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

EUROFAMCARE

National Background Report for France

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Content

"It is only since she died that I realise that my journey has been like the Stations of the Cross, and that I have been a saint….

It was horrific, but I wasn't conscious of it. I kept walking through this dark tunnel with her death at its end, putting one foot in front of the other without ever knowing where I was going."

A daughter having cared for her mother suffering from dementia.

Introduction – An Overview of Family Care

Demographic trends related to family care-giving (supply and demand)

In common with all Member States of the European Union since the seventies, France has been facing the demographic development of lower fertility and mortality rates, inexorably combined with the demographic aging of the population due to increasing life expectancy, particularly in the higher age groups.

The French population is increasing (+0.4 % during 2003). It consists of 61.7 million inhabitants (1.1.2004); 59.9 million people living in metropolitan France, and 1.8 million in the Overseas' Departments[1] (Pison, 2004).

9.8 million people are more than 65 years old, representing 16 % of the metropolitan population (ibidem). The over 85 age group consists of 1.4 million people (2.4 % of the total population) and the most marked change has occurred amongst the centenarian group; an increase in population of 11.6 thousand (Champsaur).

Life expectancy at birth (2003) is 75.9 for men and 82.9 for women (Pison, 2004). During the last decade it has increased considerably, particularly for men – with an increase of 2.4 years, and 1.5 years for women[2]. Consequently, between 1992 and 2002 the gender difference in life expectancy decreased from 8.2 to 7.3 years, and in addition, the number of older married couples slightly increased (Pison, 2003). In 1980, more women aged 60 and over were widowed (47 %) than married (41 %), whereas in 2002, the reverse can be seen, with 41 % of women widowed and 47 % married (Delbès, Gaymu, 2003). This will have an important impact on the number of potential caring spouses, including the very old – older couples are their own frontline carers: one does what the other cannot do any longer, both being highly motivated to protect themselves against having to go to an old people's home or, even worse in their minds, a nursing home.

Declining birth and mortality rates over several decades have led to: higher life expectancy in advanced age groups[3]; an increasing number and proportion of older people; and an increasing number of the very old. At the same time, the age at which one is at risk of dependency is progressively rising; the older population in general is in better health, and ill-health or disability – and consequently the need for care and assistance – are increasingly occurring in advanced old age.

1 In general, French statistics and surveys refer to the so-called metropolitan population; if there is no other indication in the following text, we will too.

2 Nevertheless, life expectancy at birth stagnated in 2003: especially due to the exceptional heat in August, the mortality has drastically increased (+4% compared to 2002; about 15,000 more deaths in August 2003) (Pison, 2004).

3 At 60 years: men (in years): 17.0 in 1980, 20.8 in 2000; women: 22.4 and 25.6 (INSEE, anonymous, 2004).

And, as in all European member states, in the 55+ age group, there is a growing female predominance[4]; combined with the higher instances of dependency of women, leading to the high probability that the cared-for person is a woman.

7 % of the 12 million people aged 60 and over are in need of help in their everyday lives (2000). Two in three dependent individuals live in a private household[5]; of the remaining third, one in two is in an institution. The high number of people living at home is mainly possible thanks to widespread family care, and to a lesser degree to professional domiciliary care. High dependency (mainly in advanced old age) generally leads to a mix of informal and formal assistance (KERJOSSE, WEBER, 2003).

Will descendant carers be less numerous in the future? This crucial question receives contradictory answers. The availability of family carers over the next few decades is supposed to be declining, especially because of increasing female participation in the labour market. However, as dependent parents are generally very old, by the time they need to be cared for, their potential caring children are more than likely to have left the labour market and will be in retirement. The availability of family carers is also supposed to be declining because of the declining birth rate; consequently there will be fewer siblings to care for old parents. The number of siblings depends on the generation; French fertility rates[6] suggest that a 'lack of caring siblings' will not become apparent for several decades[7] (Daguet, 2002). Furthermore, even in the case of an abundance of children, generally only one of them becomes the carer of the parent(s); and, irrespective of the number of siblings, each child has only one mother and one father. A complex piece of research has been carried out in France to forecast the availability of family carers up to 2040, and to what extent their number will cover the probable need for care (see above).

The family network and reciprocity

As in other European countries, eldercare in France is mainly provided by the family, sometimes assisted by professional services. 'The majority of older people are not isolated. Intergenerational relationships within the family remains important.' (Bocquet et al.) In particular, eldercare provided by a descendant is based on the notion of giving and receiving at different periods in life.

