazio, while the worst equipped are Campania, Sicily and Calabria – Presidency of the Ministry of Councils 2000: 124-146). However, even where the services offered exceed the demand, it is still a partial and limited service with respect to the existing needs (Gori 2002: 22). In March 2003 the regions which took into account a law in this sector according to the requirements contained in the Law 328 / 2000 were only two: the Valle d'Aosta and Emilia Romagna. In the other regions it was necessary to read between the lines of enclosures to the financial laws, or to laws on the conferment of functions and administrative jobs, in order to find provisions related to elderly people and their carers (Minguzzi 2003: 97). In carrying out the provisions of 328 / 2000, some regions have resorted to setting out rules, while others are proceeding towards the approval of regional plans (Ranci Ortigosa 2003: 1).

Differences in policies between local authorities appeared even in the biannual report of Parliament on the condition of the elderly person 1998-1999 (Presidenza del consiglio 2000: 124). With regards to geriatric services for the frail elderly person, it was recommended there that only one instrument for multi-dimensional geriatric assessment is used. According to the document, if the field of care is to be genuinely rationalized, it is necessary to make the procedure homogeneous and to allow for comparisons at the regional level between the single ASLs, and at the national level between the single regions.

The awareness of the heterogeneous national picture is sufficient to stimulate an attempt at achieving homogeneity, at least for medical services. In fact, in order to eliminate these differences, medical services are guaranteed to all citizens on the whole national territory by paying a minimum sum, known in Italy as the "ticket"⁷ from which citizens of 65 and over and with low family income are exempted (cfr. also § 5.5). These services guaranteed for everyone are included in the document known as "Essential Levels of Medical Assistance" (LEAS). These levels derive from the objectives of health written in the National Health Plan and were chosen on the basis of the principles of efficacy and suitability. This requires that the treatment guaranteed by LEAS be effective, useful in reducing or eliminating the disease, and appropriate for that particular pathology. If more than one treatment method satisfy all conditions, then the cheapest one must be guaranteed (Decree of the President of the Council of Ministers November 29th 2001). The decree on LEAS has however led to discussions, especially because it appears that the patient in some cases pays a considerable amount of the treatment, such as 50 % of the whole sum for the dependent elderly admitted into an RSA, while according to the legislative decree n° 229 of 1999 the strongly integrated health and social care services should all have been at the expense of the National Health Service (Guiducci 2002: 35). According to some observers (Ragaini 2002: 86),

⁷ The "ticket" is the amount that one pays as a contribution fee to medical expenses for the specialist services offered and guaranteed by the Medical System.

this indicates a clear tendency to confine to social care services (the use of which must be partially paid for by the citizen) all chronic diseases or those which are not curable, while the entire medical competence only exists for the post-acute phase, that is for very short periods of time.

3 Services for family carers

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)	X							
Counselling and Advice (e.g. in filling in forms for help)		X	X ^(a)		X	X		
Self-help support groups		X			X	X	X	
“Granny-sitting”			X					X
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X			X	X		
Weekend breaks		X			X			X
Respite care services		X ^(b)			X			X
Monetary transfers			X ^(c)	X				
Management of crises		X ^(d)			x	X	X	
Integrated planning of care for elderly and families (in hospital or at home)	X							
Special services for family carers of different ethnic groups								
Other								

- (a) This type of service, in a general sense – not intended specifically for carers – has been widely present in most of national territory for a long time now. Family advisory bureaus, in fact, belong directly to the Local Health Authority Units (ASLs), and law establishes their presence.
- (b) These services are defined by art. 16 of Law 328 / 2000, but they are of residential or semi-residential nature, in the form of temporary stays in institutions or community care centres, while there are no remarkable examples of respite care services implemented in the cared for person's home, excepting the “companionship” service provided by conscientious objectors employed by the Municipal social services, for a few hours a week.
- (c) One of the peculiarities of Italian welfare concerning services for non self-sufficient elderly people and caregiving families consists in the large diffusion of economic provisions both at a national level (disability pensions and companionship allowances) and at a local-regional and municipal-level (care allowances) and in their prevalence if compared to the quantity of services provided (Gori 2001 / a) (see also § 2.3 and 5.7.2).
- (d) Most of the (very few) existing Internet websites for caregivers are especially dedicated to families of Alzheimer's and psychiatric patients. To quote just a few (see also § 6.3):
<http://www.alzheimer-aima.it/alzheimer.html>: AIMA (Associazione Italiana Malattia di Alzheimer) includes a 'family support' section, where structures present throughout the whole national territory, self-help groups and 'hot-lines' for caregivers are listed; some local chapters of this association are also quite active, like for instance the one in Rome (www.aimaroma.it);
<http://www.alzheimer.it/index.html>: the Italian Alzheimer Federation (AI) provides a similar service as AIMA, including a hotline for carers, documentation, training courses etc.;

www.famiglia.regione.lombardia.it: website organised by the Region of Lombardy;
 DI.DI.A.PSI. (Difesa Diritti Ammalati Psicici. Including a section called 'Schizophrenia: questions and answers'): <http://www.rccr.cremona.it/didiapsi/>.

3.1 Examples

3.1.1 Good practices

The practices listed below are much more common in the northern and central regions of Italy than in the South of the country, as evidenced by the examples reported in **Appendix 7.2**:

- “Support Services for *caregivers*”;
- “Parente-sì”;
- Experience of home care services to an elderly person with dementia;
- Groups of mutual help for people who have lost one of their relatives.

3.1.2 Innovative practices

- “Custode socio-sanitario” (“social and health guardian”);
- Consultorio per carers di anziani in dimissione dall’ospedale (“Counselling centre for carers of older people being dismissed from hospital”);
- “Anziani in Casa” (“Older people at home”);
- Intensive Care;
- “CRONOS” project.

4 Supporting family carers through health and social services for older people

Families face various problems in dealing with services and they mainly complain about scarce service provision and uneven distribution of services in different areas of the country, long waiting times and high costs.

As a matter of fact the provision of public services, both home care and residential, in Italy is one of the lowest in Europe (Jacobone 1999; Paolet et al. 2000; Tomassini et al. 2004), and despite a substantial increase in home care services in the last few years, only a scanty minority of non self-sufficient elderly people is receiving them. The percentage of over 65 year old persons using home care services reaches 1 % of the population in Italy (OECD 1996; Anttonen e Sipilä 2001: 28), compared to 5.5 % in the United Kingdom, 6.5 % in Germany and almost 10 % in Scandinavia (Minguzzi 2003 / a: 37). Although more recent official data seem to indicate a certain increase in the diffusion of these services – Ministero della Salute 2003 / a: 19 - the hypothesis of a significant increase in their number in the near future seems to be quite remote since, owing to the progressive increase in the number of old people, a moderate increase in services will only serve to maintain the present level of assistance (Gori 2002:3).

The scarce diffusion of home care services should therefore be considered a major problem, above all if we consider that these are one of the most requested services, on the strength of the data of a recent survey conducted by Censis on the Italians’ opinions about health (Censis 2002 / a: 26). Territorial differences are quite marked, also with respect to available bed vacancies in nursing homes, ranging from 34 per 1000 inhabitants in the North, to 13 in Central Italy, and down to 10 in the South. Out of all older Italians cared for in residential settings, 73 % live in the North, 15 % in Central Italy and 12 % in the South (www.ageingsociety.com).

In Italy there also exist strong differences among different areas as for the provision of home care services, not only from the point of view of their diffusion, but also from the point of view of integration of different kinds of provisions; a situation that discriminates, above all, against rural areas and southern regions, where monetary transfers are more numerous (Ancitel 2001). These differences are to be considered not only in terms of diffusion of services - which implies a more or less difficult access to services - but also because users’ opinions vary according to the geographic area of residence (Censis2002\1a).

According to the above-mentioned survey, long waiting lists are the main problem of the public health system. In fact, for 63 % of the interviewees they represent the most serious problem, while for 32 % the situation has been getting worse over the last 2 years; further problems are the low quality of services

(30 %), the lack of adequate assistance for old non self-sufficient and disabled people (19 %) and the excessive economic burden of health costs to be borne by citizens (14 %) (Censis 2002a).

In order to face the problem of long waiting lists, several measures have been taken by different local health authorities, according to the Legislative Decree n.124\998 art. 3, which states the adoption of measures aimed at reducing waiting times for specialist visits, ordinary admission to hospitals and day-hospital facilities. The diffusion of such initiatives has been evidenced in a recent survey conducted by the Ministry of Health, showing among other things how almost all ASLs allow treatment to be received without previous booking and carry out the monitoring of waiting lists and waiting times, while half of them organize specific training courses for their “front office” operators (Ministry of Health 2002 / a). The problem of long waiting lists, evidenced also by the Third Report on health policies for chronic diseases⁸ (Inglese et al. 2002: 18) is strictly linked to the problem of costs (see § 5.2).

In summary, there emerges a problematic relationship between families and the public service network, where the services considered most helpful are, at the same time, perceived as the most inadequate (community care centres, availability of medicines, home care assistance, specialized health centres for Alzheimer’s disease, monetary provisions and home health care) (Censis 1999).

4.1 Health and Social Care Services

4.1.1 Health Services

The surveys by INRCA and CENSIS already mentioned above have shown that certain health services are not requested or exploited owing to the lack of adequate information, while other studies have pointed out that the reason of such phenomenon lies in the fact that carers and cared-for people do not perceive themselves as people “who need” those services (Abbatacola 2002: 124).

In Italy health care to the elderly is provided according to the following modalities:

- **Community services:** general practitioner (GP), **Programmed Home Care Assistance** (“Assistenza Domiciliare Programmata” or ADP) - that is medical home care provided to patients who are unable to go to their GPs’ studios - and **Integrated Home Care Assistance** (“Assistenza Domiciliare

⁸ This report has been promoted by the National Coordination Agency of chronic patients’ associations set up in 1996 by the Tribunale per i Diritti del Malato, an association of citizens, voluntary service workers and professional people which has the protection of citizens’ rights and the acceptance of their complaints among its aims.

Integrata” or ADI), which is offered to terminal patients, patients who are affected by severe pathologies, who are temporarily disabled, or who have been prematurely discharged from hospital;

- **Residential care** (Assistenza Residenziale) in residential institutions (RSA for non self-sufficient elderly people and residential institutions for self-sufficient or partially self-sufficient elderly people);
- **Acute care in hospitals;**
- **Mixed Assistance:** Home Hospitalisation (Ospedalizzazione Domiciliare or OD, that is the activation, at the patient’s home, of some diagnostic and therapeutic services which are generally provided in hospitals, possibly integrated, for some particular forms of assistance, with a short stay in hospital through facilitated admission and transport (Lamura et al. 2001 / b: 103-107).

4.1.1.1 Primary health care

In Italy primary health care is mainly based on GPs and on the services of first-aid stations acting on a domiciliary and residential basis for urgent medical interventions also at night and on festivities (Ministero della Salute-Reports 2003 / b: 100-101)⁹.

As for GPs, on the strength of several studies (Censis 2002 / a) they are still considered one of the main and most reliable sources of information both by the elderly and by their relatives¹⁰, even if other surveys show greater preference for specialist doctors (Censis 1999, Vaccaro 2000).

As for home health care services, although their importance has been growing over the last few years, their supply is still lower than demand, since in 2000 only 191,000 old people, that is 1.9 % of all over 60 year old persons could avail themselves of this form of assistance (Ministero della Salute 2003 / a: 19) and remarkable inadequacy is to be noted even where the service exists (Minguzzi 2003 / c: 124). As a matter of fact in the majority of cases, owing to insufficient resources and personnel, this service is limited to a few days a week and to a limited number of hours, a situation which has aroused complaints on the part of carers.

4.1.1.2 Acute hospital and Tertiary care

According to the most recent available data of the Ministry of Health for the

⁹ In 2001 a total of 2.975 first-aid units and a ratio of 2 doctors per 10.000 inhabitants were recorded, which increased further in 2002, but with strong disparities throughout the country (Ministero della Salute – Relazioni 2000 – 2001: 100-101).

¹⁰ The INRCA study on the role of women in family elderly care underlines that among carers the perceived satisfaction on the support received from one’s own GP is high in 80% of cases, and 19% of carers states that the GP provides also a relevant moral and psychological support to their caregiving activity (Lamura et al. 2001/a: 54-55).

year 2000, in Italy there are 160 public structures and 38 officially recognized private structures that have geriatric facilities for a total of 6,494 geriatric beds, i.e. an average of 11.08 for 10,000 old people, with a very uneven distribution between regions, ranging between 1.59 (Umbria) and 43.55 (Val d'Aosta), a difference that is consistent also in the number of geriatric beds in semi-residential and residential structures for old people which amount respectively to 104,292 and 1,867 (Ministero della Salute 2003 / a: 10 - 11; Mussi, Salvioli 2003: 57).

An intense debate is going on the best caregiving modalities for old people as an alternative to hospital, since hospitalisation often implies a decrease in self-sufficiency (Rozzini 2001), but the severity of some pathologies (cardiovascular, respiratory, oncological and neurological pathologies) that most often cause the old person to be admitted to hospital give rise to situations that cannot be reasonably tackled at home.

This is the reason why, despite the right emphasis set on alternatives to the hospital, it seems necessary to concentrate efforts on the reduction of complications due to the stay of severely ill old patients in hospital (Rozzini 2001: 357), also because it should be remembered that the strengthening of services outside the hospital has not led to a decrease in the hospitalisation rates, that about one third of hospital beds for severely ill people are occupied by > 65 year old patients and that recourse to day hospital is much less frequent on the part of old people than in the rest of the population and actually decreases with old age (Ministero della Salute 2003 / a: 12 – 15).

It is interesting to consider the Italians' opinions on specialist treatments: 70 % of the interviewees considers them adequate, while in the South only 35 % judge them as satisfactory. In particular both residential services and daily services for disabled and non self-sufficient elderly people are considered inadequate by more than 60 % of respondents (Censis 2002 / a: 26).

4.1.1.3 Are there long-term hospital care facilities (includes public and private clinics)?

The problem of long-term hospital care was first dealt with in 1988, when a decree defined quality and quantity standards of hospital staff. Already in 1995 Ministry guidelines had stated the need to differentiate the hospital network into two main operative categories: one for acute cases and the other for rehabilitation and thus activate long-term hospital care (Pesaresi 2000 – www.fondazioneismithkline.it/t20005art2.htm).

Despite these measures, there has not been a real development of long-term care; on the contrary, from 1989 to 1997 there has been a reduction in the number of geriatric beds both in the public and in the private structures (from 12,332 to 10,773, i.e. -12 %), while there has been an increase in the days of hospital stay (+25.5 %) and in the average length of hospital stay (from 58.5 to 59.3 days). This reduction refers in particular to public structures, in which the

average period of stay is much shorter than in private structures (according to data of 1997) and lasts 27 days, compared to 91 days of the latter.

On the whole, long hospital stays after a period of acute disease are quite unusual in public structures (which offer on the whole 2,970 beds, i.e. 7.6 % of the total), which points out a strong prevalence of private structures and besides shows a very uneven territorial distribution, since 69 % of beds in public structures is concentrated in 4 regions (Piedmont, Lombardy, Veneto and Emilia-Romagna) (Ministero della Sanità 1998), while half of beds in public and private structures are concentrated in the Lazio Region.

Health residential care is mainly provided in Health Care Residences (HCRs) (Residenze Sanitarie Assistenziali or R.S.A.) for old and for disabled people, in sheltered homes and in the so-called Nuclei of Residential health care (Nuclei di Assistenza Residenziale: NAR, usually within HCRs). The provision of these services does not fulfil the demand and does not correspond to the rules in the case of Health Care Residences, while the situation appears to be better in the case of the number of beds in sheltered homes (Pesaresi 2002: 75). However, there emerges a lack of structures for long stays for non self-sufficient people in hospital. In fact, only 3.5 % of facilities today accept non self-sufficient older adults (www.ageingsociety.com), so that it often happens that residential homes designed for self-sufficient elderly people are improperly transformed into long care hospital centres.

4.1.1.4 Are there hospice / palliative / terminal care facilities?

Activities and structures devoted to the care and assistance of terminal patients have been only recently officially recognized in Italy by a decree of the Ministry of Health (Law 39 / 1999), even if initiatives in this sector had already been implemented mostly by private associations (Rivista Italiana di cure palliative - www.zadig.it/news2001/med/0228-1.htm).

The official estimate is that home care services, preferred in most cases both by patients and their relatives, are necessary - or at least possible - in 75-85 % of cases, while for the remaining 15-25 % of cases assistance provided in specific structures (hospices) seems to be required (Ministero della Salute 2003 / c:117-118).

Several kinds of home care for terminal oncological patients have been started in Italy, often on the initiative of volunteer organisations, and they are mainly based on the complex service network existing in the community and on the pivotal role of MMGs during the whole assistance process (Borin 2001:380).

The same, above-mentioned decree stresses the importance of adequate information on the meaning and purposes of palliative activities and therefore the need to inquire about people's knowledge as to these services. For this reason the Ministry of Health has recently promoted a survey aimed at checking what people know about the existence of public and private structures on

the territory, to collect people's opinions on the usefulness of public services that provide this sort of care and to identify the source of information that would most suit citizens¹¹. The survey shows that 62 % of the sample utterly ignores the meaning of the expression "palliative treatment" (women between 35 and 54 years old seem to be the best informed), 85 % do not know at all about the existence of institutions that provide this kind of treatment (particularly in the case of private structures). However, this service is considered as very useful by more than a half of the sample and 54 % considers the family doctor as the most adequate source of information (even if 29 % suggest it should be the hospital) (Rivista Italiana dei palliativi – www.zadig.it/news2001/med/0228-1.htm; www.nursesarea.it/cpalliative.htm; www.istituto.org/it/ist_cure.asp; www.dica33.it/argomenti/cure_palliative/pallia5.asp).

4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?

It very often happens, especially in Southern Italy and in the case of severely affected old patients, that relatives are often required both in hospitals and in many residential homes to provide night assistance and personal care.

This inadequacy of care structures makes the resort to so called "badanti" (privately paid carers) more and more common, so that it very often happens that lists of privately paid carers "accredited" by the health structure are to be found in hospital wards, to whom the relatives of the older person are "kindly" requested to refer to. This takes place mainly for ensuring night care in hospitals, but in some residential homes it can also be "suggested" for everyday routine care work, on the basis of a supposed lack of internal staff. The problem has so far not clearly emerged in official studies or documents – with some exceptions, see Ambito Territoriale Sociale (2003: 61) or Polverini and Lamura (2004: 3) – also because its solution through the employment of further internal staff would imply higher costs for employers (among whom the public ones), and furthermore because it represents a clear example of conflict between the rights of the employed care workers, on the one hand, and the rights of services users, on the other hand.

4.1.2 Social services

4.1.2.1 Residential care (long-term, respite)

4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of residential care (sheltered housing, residential homes)

The only nation-wide survey that gives information on old people living in institutions and in residential homes in particular, considered by age, is the popula-

¹¹ This survey has been based on a representative sample of 1009 subjects of the over 14 year old Italian population (www.zadig.it/news2001/med/0228-1.htm).

tion census, which is carried out every 10 years. The latests data currently available are the those of the 1991 census (see table below), since the data of the 2001 census are still being elaborated (Bonarini 2000 / b: 151), the only exception being represent by a recent publication by Tomassini and colleagues (2004) who, using own preliminary elaborations, has shown that the already low percentage of over 85 year old persons living in residential institutions has dropped of almost 50 % between 1991 and 2001, passing from 14-15 % to 7-8 % for women and from 6-7 % to 3-4 % for men.