4 Age group ≥85 years: 71% women – age group ≥100 years: 87%.

5 Including those in sheltered housing (*logements-foyers*).

6 Number of children/woman aged 15-50 years.

7 Between 1946 and 95 the French fertility rate has been one of the highest in occidental countries of Europe. During the baby boom after the Second World War: between 2.6 and 3.0. Since 1965, it fall seriously down and stabilized during the seventies on about 1.8 with a slightly increase (Daguet, 1996). Fertility rate of the last years: 2000: 1.88 – 2001: 189 – 2002: 1.88 (Pison, 2003).

The public (state and local) care service provision

In the public philosophy of care provision to the old, the key role within socio-gerontological policy is played by the home-helper. At the end of the seventies, metropolitan France was fully served, geographically speaking, by home-help with the firm intention that all needs would be progressively met. Simultaneously, paramedical home services have been developed, and the first political programme has been set up for home improvements for elderly people. Until the late eighties, the basic pillar of care, the family, was not taken into account. Only in the mid-eighties did the first congresses[8] and publications on family care appear, but they did not have any impact on socio-gerontological policy.

The risk of dependency is not part of the French social protection system. Nevertheless, at the end of the nineties, a special allowance (PSD[9]) was created for dependent people aged 60 and over, with a modest income[10], which was replaced some years later by an analogous benefit (APA[11]) (see chapter 2.1.2).

Jacquat states in his report to the National Assembly that, in general, the financing available for dealing with loss of autonomy is insufficient to cover the need (Jacquat, p 9). For some years – and especially since Germany created its dependency insurance – there has been sporadic political debate on setting up an analogous 5th pillar in France, but as there still is no concrete basis to justify hope that this will happen, over the last decade private dependency insurance schemes have been developed: 850,000 subscriptions in 1999, 1 million in 2000, and 1.2 million in 2001 (Sénat, 2004).

The care 'market' – problems in supply and demand

There is no doubt that the whole care system would break down if the family stopped working.

Domiciliary services for older dependents are mainly provided by private non-profit making associations (generally belonging to a national federation) and by public organisations (municipalities). Although needs are not covered, the private benefit making market seems to have minor importance. This is probably due to French laicisation (1901) leading to the 'national expectation' that any assistance or support falls under the social obligation of the state and of NGOs. 'Benefit-thinking' is taboo in this area.

Nevertheless, in time, commercial homes could gain a small part of the residential care sector. As far as we know, their role in the domiciliary sector is even more limited. The only field where privately paid home help is important is the individual employment of a daily maid. In particular, older people who

[8] E.g. a conference organised in Paris in October 1987 (Fondation de France).
[9] PSD – *Prestation Spécifique Dépendance* (specific dependency allowance).
[10] December 1999: 110,000 beneficiaries.
[11] APA – *Allocation personalisée à l'autonomie* (personalized allowance for autonomy).

are reasonably financially comfortable tend to give priority to this kind of help (no figures were found on this topic.)

Other informal unpaid care (volunteers, neighbours, friends, church etc.)

Care giving within the neighbourhood and friendship network depends on the level, the kind, and the duration of dependency. The higher the responsibility for the cared-for person is, the fewer are the numbers of people willing to take on care tasks. Friends and neighbours prefer 'light' tasks such as shopping, sitting with the cared-for person, conversation, reading aloud, or just being present for an hour or two while the main carer is out.

Findings from the national HID[12] survey indicate that 7 % of cared-for people, irrespective of their age, get help from friends or neighbours (Goillot, Mormiche, 2002, table 271).

Note: the HID surveys were conducted by INSEE[13] and indicated the numbers within the population living in an 'ordinary household'[14] (1999), and those in institutions (1998). Both surveys include all age groups (0-9 years to ≥90). – The individuals or their carers were interviewed meaning that answers did not correspond to objective medical assessment but reflected subjective perceptions of those interviewed (Goillot, Mormiche, 2001, 2002, 2003).

Estimated needs for care in the 60+ age group based on disability levels

The notion of 'need for care' covers very different levels of need, so need is not easy to define, and the older population in need of help is difficult to identify (Collin et al.). Estimates are based on the HID survey (Goillot, Mormiche, 2001, 2002, 2003).