Table 4: Percentage of older people living in residential homes in Italy by age group (1991)

	65-69	70-74	75-79	80-84	85-89	90+	Total
Percentage of older people living in residential homes by age group	0.3	0.5	1.2	2.6	5.0	7.9	1.0

Source: Istat, Statistiche della Previdenza della Sanità e dell'assistenza sociale 1992 / 1993

Though the Department of Social Affairs of the Presidenza del Consiglio dei Ministri (Presidenza del Consiglio dei Ministri 2000; Ministero dell'Interno 2000), and Istat (Istat 1992, 1993) conduct other surveys on residential structures for old people, they do not collect information about the characteristics of the people who live in the residential structures (Bonarini 2002 / a: 136).

The percentage of old people who live in residential homes in Italy is 2 % of the total of old people (Eurostat 2000: 65) and this percentage corresponds to **a half** or even **one third** compared to the majority of industrialized countries (Van Oyen 2001:49-50; Jacobzone S. et al - OECD 1998)¹². On evaluating these data it must be remembered that 2 % also includes other categories of users who "improperly" occupy the 212,624 beds (this figure applies to 1998) designed for self-sufficient old people in residential structures (Presidenza del Consiglio dei Ministri 2000: 115).

Finally, one of the few longitudinal surveys on this topic Italy shows that, after one year, the average number of services exploited by caregivers slightly decreases, and that this is due to the lower use of non residential intermediate services (day hospital and community care centres), in favour of residential and home care services with a higher health care specialisation (in particular hospital stay and integrated home care services) (Tamanza 2002: 40).

4.1.2.1.2 Criteria for admission (degree of dependency, income, etc.)

Residential services with a mainly "social care" character for older people (residential homes, sheltered homes, accommodation communities, etc.) are traditionally intended for independent or only slightly dependent people (look-

¹² This rate reaches 5% in Germany, Japan, UK and USA, 6% in Canada, 6,5% in Australia, Belgium and France and 9% in Sweden.

ing for accommodation and recreational services, with a limited medical component), but the increasing (and by now prevailing) demand of admission on the part of dependent people is currently causing their re-conversion into mixed structures (www.retetoscana.it/polsoc/anziani/definizioni.htm).

Admission depends usually on the degree of dependency of the old person (a certificate of the family doctor is required) and on the level of family income, and in case the old person's personal income is not sufficient to pay for accommodation charges, the Social Services of the Municipality will contribute to expenses (but see also § 2.1.4 for the difficulties related to this). According to recent data (www.ageingsociety.com), only 5 % of elderly people who make use of services offered by residential care do not pay anything, whilst expenses for 62 % of residents fall entirely upon the family, whereas in 33 % of cases health care costs are partially covered by the National Health System fund. Furthermore, considering the average income of an elderly person and the average fee for a residential home, the most likely hypothesis is that the families of at least 35-40 % of the residents take it upon themselves to contribute a part of the fee, for the equivalent of about 250-500 euros per month.

4.1.2.1.3 *Public / private / NGO status*

Not few of old people's residences with a social care character (residential homes in particular) are public and are managed by Municipalities and by IPABs (Institutes for Care and Charity), but the recent reform enforced by Law 328 / 2000, art. 10 (www.socialinfo.it/approfondimenti/ansdipp/RiformaIPAB.htm; www.terzaeta.com/news/agosto2001/08_08_2001.html; www.ipab.it) has somewhat promoted a change in this picture. The most recent data available, referred to the year 2000, reveal in any case that 38 % of residential facilities for older adults are public, 58 % are private and the remaining 4 % are mixed structures, with relevant differences between social-assistance and health-care structures, where no-profit institutions have a 42 % and 25.8 % presence, respectively (www.ageingsociety.com).

4.1.2.1.4 *Does residential care involve the participation of carers or work with carers?*

Cases in which participation of family carers is requested in caring for institutionalised (besides hospitalised) elderly persons are frequent, specifically in terms of provision of active contributions to care. Sometimes this is actually the condition sine qua non for the patient's admission to the caring facility (cfr. § 4.1.1.5).

One should not forget, however, that the involvement of family carers in terms of participation in the new community life of their elderly relative presents a number of positive aspects. Often, in fact, admission of one's elderly relative to a caring residence leads to feelings of impotence and frustration: the situation is perceived as a journey with no return, as a kind of definitive break with the

past. Initiatives aimed at promoting active participation and involvement of family members should therefore be seen in a positive light – also because of their minimizing effects upon the feelings of guilt that are so frequent in caregivers.

In the context of such initiatives, the institution of integrated day-care centres in various kinds of community settings should be mentioned. Thanks to their type of organization - that allows for the possibility of the older person to keep on living at home, although affected by psychiatric and behavioural disorders - they are successful in making the family feel involved, supported and surrogated in caregiving activities, both through systematic group-work and counselling, and through educational activities proper – in the shape of courses, thematic seminars and institution of self-help groups (Angelini et al. 2003: 163-164).

4.1.2.2 **Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)**

As mentioned above, although community care is the preferred form of care in Italy, the availability of formal home care services is very low in the country, due to the widespread use of informal support networks, including foreign immigrants employed by many families as personal assistants of the older person. This has been somehow not only tolerated, but in a certain extent even promoted by the supplementary forms of financial help which Municipalities and Regions have been adding to the already available State ones (Credendino 1997), in terms of statutory monetary transfers in favour of people providing care to non self-sufficient old people at home. Most of them address primarily the needs of older people living alone – being the consistency of the older person's support network one of the inclusion criteria of such monetary transfers - but not seldom resources are made available (on a means tested basis) also to families who provide care, the most innovative programmes including non-kin caregivers.

4.1.2.2.1 *Home-help*

It is to be remembered that in Italy the category "home help" includes people who do the housework and help with personal care and hygiene as well, and while in the former case the service pertains to social services, in the latter case the situation is more complex as far as its management is concerned (for management see § 4.2.1).

All forms of assistance included in this category are managed by Municipalities through SAD (Servizio di Assistenza Domiciliare: Home Care Service) and include help in the housework, in the shopping, in the purchase of medicines, transport and companionship and in certain areas, hairdressing, manicure and pedicure as well (see for instance www.comunecatania.it/servizi/servizisociali/)

aiutodom.htm). In the better organised areas of the Northern and Central Italian regions, municipal home care is integrated with health home care in what is called Integrated Home Care (ADI) for most severe, care-intensive cases (see also § 4.1.1).

4.1.2.2.2 Personal care

This service includes, in particular, personal hygiene, help to get up and go to bed, to wear clothes, to eat meals, to take a bath, transport and relations with doctors. Access to this service depends on income and charges are determined by the Municipality (<http://www.selfhelp.it/casa.htm>).

This form of help is available to the carer family as a whole; in fact it can be enjoyed by natural families and by families entrusted with the care of severely handicapped people, either physically or mentally handicapped, or both, but it depends on the family income and a contribution to expenses is required if the family income is higher than a certain, stated amount (D.P.R.S. 19 / 06 / 2000).

4.1.2.2.3 Meals service

This service is managed by Municipalities and is intended either for people older than 65, who live alone or with their spouse, are partially or totally non self-sufficient and benefit of any family assistance, or for disabled and invalid people who live in families made up by people older than 60 (www.comune.jesi.an.it/MV/schede/css/dom_ausilio.pdf).

4.1.2.2.4 Other home care services (transports, laundry, shopping etc.)

(see § 4.1.2.2.1)

4.1.2.2.5 Community Care Centres

Community Care Centres, in Italy, do not identify with a structure, but rather with an organizational function, a managerial strategy carried out by the Municipal Social Services within the social context (although currently overlapping with the similar activity carried out by the just established “Social Promotion Offices” – Uffici di Promozione Sociale, UPS – see Law 328 / 2000), and in the health care context proper, by the Health Districts. The main task of these structures is to keep track of requests and assess needs (in the form of Assessment Units), with the aim of introducing the user into the integrated socio-sanitary services network.

4.1.2.2.6 Day care (“protective” care)

The Day care services are socio-sanitary structures open to the community, which offer semi-residential accommodation to old non self-sufficient people and with a partial handicap of their functional abilities, where rehabilitation services, recreational services, personal care and hygiene, and meals are pro-

vided ([http://www.comune.castelnovo-di-sotto.re.it/INFORMA/urpsitoweb5.nsf/ServTerrCentroDiurno/\\$first?OpenDocument](http://www.comune.castelnovo-di-sotto.re.it/INFORMA/urpsitoweb5.nsf/ServTerrCentroDiurno/$first?OpenDocument)).

The Day care service is viewed as one of the most adequate answers to the needs both of old patients and of their families (Taccani 2001). The above mentioned Censis research on caregiving to patients affected by Alzheimer's disease has pointed out its faults and inadequacy since it is considered the most useful service by 30.7 % of the sample but, at the same time, 27.8 % of the same respondents define it as the most inadequate service (Censis 1999; Vaccaro 2000).

4.1.2.3 Other social services

Several training activities, including language courses, have been activated for immigrants, such as for instance the Serdom Project (Socci et al. 2001; Piva 2002: 76).

The need of ensuring a **better specific qualification** to the working carers currently employed in Italy in the field of home care concerns both personal assistants directly hired by the family, as well as care workers employed by private agencies, often providing services on behalf of public authorities. Empirical evidence on this need is confirmed by recent studies. As far as **personal assistants** directly hired by Italian families are concerned, a research carried out between 2002 and 2003 by INRCA (Italian National Research Centre on Ageing) on about 220 foreign women providing care to dependent elderly in a Central Italian region shows that **94 % of them has no care work qualification at all** (Lucchetti et al 2003: 25), although it should be pointed out that well 12 % of them has a university degree and a further 38 % a high school diploma. When we compare these data with those collected in a parallel study on **foreign home care workers employed in social cooperatives** (i.e. non profit care agency), which provides care services on behalf of the municipalities' social care services, it can be found that, by comparatively similar educational level (11 % with university degree, 56 % with a high school diploma), **only a slightly higher percentage (27 %) has previously worked in the care sector, and only 52 % has had training opportunities** in this field (Sartini et al 2003: 15-16).

These surveys, besides confirming how dramatic the need for even very basic information on care topics among these workers is in Italy, allow to unveil also other major gaps which need to be filled in order to improve the overall quality of care supply in this Mediterranean country. One of them is the **very poor linguistic skills** of many foreign care workers, which - besides limiting their own integration opportunities - represent also an obstacle for a good communication with the cared for person and his / her family (which is in fact by the way lamented by 28 % of the interviewed personal assistants): 36 % of families' personal assistants (36 %) and 16 % of employed home care workers have none or a just sufficient understanding of the Italian language (but this

percentages reach 71 % and 52 % for the written language!) (Lucchetti et al 2003: 22, 57; Sartini et al 2003: 36).

This situation is reflected by the **training needs** explicitly expressed by foreign workers themselves, who identify in the first place the wish to improve their knowledge in care work-related topics (31 %), the pointed out need for a better preparation in the Italian language (15 %), on computer-related topics (13 %), safety and worker's rights (9 %), a foreign language (9 %), health related topics (7.5 %) and topics related to other job opportunities (6 %) (Sartini et al 2003: 44).

4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modeling of both home and other support care services

4.2.1 Who manages and supervises home care services?

Home care services take in Italy many different forms (Minguzzi 2003 / c: 121), and it is not always easy to state who is responsible for them. In fact, even if social services in general (e.g. the cleaning of rooms) are managed by Municipal Authorities and health services (e.g. medical care and nursing) pertain to ASLs (Local Health Agency), there are mixed situations in which the division of these responsibilities does not follow this pattern, but are all attributed to the one or to the other agency (usually the ASL).

4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorized to run these quality controls?

In Italy the quality control of health and socio-sanitary services is more and more often accomplished by means of institutional accreditation, thanks to which "after an evaluating procedure, public and private structures, and the professional people who request it, acquire the status of subjects qualified to deliver health and socio-sanitary services on behalf of the National Health System (NHS) (Dlgs 502 / 92). As far as the NHS is concerned, this form of institutional accreditation abolishes the previous system based on "temporary agreements" and its use has recently been formally extended also to social services (Law 328 / 2000). This measure activates a permanent process of promotion and improvement of the quality of services thus offering citizens guarantees on the real quality of the services provided (Battistella 2001:133).

Regions are entrusted both with the task of ascertain of the minimum requisites of quality (even if not all Regions have adopted suitable measures so far) thus guaranteeing that those requisites continue to be respected and maintained and with the determination of criteria for the definition of the tariffs that

Municipal Authorities will have to pay the accredited subjects. Municipal Authorities, on the other hand, are entrusted with the task of controlling and accrediting (art. 8-10-11 Dlgs 502 / 92). A great fault of these norms refers to the fact that no really clear definition of what is meant by "accreditation" is given (Pavolini 2001: 203).

Until the beginning of the 90s, this system has been growing in a public-private model of relations based on a sort of "mutual accommodation" model (Ranci 1999), consisting in an often implicit agreement between local public authorities and private service providers, with public funding granted without rigorous controls nor selection of the providers, the latter being responsible for the delivery of services without being involved in their plan (Ranci 1999, Pavolini 2001). In the last decade, as a consequence of higher expectations from the users and their families – also in connection with the series of corruption scandals which shook the Italian social and political system in the first half of the 90s – the need for higher service efficiency and quality pushed many Regions and Municipalities towards the introduction of new systems of care delivery, mainly identifiable as follows (Pavolini 2001, Ascoli e Pavolini 2001):

- **residential care:** the Regions grant the authorisations for running residential institutions, and municipalities pay for those residents who are unable to pay themselves the fees;
- **home care:** the "contracting-out" model is introduced, which select the service providers through tenders based on the "economically more convenient proposal".

In the very last few years, in order to increase the empowerment of users, the flexibility of the private care market as well as the service quality, three further measures have been introduced in the Italian care service sectors (Pavolini 2001: 196-199; Ranci 2001; Da Roit and Gori 2002): the **accreditation** (i.e. in which the public authority, besides funding, identifies minimum services standards to accredit all those providers that responds to these requirements); the **vouchers** (i.e. documents which the public authority grants to the users, enabling the latter to receive the needed services from accredited providers); and the **local care payments**, which are monetary transfers granted by local authorities, in addition to those already provided by the central State (see also § 2.3).

4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?

When dealing with care workers, a double distinction is to be made between first and second level, and between a social area and a health area. As for the training of the first level, University courses in nursing, rehabilitation and prevention have been activated for the health sector, while in the social sector a University course in Social Services has been activated. All these courses last

three years. As for the training of the second level, it implies several qualifications and specializations, but the main professionals who provide personal assistance to old people both at home and in residential homes are the so-called OTA (Technical Operators in the field of Assistance), OSA (Social Operators in the field of Assistance) and OSS (Socio-Sanitary Operators) (www.offertafomativa.miur.it/corsi/).

Especially in the sector of privately paid assistance at home there is no reliable training and workers have a very low qualification level; besides, their category only has extremely reduced forms of professional protection (Gori 2002: 25).

In general, the organization of carers' training is left to the Regions that are presently organizing courses for socio-sanitary operators with training modules that certify **“the qualification of home care, support and companionship to the family and to the person,”** aiming at the training of accredited home workers. The Ministero del Lavoro e delle Politiche Sociali, has appointed a work group on social professions in order to adopt the same criteria for the same professional level all over Italy (Piva 2002: 76; Studio Come 2002; www.forumterzosettore.it/documenti.pic1?DOC_ID=118).

For our specific purposes, it is noteworthy to mention that the curricula degree courses for medical doctors, qualified nurses and social workers contemplate subjects where, although the caring specificity of older subjects is considered, no consideration as yet is afforded either for matters such as family involvement in caring processes addressed to older adults, or to ways in which services should relate with, and support caregivers.

4.2.4 Is training compulsory?

Training of care workers employed in formal care services at the various levels is compulsory and is regulated by national and regional rules. However, a wide debate on the precise definition of different social professions is currently taking place in order to reach uniformity at a national level.

No training is required instead for home carers privately hired as personal assistants by families, but many Municipalities are currently introducing systems of accreditations which connect the provision of local care allowances to the hiring of trained personnel only (Polverini and Lamura 2004).

4.2.5 Are there problems in the recruitment and retention of care workers?

In Italy the problem of care staff recruitment has been “solved” in the last few years through an increasing recruitment of foreign personnel. In fact the local supply of home care workers for old people on the Italian labour market is much lower than the demand, since local people are not willing to accept a job that is considered tiring and wearing. This attitude of the local workforce has increased recourse to foreign workers who, at least during the first period of

their stay in Italy, seem to be more ready to work in occupational sectors that are characterized by great uncertainty and are considered menial by the locals (Socci et al. 2001: 13).

However, this makes clear that one of the main problems of the labour supply in the care services sector in Italy is not the quantitative shortage of care workers, but rather their low qualification with respect to the increasingly complex care needs of the ageing Italian population. The peculiar solution found by many Italian families to support their mostly elderly dependent members, i.e. to resort to the support provided by foreign immigrants, mainly on an undeclared basis, makes evident that in the Italian context a supplementary problem of safeguarding the basic rights of such workers exists in more pronounced terms as in other, non-Mediterranean countries (for a more in-depth analysis of the issue of labour supply in the care sector in Italy, refer to Polverini and Lamura 2004).

4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels)

Integration between social and health sectors should now take place, thanks to the recent institution of “Ambiti Territoriali” (National Plan for Social Interventions and Services, 2001-2003) consisting of aggregations between various municipalities and meant to coincide with the existing Health Districts (cfr. § 4.1.2.2.5). They are intended to become the front-line centres for health and social services integration. Professional integration on the other hand, is currently materializing in the more and more widespread multidimensional type of case assessment, so called because involving simultaneously both health and social professional specialties, in order to achieve solutions aimed at the whole range of presenting needs, taken as an integrated whole. However, it should be underlined that only in some regions of Northern and Central Italy this process is taking place at a “promising” pace.

4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?

Although the topic of the participation of users and of family carers in the “care path” of the elderly is not a new one in the Italian context, especially within the “quality of care” debate, it has not been systematically implemented in most services' everyday praxis, apart from some existing guidelines, so that, especially in the Southern part of the country, their involvement is often left to the good will and private initiative of individual professionals at a local level.

5 The Cost – Benefits of Caring

The GDP for the country: these data will be obtained from OECD / centrally.

5.1 What percentage of public spending is given to pensions, social welfare and health?

For the year 2000, trend figures out of overall expenditure for social protection – which totally reached the amount of 262.472 million Euros circa (MINISTERO DEL TESORO 2000: 15) – were the following:

- 188.212 million Euros (**16 % of GDP**) for social security, of which 89.5 % in pensions and annuities, 2.9 % for TFR (this being a “una tantum” payment granted to employees after they quit a job, calculated on the basis of the number of years they worked for that job), 1.9 % for allowances related to illness, on-the-job accidents and maternity leave, 2.5 % for unemployment benefits, 3.18 % for kind of benefits);
- 16.094 million Euros (**1.41 % of GDP**) spent for social care expenses, of which 20 % for social care, 13.7 % for social pensions, 51.3 % for invalidity pensions, 6.4 % for war pensions and 8.6 % for other kinds of benefits;
- 58.166 million Euros (**5.10 % of GDP**) for health care expenses, of which 14 % for pharmaceuticals, 55.5 % for hospital care, 30.5 % for other care services.

It should be underlined that, on a comparative level, health and social costs in Italy seem to be among the highest in Europe, with 63 % of resources assigned to older people (compared to 44 % in France and 42 % in Germany), which is however due to the much higher amount spent on pensions rather than on services. Furthermore, in dynamic terms, in the last 5 years medical care for people over 65 years of age has increased by about 30 % and those of care services have more than doubled (DPEF 2004 / 2007: 60-62).