Following these results, there are 800,000 people aged 60 and above in need of help, representing 7 % of the 60+ population. Amongst those living in a private household (44 %), 56 % are heavily dependent, often bedridden, and 44 % are housebound.

Dress[15] elaborated projections for the old dependent population in need of help until 2040, as well as for their potential carers. The part devoted to the elderly concerns dependent people aged 60 and above, and is based on the HID survey (1998 / 99). The authors underline that the demographic aging of the French population will lead to an increase in the number of dependent people aged 60+ during the next four decades. Projections from the National Office for Statistics (INSEE) state that close family, friends and neighbours will continue to play a frontline position in eldercare. Although the increase in numbers of the potential carer generation (aged from 50 to 79) will, under con-

[12] HID: Handicaps–Incapacités–Dépendance (Handicaps–Incapacities–Dependency).
[13] INSEE: National Office for Statistics and Economy.
[14] Including sheltered housing (*logements-foyers*).
[15] DRESS: Direction de la Recherche, des Études de l'Évaluation et des Statistiques, Ministry for Employment and Solidarity.

servative estimates, be slower than that of the dependent old, they conclude that a possible increase of female participation in the labour market of women aged 55 and over (due to rising retirement age) may exacerbate the phenomena, but, combined with other, individual factors, by 2040 an increase, as well as a decrease in the numbers of potential carers is possible (Bontout et al., p 1).

A short overview of the current state of the socio-political discussion in France, related to the financial situation of long-term care insurance and health insurance and its consequences for family care. This will also include reference to the national socio-economic and demographic context.

- The state is having to face a complex demographic development combined with increasing unemployment – and, consequently, decreasing social contributions to pension funds and health insurance, both leading to enormous deficits. The steadily growing deficit of the national health insurance system was projected to reach 11.1 billion euros in 2004. In 2003, the government therefore put its reform on the agenda, which might reinforce the negative consequences of individual expenditure on frail and ill old people, which started two years ago. – Since the labour market crisis, private compulsory health and old-age insurance schemes (*caisses complémentaires de retraite*), like social security, have had to contend with less income from social contributions; consequently their compulsory social action fund (1 % of the collected contributions) has drastically dropped off, dragging down with it their financial help towards older people. Furthermore, there is an increasing number of people living under or near the poverty line, affecting the public *Aide sociale* which also has to finance the dependency allowance (APA) and part of the domiciliary and residential eldercare. Consequently, there are rising doubts about a possible improvement during the next few years of the financing of the following: social and medical care services for the old population; health prevention; re-education; rehabilitation; and the residential care sector. There are fears that the state's indebtedness, and particularly the reform of the health insurance system will lead to an expenditure shift from the state to the population via taxes, social contributions, and individual cost sharing in the different fields. This development is not really conducive to the improvement of the family carers' situation – on the contrary, the carers' burden, in all certainty, will increase.
- KAT Repercussions from the high mortality rate among the very old and frail during the heat wave of August 2003, as well as the 15,000 other deaths in the older population during that time, are important topics on the socio-political agenda and are still being largely reported by the mass media, resulting in high public expectation that the government should take action. In May 2004, to avert a repetition, based on the admission that wrong government decisions had been made in 2003, the Minister for Health and Social Protection published the following plan: the government was to set up an intervention scheme involving all political authorities and NGOs; the idea being to set up a programme of co-ordination between the different ministries and all public and private institutions, on national, regional and local levels.
- Since 2001, which was the year of the disabled person, and under considerable NGO pressure, French policy on the disabled has gained more importance e.g., a new law was created to update and improve the 30,000 medico-social institutions for the old and disabled (residential and domiciliary services), including obligatory quality evaluation. However, since the existence of the new government, "Raffarin III" (March 2004), this intention seems to have lost priority under the pressure of the risk of another very hot summer (see below: point 4 and chapter 2.2.2).
- The government Raffarin III has introduced the following changes in the socio-gerontological area:
  - The establishment of a minister for the Elderly within the new Ministry for Health and Social Protection, to which the former 'Older Persons' section has been transferred. Over the years 2001-2003 / 04 official and unofficial discussions led to the impression of more 'respectable' financial treatment of the problems faced by the disabled population (Lasfargues); since a political interest-shift from the disabled to the old population occurred. – How far this new mix of health and social affairs will be advantageous to both, is unpredictable.
  - The setting-up of the above-mentioned prevention plan in the event of another very hot summer.
- The enormous lack of council flats (with low rents) is a major preoccupation of the public. The *Conseil économique et social*[16], in its report in January 2004, denounced the serious housing crises: more than three million people are experiencing very bad housing conditions or waiting for a flat, while the construction in the social housing sector of low rent flats (HLM[17]) has been continuously decreasing for years. In 2003, the government announced financing for the construction of 80,000 'social flats' in 2004; it appears, in June 2004, that this meagre objective will not be reached. People in retirement with low pensions are concerned with this issue (http://www.maire-info.com/articles/article.asp?param=3851).
- Fighting against poverty, irrespective of age, is an urgent issue insufficiently taken into consideration; living below the poverty line is more frequent among older widows and former agricultural workers than in other social groups.