5.2 How much - private and public - is spent on long term care (LTC)?

Making an articulated assessment on this topic is a very complex feat, concerning, as it does, a number of varied care provision typologies, at different levels of delivery. One needs to evaluate an expenditure divided into two components, a public one (met by State, Regions, Provinces, Municipalities as well as by the NHS, and characterized by a high degree of local differentiation) and a private one, plus a third ‘informal’ component, concerning care provided free of costs by family members. One first attempt at articulately assessing such expenditure was made in a study carried out in 1998 (ASSR 2002: 16), according to which it has been estimated that in that year expenses for long-term

care in Italy amounted to 3.883 billion euros, as public expenditure (0.36 % of PIL) and 2.457 billion euros as private expenditure (0.23 % of PIL). Besides, families provide home care to dependent elderly persons for an overall value allegedly amounting to 4.841 billion euros. The total sum for 1998 was estimated at 11.181 billion euros.

5.3 Are there additional costs associated with using any public health and social services?

The use of the National Health Service in Italy is subordinated to the payment of a ticket (cfr. § 2.4) in order for the user to have access to public expenditures. However, when a person is over 65 year old and or when he / she suffers from an officially recognised “chronic and disabling disease” (see above section 2.1.2, point 7), this is free. The additional costs are mainly connected with the phenomenon of long waiting lists. This “forces” the users to turn to the specialist market and to pay for it privately, in order to accelerate the long waiting times between booking and having exams, check-ups, but also surgical operations, existing in the public health system (cfr. § 4).

Further additional costs, often undeclared, are those linked to day-care and especially night-care in hospitals. Regular staff cannot always guarantee an adequate support of this type, and often the families of hospitalised elderly people have to resort to private carers. This kind of ‘market’ is usually not regulated, so the families turn to caring persons “suggested” by the hospital, often paying them on an undeclared basis.

With regard to social services, these are addressed mainly to people who declare low incomes. As to services rendered, currently some confusion reigns in matters of which agencies can offer which services to which users, for how much. One of the reasons lies in a die-hard cultural misconception, which in Italy does not consider care as a right to be claimed by each and every citizen, but rather as a concession from above, similar to some sort of ‘charity’. Users are required to contribute a partial fee (except for those totally devoid of means), and it often happens that relatives obliged to the “alimony” are required to pay, too, through a not always legitimate praxis (cfr. also § 2.1.3) (Dogliotti et al. 1999: 82).

5.4 What is the estimated public / private mix in health care?

Although the law 328 / 2000 on the reform of social services has attempted to re-design the boundaries between public and private, through a series of measures - reformulated in the direction of public / private mix - defining responsibilities and competences in managing territorial public services (Miniguzzi 2003a: 84-85), the existing public / private mix in Italy does not reach yet optimal levels, especially in long term care. Part of the problem lies in the fact that the privately paid home care market in particular evades controls from the

legislator in spite of its increasing importance in Italy (according to OCSE even greater than the social services, OCSE 1996). With reference to the amount of care given, privately paid care is the second form of care for the elderly at home, after the informal network and before the social services (Gori 2002: 24-25).

More generally speaking, the reality on caring in our country is characterized by a widespread private market which is mainly activated to face situation of chronicity, that is for long periods of time. Conversely, in primary and secondary care, public services give more adequate results. Primary care is totally public, while a mix exists in secondary care: public hospitals are 61 % of the total, with 82 % of the total admissions, and the outpatient procedures take place in public structures in 81 % of cases. In the long-term care, the situation is reversed: RSAs are public in 19 % of cases, against 81 % of the private sector, and public nursing homes are 15 % (Lamura 2002). According to other researchers, privately managed residential care facilities make up 58 %, public ones 38 % and 4 % are of a mixed type (www.ageingsociety.com).

Privately paid home care, as mentioned, is excluded from this analysis. The private market keeps on growing due to the weakening of the care obligations of families and to a public system confined to play a residual role, such that nowadays this represents the main source for obtaining care services, once the provision of family care is no longer possible. It is largely an informal market, which also exists because it evades public regulations which are too strict and poorly adequate for the needs of both the worker (especially if they are immigrants, and mainly women from eastern countries who work alone) and the cared-for elderly person.

5.5 What are the minimum, maximum and average costs of using residential care, in relation to average wages?

The net average wage disposable in Italy in 2001 was 18,341 Euro per capita (calculated by dividing the net national wages available of 1,044,856 million Euros, by the total population of 56,966,000 individuals). Concerning family wages with an elderly “head of the family”, studies have showed that the average wage varied according to age (the older one gets, the lower the wage) and gender of the “head of the family” (if male, the wage was higher) as well as to the geographical area (higher wages in the north) (Clerici 1999). For example, by citing the two extreme cases, in 1996 in families with a male head of the family, an elderly person from the North-West between 60 and 69 had an annual wage of 10,503.96 Euros (calculated by dividing the family wage by number of family members), while in families with a female head of the family, an elderly person aged 80+, living in the South had an annual wage of 6,586.76 Euros. Other studies show that, especially in the elderly population aged 75+, the individual wage is lower than the average family wage, while pensioners

often have a wage higher than this average, and therefore they act as “donors” to young and / or unemployed family members (Pollastri 2000: 57).

As for the costs of residential care, these are considered too high. In fact there exists a considerable economic stimulation for keeping the elderly at home, due literally to the high costs that one usually has to pay for residential care. The family costs for private care at home are often lower than the residential fees (Gori 2002: 24). In fact, if there were to be a possible admission of a dependent elderly person looked after at home, many carers think this is a positive action, but they do not believe that it is feasible due to the high costs (Lamura 2001d: 67).

Here below we report some examples of the different local realities. By residential care, it is understood that these are old people’s homes and RSAs. One has to take into account that RSAs all operate within the National Health Service, while for old people’s homes this is true only for a few cases:

Ravenna and province (Emilia Romagna region): For an RSA: daily rates start from a minimum of 39.79 (1,193.70 per month, 14,523.35 per year) Euros to a maximum of 43.90 (1,317 per month, 16,025.50 per year), according to the choice (average: 41.85 euros per day, 1,255.50 per month, 15,274.42 per year). A ranking based on the degree of dependence of the elderly person does not exist, differences derive only from the facilities chosen (http://www.comune.ra.it/comune/pubblica_utilita/guidafamiglie/anziani.htm);

Lombardy: In Lombardy on May 1st 2003, a new ranking and remuneration system for the rates of RSAs and hospices was introduced, based on parameters connected to the mobility of the guest, to their cognitive ability and to co morbidity was introduced. Eight classes have been drawn up, and the costs vary on the basis of the parameters described above, from a minimum of 23 Euros a day (690 a month, 8,280 a year, class 8), to a maximum of 47.50 Euros a day (1,425 a month, 17,100 a year, class 1). Average: 32.25 euros per day, 1,057.50 per month, 12,690 per year (<http://www.famiglia.regione.lombardia.it/anz/12904.asp>).

Marche: In this region, the rates of old people’s homes and RSAs vary from a minimum of 25 Euros a day (750 a month, 9,000 a year) to a maximum of 60 (1,800 a month, 21,600 a year), depending on the degree of dependence (average: 42.50 euros per day, 1,275 per month, 15,300 per year). Contribution to these costs by the elderly persons and their families varies from 40 to 60 % according to the type of convention of the residential care.

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)? Is it funded through taxation or social contributions?

As previously mentioned, funding of care for elderly people in the present form for long term care (mainly through monetary transfers), is not enough to sup-

port family carers in their care work. However, at present, these financings are totally covered through the general tax system, even if there is a tendency to increase these taxes at the expenses of the user. In the Emilia Romagna region for example, with the L.R. 2 / 2003 a social fund for the dependency of elderly people has been introduced. This “will start off using public resources” (Minguzzi 2003a: 104) and should be financed by increasing the regional personal tax aliquot. This fund will totally or partially cover interventions aimed at guaranteeing assistance and care for dependent people, and should reach the amount of 800 million Euro for the regional territory (Minguzzi 2003b: 204).

Regarding exemption from the contribution to the costs of the health services (ticket, cfr. § 5.2), the Legislative Decree of April 29th 1998, n° 124 fixes the criteria. Such exemption is recognized in the following cases:

- the economic situation of the family nucleus (which in some cases is connected to age, for example citizens of 65 and over belonging to a family nucleus with a total income referred to the previous year not exceeding 36,152 Euro);
- specific disease conditions, within the limits of the services offered.

5.7 Funding of family carers

At a State level, no benefits are directly provided to family carers, since all existing provisions are granted to the person needing care, including the “care allowance” granted to persons “fully dependent from support provided by others”, with the explicit aim of contributing to the extra care costs deriving from such situation of need (see more details in paragraph 2.1.2). However, it should be underlined that in the last few years several local administrations (i.e. municipal, provincial and regional authorities) have introduced forms of monetary supports (such as allowances and vouchers) addressing directly family caregivers. This trend reflects the aim of both relieving carers’ burden and, at the same time, reduce the tendency to resort to institutionalisation, which has a high financial impact especially on the budget of municipalities, which are called to pay the amount of the monthly fee due to the residential service organisation which the elderly person is unable to cover with his / her own income (Lamura et al 2001c). Some examples of these allowances and vouchers are reported in the following table:

5.7.1 Are family carers given any benefits (cash, pension credits / rights, allowances etc.) for their care? Are these means tested?

	Attendance allowance	Care voucher*
Restrictions	Based on income and support needs	Based on income
Who is paid?	The family of the cared for	The primary caregiver
Taxable	No	No
Who pays?	Municipalities or local Health Authority	Municipality
Pension credits	None	None
Levels of payment / month	Three examples: Bologna: 300-450 Euros; Milano*: 70-929 Euros; Ancona: 77.50-309.87 Euros.	Example for Milan*: 300 Euros (to family carer) or 450 euro (if a private personal assistant is hired)
Number of recipients in 2002	Not available (see paragraph 5.7.2)	Not available

* In this municipality the care voucher has been introduced to substitute the care allowance (Municipal Act n. 1245 of Comune di Milano, 27 May 2003). During 2003 the main principles of the care voucher have been used by the Region of Lombardy to implement an overall programme for the whole region (Polverini and Lamura 2004).

A further support, provided for in the Law 328 / 2000 (art. 16), consists in the concession of loans by the municipalities, tax free, with agreements on the return of the loan, in order to help overcome economic difficulties even temporarily, or to solve problems connected with families having dependent members. This is included in the system of home care and support services, even through economic benefits, particularly for families which take on the responsibility of accepting and taking care of people with physical, psychiatric and sensorial disabilities and of other people in difficulty, of entrusted children, of elderly people.

Social security benefits: There are not many instances of social security credits or benefits covering caring activities in Italy. One possible reason is that unemployed carers can claim a financial allowance, which is then considered by the disbursing agency, as sufficient also to fund caring expenses incurred for the elderly relative. Another – possibly more correct – reason is that the above-mentioned financial support might be considered as recognition of carers’ activity as a sort of “cost-opportunity” benefit to compensate them for the professional financial benefits they have had to renounce (also in view of future losses, such as the consequences of curtailed pension contributions due to early retirement) in favour of an activity which ultimately translates into a reduction in the taxation burden for the whole community (Tarabelli et al, 2001:251).

The very few security benefits allotted to activities carried out by family caregivers, are especially destined to persons employed in the labour market (in point of fact, they represent an opportunity merely for people working in the

public sector), as mentioned in § 2.2.3 with reference to Laws 335 / 1995 and 53 / 2000. One must also take into account, however, that in the case of a person who takes advantage of the right of continuous or split unpaid leave up to two years, this period of leave is not calculated either in the length of service or in the social-insurance scheme (cfr. § 2.2.3).

5.7.2 Is there any information on the take up of benefits or services?

No national data exist with reference to the take up of benefits received by carers, since the various Municipalities and other local authorities providing such service establish different access and disbursement criteria (see table in § 5.7.1). However, some estimates report that these measures are particularly widespread in the Centre / North (64 % disbursed by the municipalities or Health Authorities) more than in the South (12 %) (see <http://www.edscuola.it/archivio/handicap/assegnicura.html>). It can furthermore be noted that for instance in the Ancona municipality, the amount varies according to disease type and severity (e.g. Alzheimer's, or "bedridden" person), and to income, whereas in Bologna another parameter which is taken into account besides income and disease severity, is whether or not the dependent elderly person receives the care allowance. The Milan municipality disburses a sum ranging from 70 to 929 euros per month, according to type of pathology and to income. Within the above amount is included also a contribution from those having obligations towards the dependent elderly person, a not altogether legal procedure (Dogliotti et al, 1999: 82). In actual fact, these care allowances are no longer disbursed by the Milan Municipality, that replaced them with another service, the socio / health care voucher, motivating its choice with the greater procedural simplification it implies. The service, in fact, involves disbursement of two standard amounts only, according to whether care be provided to the dependent elderly person by a family member, or by a paid carer. If, on the one hand, this scheme implies a positive reduction in staff, and a saving of time in assessment procedures, on the other, it also means a lowering in quality standards versus the previous individualized plan.

5.7.3 Are there tax benefits and allowances for family carers?

Introduction: differences between "deductible" and "detractable" contributions

"Deductible" contributions are those deducted directly from the wage, before calculating the tax due. Therefore a deductible cost leads to a reduction in the wage taxable for the whole amount of the sum considered. This is not subject to payment of the tax aliquot, which every wage group is submitted to.

"Deductible" contributions are those deducted from the tax which has already been calculated. Therefore a deductible cost leads to a reduction in taxes to

be paid equivalent to a fixed percentage of the cost sustained (at present in Italy, this is 19 %), no matter what the declared wage is.

With reference to the recent re-organization of taxation norms (Agenzia delle Entrate, 2003), the main allowances for disabled persons and family caregivers can be summarised as follows.

a) Deductible costs

A very important innovation of the 328 / 2000 is the action on the fiscal policies through the introduction of deductions for families with special care burdens, as a measure for overcoming the problem of care that is totally disbursed by public services, but also as a measure to discourage irregular forms of care work (Minguzzi 2003a:89).

Medical costs for economically independent family members: medical costs related to pathologies which are exempted from contribution to public medical costs, by family members not fiscally at their expenses, for which the relative deductions do not find place in the taxes of the latter (for example, those exempted from public costs for the pathology and its severity require a private intervention of 10 thousand Euros, 19 % - 1,900 Euros – of which is deductible. But if the income of the tax-payer for that year does not allow to recuperate more than 300 Euros, the difference can be recuperated by another family member. The maximum amount of medical costs indicated in this paragraph cannot however exceed 6,197.48 Euros. The deduction of the sum will be calculated on the amount that exceeds 129.11 Euros.

Costs for vehicles for disabled people: costs for buying motorbikes or cars even if they are produced in series and then adapted for the disabled person; for cars even if they are not adapted for the transport of blind and deaf and dumb people; for persons with psychiatric or mental disabilities such that a maintenance allowance has been recognized. Deduction is due only to one vehicle and can be calculated (at 19 %) out of a maximum import of costs of 18,075.99 Euros. In addition, Value Added Tax is reduced to 4 % for purchasing them, and full exemption is granted with respect to the circulation tax (which in Italy each circulating vehicle has to pay yearly) and to the property transfer tax, in case of purchase / sell of the vehicle.

Other technical and computerized aids: Possibility of deducting from IRPEF 19 % of expenses for technical and computerized aids (fax, modem, PC, touch screen,??), VAT reduced to 4 % for purchasing them, possibility of deducting purchase costs and maintenance of guide-dogs for blind persons, possibility of deducting from IRPEF 19 % of expenses for interpreting services of deaf and dumb people.

Removal of architectonic barriers: deduction of 36 % on all expenses related to the removal of architectonic barriers.

Children (although probably not relevant in most cases of elderly care): for each disabled children a non means-tested deduction of 774.69 Euros is granted.

b) “Deductible” costs

Health-care costs: possibility of deducting from overall income the whole amount of general health-care expenses and of specific care services.

Contributions for those assigned to family and domestic work: deductions on contributions paid for house-maids, baby-sitters and carers can be (done) made. This measure is appreciable, but the contributions for those assigned to family and domestic work are deductible up to a maximum of 1,549.37 Euros a year, a sum which is rather low.

(For more information see: http://www.governo.it/GovernoInforma/Dossier/agevolazioni_fiscali_disabili/doc/agevolazioni_disabili.pdf)

5.7.4 Carers’ or Users’ contribution to elderly care costs

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		
				Partly reimbursed	wholly reimbursed	Based on severity
General practitioner	X					
Specialist doctor		X	¹³	X		X
Psychologist		X		X		
Acute Hospital	X	X				X
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)	X	X		X ¹⁴	X ¹⁵	X
Day hospital	X	X				
Home care for terminal patients	X	X				
Rehabilitation at home	X	X				
Nursing care at home (Day / Night)	X	X				
Laboratory tests or other diagnostic tests at home	X	X			X	
Telemedicine for monitoring	X					
Other, specify						

¹³ “Undeclared” transactions are here relevant

¹⁴ different from Region to Region

¹⁵ different from Region to Region

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care / old people's home		X	X	X ¹⁶	X ¹⁷	
Temporary admission into residential care / old people's home in order to relieve the family carer		X	X	X ¹⁸	X ¹⁹	
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)		X	X			
Laundry service	X		X			
Special transport services	X	X	X	X	X	
Hairdresser at home			X			
Meals at home	X		X	X	X	
Chiropodist / Podologist		X				
Telerecue / Tele-alarm (connection with the central first-aid station)		X				
Care aids	X	X				
Home modifications	X	X	X	X	X	
Company for the elderly	X		X			
Social worker	X					
Day care (public or private) in community centre or old people's home			X			
Night care (public or private) at home or old people's home			X ²⁰			
Private cohabitant assistant (“paid carer”)		X	X ²¹			

¹⁶ depends on Municipality/Region#

¹⁷ depends on Municipality/Region#

¹⁸ depends on Municipality/Region#

¹⁹ depends on Municipality/Region#

²⁰ Some undeclared work is present here

²¹ Some undeclared work is present here

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Daily private home care for hygiene and personal care			X ²²			
Social home care for help and cleaning services / "Home help"			X ²³			
Social home care for hygiene and personal care			X	X	X	
Telephone service offered by associations for the elderly (friend-phone, etc.)			X	X	X	
Counselling and advice services for the elderly	X					
Social recreational centre	X					
Other, specify	X			X	X	

²² Relevant undeclared work is present here

²³ Relevant undeclared work is present here

c. Special services for family carers	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring	X		X			
Telephone service offered by associations for family members	X					
Internet Services	X					
Support or self-help groups for family members	X					
Counselling services for family carers	X		X			
Regular relief home service (supervision of the elderly for a few hours a day during the week)			X		X	
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)			X			
Assessment of the needs	X		X			
Monetary transfers	X					
Management of crises	X					
Integrated planning of care for the elderly and families at home or in hospital	X					
Services for family carers of different ethnic groups						
Other, specify	X		X			

6 Current trends and future perspectives

6.1 What are the major policy and practice issues debated on family care of the elderly in your country from the carers' point of view? Are older people and / or carer abuse among these issues?

At present, one of the most debated topics related to family care of the elderly regards the possible introduction of a long-term care insurance, which theoretically all political parties (both at the government and in the opposition) seem to agree upon even if on different terms. The pensioners of the three general trade unions CGIL, CISL and UIL have collected more than one million signatures in favour of this proposal, which should be financed by the general system of taxation. This is therefore founded on intergenerational solidarity. The government has instead advanced a hypothesis which foresees the concentration into a single national fund of all the resources that under different names are presently used for this objective (Progetto di legge 2166, 2003), a measure, according to the trade unionists, that is not sufficient to answer the request of increasing this fund (Minelli 2002: 12-13). There are also other interventions in favour of this fund, with an estimated 11 billion Euros for its efficient operation. Four would come from the State (this is how much it actually spends now), while the remaining sum, it is proposed, would be divided between the active population and the pensioners, with an individual cost estimated at 10 Euros a month (Beltrametti 2003). According to others, the necessary resources to support this new insurance system for the next 10 years would be 4 billion Euros which should guarantee home care and support to families (Todaro-Del Bufalo: 2003). On March 11th 2003 the draft of a law was proposed by left-wing parties, entitled "Institution of a fund for dependent people", which foresees an extra tax on the wages of independent people as financial resource (http://www.lomb.cgil.it/spibg/non_autosuff.htm).

Apart from the above, a new awareness of the difficulties of family carers in performing their tasks is slowly making its appearance in Italy, even if the solutions seem to be proposed in most cases in a rhetorical manner, not always based on a comprehensive picture of the phenomenon, or with a real interest in solving the problems. In the latest National Health Plan (PSN) 2003-2005, at point 2.2 there is mention of the promotion of an "integrated network of social and medical services for the care of chronic patients, elderly people and disabled people", and the Plan considers that older people live better in their own home and within the family context. In line with other European countries, Italy too aims at intervening in support of dependent people by combining monetary transfers to families and the provision of direct services, in order to support family and informal care work (according to the motto "cash and care") (PSN 2003-2005). Amongst the strategic objectives of PSN 2003-2005, the introduc-

tion of a long term care insurance for financing the risk of dependency of the population - for which the approval of a law *ad hoc* is necessary - is also mentioned, as it is in the Ministry of Work and Social Policies's "White Book on Welfare". Moreover, according to the ministerial document, the dependency of people in chronic conditions (either elderly or disabled), has still not received adequate responses, and the measures in favour of these people and their families are considered urgent and undelayable (Libro Bianco sul Welfare 2003: 39).

However, these measures still haven't found realisation, and the bill for the introduction of the long term care insurance is currently shelved for the lack of fundings (Agresti 2004). The latter motivation is currently used for stopping further innovation in this and other care related sectors, as shown also by the Document of Economic-Financial Programming 2004-2007, which, while acknowledging the need for the development of care services to support families, underlines the increasingly difficulty to find the necessary resources to finance more qualified (and therefore more onerous) social services (DPEF 2004 / 2007: 60-62). However, as mentioned in § 2.1.1, it seems positive at least that the debate upon possible ways of recruiting further financial resources to fund better care services is currently attracting increasing interest (Da Roit-Gori 2002: 132-133).

With regard to the topic of elder abuse, the issue appears to be quite widespread in Italy, especially in residential homes (Dogliotti et al, 1999: 80) and less when elderly people are cared for at home - although evidence is not wholly lacking of alleged neglect of elderly parents by children or family carers. As to "abuse" of family carers by elderly persons, the topic is not even debated in Italy, although it is latent, in the sense that many carers have a very strong sensation of being "tyrannized" by the dependent elderly family members they care for. In particular, some studies highlight the fact that when the carer is the spouse (in most cases female), feelings of tension, pain, fear and uselessness (e.g. "I feel I am not appreciated for what I do as much as I would like"; "it's as if he / she expects me to look after him / her as if I were the only person he / she can depend on", etc.) are more frequent than in other types of carers, although these feelings are quite frequent also among daughters (Lamura et al. 1999: 61-63; Lamura et al 2001 / b).

6.2 Do you expect there to be any changing trends in services to support family carers, e.g. more state or more family support, more services or more cash?

If we neglect the issue of the long term care insurance described in previous paragraph, compared to other European countries Italy stands out for the absence of strong proposals that deal with support services for family carers of elderly people. On paper, many different changes in the policies have been written down, but these are mainly general indications that do not go into any

detail. Some mention that in the next few years the resources devoted to this issue may increase, but due to the predicted increase in the elderly population, a certain increment in resources will only guarantee the preservation of what is already existent. Therefore, the lack of public services for dependent elderly people will constitute a fundamental issue of the Italian reality even in the future (Gori 2002: 23). The possible development in a short time of forms of supplement to the national insurance is also predicted, in order for families to ensure themselves with an adequate financial coverage for future needs. Compulsory loans should also be enforced in order to cover the risks of possible dependency, based on the model of the German long term care insurance scheme. A substantial transfer of power to the Regions concerning the issue of care, presently dependent on the State, is foreseen, but it is feared that law 328 / 2000 risks of being deprived of its contents if there is no adequate economic coverage (Minguzzi 2003d: 185). According to the National Health Plan 2003-2005, the aim is to make the management of the existing services more efficient and adequate, by means of greater support to families which are involved in caring, and to the informal care network (PSN 2003-2005) but, as already mentioned above, no concrete indications are provided on how this is to be reached.

Even if changes are not foreseen, they are nonetheless required. The third report on the policies of chronicity promoted by the National coordination of the associations for chronic patients, founded in 1996 by the Court for patients' rights (cfr. § 4), is directed to the Government and Parliament with a series of proposals, such as the urgency of financing the outline of the law on care. The report also underlines the necessity of an outline of a law to grant appropriate protection to chronicity, of a single text on the medical laws included in the latest reform, of integrating the Regulations in assessing chronic and disabling diseases, for the many pathologies which are not recognized nor covered. It also proposes a reform of the norms on the recognition of disability, due to the inadequacy of the current ones and of the excessive bureaucracy burden for the citizens (Inglese et al, 2003: 88-89).

Furthermore, since family support will continue to weaken and the advantages of growing older at home will be increasingly recognized, the request for privately paid care cannot increase (Gori 2002: 24). Therefore, in this sector one would expect an improvement of the policies in relation to the access modalities, which are at present almost always "illegal" and based upon the economic resources of the family (Da Roit 2002: 45). Faced with these problems, the Government has carried out only the first steps with the introduction of the Law 189 / 2002 (Law Bossi-Fini), that deals with innovations concerning immigration and exile of non-EU citizens.

6.3 What is the role played by carer groups, organisations, "pressure groups"?

Most relevant pressure groups involved in promoting support measures for family carers are older people's organisations and associations of relatives of persons suffering from dementia. Some of them play also a relevant political back-up role, for instance the no-profit organisation A.U.S.E.R. (a voluntary association for elderly care), which recently has published the "manifesto of carers' rights" (AUSER 2001b:28) and promoted a national conference on the topic of "Supporting carers for the rights of the persons cared for" (Sarno, 2001: 25).

A crucial role in this sense is also played by the Italian Association of Persons suffering from Alzheimer (AIMA) and the Italian Alzheimer Federation (AI). AIMA, which was founded in 1985 (<http://www.alzheimer-aima.it/alzheimer.html>), numbers groups working in all Italian regions and seeks to achieve a network of solidarity and mutual help throughout the country. AIMA's set task is to support those who live beside a person with dementia and to inform and train them in the competences which are necessary for the management of all aspects of this disease. Support is provided also by support groups, by "Alzheimer labs" to teach family carers how to address the disease, to inform them on techniques, opportunities and services, to update them on research and new discoveries both in the medical field and in the social and legal ones. As far as the Italian Alzheimer Association is concerned (<http://www.alzheimer.it/index.html>), its aims are similar to those of AIMA, including a hotline for caregivers, informative materials, handbooks and documents, training course for family carers, volunteers and practitioners as well as a newsletter and public initiatives to support the rights of caregivers and of demented persons.

Both associations are often invited as official representatives for family carers' needs, also on the political-social level. The battles they have fought (for visibility of the Alzheimer issue, for free medications, for services, for a salary for the family carer) have brought them closer and closer to society at large, and have invested them with the role of privileged interlocutors of public and other established institutions.

6.4 Are there any tensions between carers' interests and those of older people?

The main interest of dependent older persons is to be cared for, whereas the main interest of those carers who feel overburdened in their tasks is to receive help and some respite in their caring activity, with the result - satisfactory to them, but probably not always also to the dependent older relative - of a reduction in the time they devote to caring. It is therefore not surprising that some degree of tension should arise between these conflicting interests.

However, since usually public help and support which carers can easily “take advantage of” are not often available, in the “conflict of interests” between carers and dependent elderly both can sometimes feel penalized, which explains also the frequent resort to private forms of care in order to try to respond more appropriately to the needs of both parties.

6.5 State of research and future research needs (neglected issues and innovations)

Only in these last few years research has taken more systematic steps towards an in-depth understanding of carers' needs. The leading Italian institution for statistics (ISTAT) has carried out a survey of the current features and tendencies of this phenomenon (Sabbadini 2001: 21-24), taking note, among other things, of the changes in informal care networks and of the amount of caregivers, which appears to have been stable over the years, though increasing in average age. Another aspect that has been addressed is the drop in number of families with elderly members receiving support, whilst the reverse has taken place for families with children and working mothers. ISTAT has also addressed gender differences, and has established that informal care networks are most widespread in the North-East and least in the South. Apart from this general type of information, research upon carers in Italy is carried out by few institutes, among which are INRCA, Censis (2001), Studio Come (Casale 2003) and Tacconi (2001). With regard to the role played by INRCA, in the last few years its Gerontological Research Department has been involved in several research projects on this topic, among which the most relevant are “The role of women in the family care of the dependent elderly”, funded in 1996-1998 by the Italian Research Council and “Carers of Older People in Europe” (C.O.P.E.), funded by the EU in 1998-2001 (which represented the “parent” study of the current project EUROFAMCARE).

Thanks also to these research efforts, attention to family caregivers in Italy is gaining momentum, although the first results achieved have not roused sufficient interest in policy makers to stimulate them into initiating concrete support measures in favour of caregivers at a national level. Among the aspects which seem to have been neglected so far and therefore would need more attention in the future, a central role is that of paid private care at home, as already mentioned, a widespread phenomenon in Italy which gives rise to concern, especially for the high level of undeclared forms of payment of care workers. Its increasing diffusion has registered too little attention on the part of both the policy-makers and the scientific community, thus creating a hiatus between debate and real life. Only very recently, in association with the legalisation campaign of irregular immigrants, the public debate has focused more on this issue, reaching in some studies also a good comprehensive picture of the overall implications which this phenomenon has in terms of family care of the elderly (Gori 2002, Piva 2002, Da Roit & Castegnaro 2004).

As regards innovations, what above all appears to be necessary is a process of scientific monitoring related to at least some of the innovative practices introduced in local contexts. In Italy, in fact, a general picture describing the chronological development of the “caregiver phenomenon” does not exist – either with respect to service evolution or to people’s willingness to provide care to their elderly family members. This is caused not by neglect, but mainly because the scientific community has only been showing an interest in this area for a very short time. It appears to be recommendable, therefore, that cohort investigations be initiated at a national level. This would make it possible to capture general change trends, beyond - as already mentioned - monitoring single innovative practices such as for instance those described in the § 7.2 below.

6.6 New technologies – are there developments which can help in the care of older people and support family carers?

There are a few private firms who are introducing comfort devices and technical aids into elderly persons’ houses according to their disabilities and needs, such as security alarm systems, video-telephones, mechanized shutter lock, tele-medicine devices, transponder or mechanised door (or window) opener, data network (for rapid shared access to Internet), bedroom intercom, visual and auditory signals, remote control apparatus of certain functions via phone, SMS or Internet, etc. These new technology products are undoubtedly of great help both to elderly persons and to their families (Marcellini et al 2000), but their negative aspect is represented by their high costs, especially since in the great majority of cases the users themselves have to pay totally for them, except when used in residential care facilities endowed with them.

6.7 Comments and recommendations from the authors

The situation of family carers in Italy seems to be characterised by some core trends, which deeply influence the circumstances of caregiving activities in this country: the diffuse resort to the care work provided by mainly foreign immigrants, hired by the families as personal assistants of the dependent older person; the prevalence the traditional strong preference of most Italians for home-based care, rather than residential care; the gradually decreasing availability of female caregivers due to the increasing female employment in the labour market (in terms of both number of employed women and length of working life); the relatively high the prevalence, among public support services, of monetary transfers instead of the provision of direct services.

All these phenomena contribute to explain why, in the current situation, Italian family carers of dependent elderly seem to concentrate their support needs on the following aspects:

- **counselling services** to find the most appropriate solution among those proposed by the market, to which monetary transfers inevitably force to refer to the provision of care (carers as “buyers” of services);
- **reconciliation of working duties and care responsibilities**, in order to better face the challenge represented by the need / wish of economic independence, on the one hand, and the need / wish to still provide personally care to dependent parents and relatives; this will have to include a better recognition of periods of care;
- **ad hoc respite services** for those carers who are most intensively involved in the provision of everyday care to severely dependent relatives, especially whenever behavioural disturbances of the latter might make this care particularly burdensome;
- **a better recognition, by service providers, of the central role played by family carers** as implicitly assumed by several care programmes and services existing today in Italy, whose implementation and long-term success is institutionally made dependent from a relevant support work provided by family carers, which however can no longer be taken for granted as it was the case in the past.

The general lack of comprehensive support programmes for caregivers at a national and, with few exceptions, regional and local level, makes a continuation of current conditions for family caregiving in Italy not bearable on the long term, for demographic, economic and social reasons, so that two main alternative approaches can be possibly identified for the future:

- an quantitative and qualitative increase in the provision of direct care services to the dependent elderly persons, which reduces the negative impact of care tasks on family carers, thus assuming a residual role from their part within the elderly care system;
- the development and implementation of appropriate support measures for caregivers, which build upon and recognise the centrality of their role for the assistance of the elderly, but tries to facilitate it through a series of interventions which integrate those aimed directly to the older person.

A combination of the two approaches, in some cases closer to the former one, in others to the latter one, would in our opinion probably represent the best way to take into account the variety of the caregiving situations, and provide the qualified, personalised support that both the older persons and their family carers deserve from any society which wishes to be called “civilised”.

7 Appendix to the National Background Report for Italy

7.1 Socio-demographic data

7.1.1 Profile of the elderly population past trends and future projections

No information provided.

7.1.1.1 Life expectancy at birth (male / female) and at age 60 years

No information provided.

7.1.1.2 % of > 65 year-olds in total population by 5 or 10 year age groups

No information provided.

7.1.1.3 Marital status of > 65s (by gender and age group)

No information provided.

7.1.1.4 Living alone and co-residence of the > 65s by gender and 5-year age groups

No information provided.

7.1.1.5 Urban / rural distribution by age (if available and / or relevant)

No information provided.

7.1.1.6 Disability rates amongst those > 65 years

No information provided.

7.1.1.7 Income distribution for top and bottom deciles i.e. % aged > 65 years in top 20 % of income, or % > 65s in top 20 %, and the same for poorest 20 % income groups

No information provided.

7.1.1.8 % > 65 year-olds in different ethnic groups (if available / relevant)

No information provided.

7.1.1.9 % Home ownership (urban / rural areas) by age group

No information provided.

7.1.1.10 Housing standards / conditions if available by age group – % without indoor plumbing, electricity, TV, telephone, floor and lift

No information provided.

7.2 Examples of good or innovative practices in support services

Good practices

- In the territory of San Donato Municipality, near Milan, the social cooperative “Solidarietà e progresso” (Solidarity and Progress) has realized a project named “**Support Services for caregivers**”, presented in 2001 on the basis of the regional Law 23 / 1999 “Regional policies for the family”. The service was free, it was implemented for one year and the project was elaborated so as to integrate socio-sanitary services already existing in the territory. The service aims at providing carers with the forms of support such as information service, counselling and advice, and first assessments of the project seem to be positive about the impact on well-being of caregivers (Corradini et al. 2002: 214-221).
- Another interesting form of experimentation called “**Parente-sì**” has been carried out in the ASL of the province of Milan 2. Its focus was the re-appropriation of “time for oneself” on the part of carers of non self-sufficient elderly people assisted at home. The experiment, that lasted 6 months and involved 20 families that received support for 4 hours a week with the participation of several social operators, has showed how difficult it is for the carers to leave the isolation in which their caregiving tasks have confined them. This is why there seems evident the need for projects that can guarantee continuity of care to the assisted person and help and counselling to the carer (Corradini et al. 2002: 210-213).
- In one ASL in Rome an **experience of home care services for demented elderly person** was carried out, centred on a complex network of services: Geriatric Day Hospital, Community Care Centre, ADI, RSA, groups of help for carers, Telephone line for carers’ information and training and courses for home carers in order to alleviate caregivers’ stress (Bartorelli 1999: 45).
- In several parts of Italy, **groups of mutual help for people who lost one of their relatives** have grown and become a very important social resource since professional people and social services are not always able to respond to the complex needs linked to death (Pangrazzi 2002: 7).

Innovative practices

- The new role of “health and social guardian” (custode socio-sanitario) has recently been introduced by the Milan Municipality the function of identifying needs of elderly people in difficulty, through their daily contact with those living in a specific district, and acting as timely initiators of the necessary interventions by public and private service deliverers, voluntary

worker associations, parishes and any other relevant social resources present on the territory (www.centromaderna.it/anziani/newsletter.asp). The relevance of such an initiative is further enhanced by the fact of its linking up with another project of great socio-medical relevance: the “counselling bureau for the elderly” (sportello unico per l’anziano), implemented with the aim of taking charge of situations which place elderly people at risk, and supporting caregivers in their problem-solving difficulties throughout their caring. On the basis of this first experimental project, the idea is currently being implemented also at the national level by the Italian Ministry of Health (www.governo.it/GovernoInforma/Dossier/anziani_caldo/caratteristiche.html).

- In another Municipality in Northern Italy, Modena, a **counselling service for carers of older people being discharged from hospital** has been recently implemented. Currently this centre, which cooperates with the Specialisation School in Community Medicine of the University of Modena and Reggio Emilia, is still working only a few hours per week, providing mainly an orienteering service, but its long-term aim is to strengthen all kinds of support to carers, according to the critical needs mentioned by carers themselves. To this purpose, the EUROFAMCARE questionnaire is currently being administered to family carers of the older people admitted in the long-term care wards of the local hospital (information based on a telephone interview with the responsible of the service).
- The Florence Municipality, with the legal advice of **Studio Come** has implemented a project called “Older Adults at Home” (Anziani a Casa) with the aim of overcoming the separation between the private services “market” – based upon family responsibility and usually devoid of security – on the one hand, and the public offer - reserved to the minority of citizens belonging to the weaker brackets - on the other. The novelty of this project in comparison to similar experimentations currently in progress – such as for instance those implemented within the context of the SERDOM project, located in the Northern Italy scenarios of cities like Modena, Parma and Turin (Polverini and Lamura 2004; www.comune.modena.it/serdom/sito/stampa.htm) - lies in the fact that Florence is the first Municipality to respond to the need of offering financial support and security in conjunction, while establishing also a community information service referring to family caregivers and local solidarity networks (Di Santo 2003: 8).
- The project **Intensive Care**, is an initiative of free home care for families that have a relative affected by Alzheimer’s disease and who live in Milan (the initiative is promoted by Fondazione Manuli) and it aims at giving respite 4 hours a day for 5 days a week during a year. This experience can be considered absolutely innovative both for its means and its modalities since it offers the carer the optimisation of his / her own personal resources

and promotes a **continuum** of caregiving, information and support to the family (Bertani et al. 2003:15).

- Another innovative project, implemented in the European context, is the Progetto CRONOS, addressed to persons with Alzheimer's disease, their families and all the specialists involved in this issue. The most noteworthy feature is the Internet website entirely devoted to the project, that the Ministry of Health has set up at a national level. Besides providing information on the disease, the site also offers a possibility of discussion and confrontation between doctors, families and care providers, and useful information for carers in finding their way among the various services: the site offers also a list of Assessment Units and working Centres involved in the project, throughout the whole Country (<http://212.38.48.166/main.htm>). However, the project has been funded only until the end of 2003, so that despite its positive results there is uncertainty about its future development.

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