[16] Consultative body advising the government on economic and social matters.
[17] HLM – Habitation à loyer modéré.

Country specific issues

The organisation LEEM[18] criticises several medical abnormalities concerning the old population due to age discrimination; some examples are as follows:

- iatrogenic accidents are twice as high after the age of 64 than before
- insufficient age-related medical treatment contrary to the official position condemning age discrimination: in the case of colorectal cancer, 50 % of the under 65s receive radiotherapy but only 25 % of the over 70s; while 86 % of the under 65s have access to chemotherapy but only 24 % of patients aged 75 and above have access
- depression is not sufficiently taken into consideration amongst the old population: France has the highest rate of suicide of older people in Europe (nearly 3,000 in 1999) (LEEM)

[18] Les enterprises du medicament.

1 Profile of family carers of older people

Although the family is the main provider of eldercare in France, this fact still tends to be neglected, leading to a lack of research. Only at the end of the nineties, did it become a more important issue, due to the political debate on financing the dependency of the old population. Bocquet et al. underline that the notion of help within the family is difficult to define because of its context of the relationship existing 'forever': help and assistance given to old family members is the consequence of a long history of relationship and mutual exchange (Bocquet et al.).

Other main critical points are: 1. Surveys on family eldercare tend to focus on tasks generally provided by women – like personal hygiene or housework –, thus neglecting many tasks provided by men, husbands as well as sons; this seems to be the case for the HID survey, too, which was the only source of nation-wide statistics on family carers that could be found. 2. The published data (HID) on the characteristics of family carers include those who care for younger adults and children.[19]

1.1 Number of carers

The only figures found on the number and type of carers each cared-for person has, are the following, produced by Aliaga et al. However, care is needed with their interpretation as the figures include all age groups (Aliaga et al., 2002 / 03 p 635).

1 informal carer, no professional carer	1,080,000
2 informal carers, no professional carer	510,000
only professional support	690,000
1 informal carer + professionals	590,000
several informal carers + 1 professional carer	360,000
Total cared for persons, aged ≥ 60 years	**3,200,000**

Source: Aliaga et al., 2002 / 03 p 635

To give an approximate estimate of the older population, we proceeded to the following hypothetical calculation: the HID survey identified 524,000 heavily dependent individuals in the population over 60 years old living in a private household (Collin et al., table T03). About 60 % are cared for by an informal carer (Goillot, Mormiche, 2002, p 248). Based on the hypothesis that no informal carer cares for more than one person (unrealistic hypothesis, but we did not find data on the number of cared-for persons / carer either), that would

[19] It is possible to ask INSEE for a special data processing (we did not afford the costs).

mean at least 300,000 informal carers. This vague approximation includes family members, neighbours and friends.

There is a clear predominance of informal caregivers, and 85 % belong to the family of the cared-for old person (ibidem).

1.2 Age of carers

The highest likelihood seems to be that someone will become a family carer at the age of between about 60 and 75.

The higher the age of the dependent relative, the less is the likelihood of the existence of a caring spouse (60-69 years: 51 %; ≥90 years: 7 %) because of male over-mortality up to a certain age. There is no breakdown of these figures by both age and gender. Frequently, at least one half of a couple is dependent, often both are dependent. They care for each other, undertaking what he or she is still able to do, both of them highly motivated by the will to remain together and not to go into residential care. It is very difficult, if not impossible, to know which of the two is the main carer – if there is one. Also, the higher the age of the dependent relative, the more adult children appear in caring roles (60-69 years old: 31 %; 90 years old and above: 55 %) as with grandchildren (60-69 years old: 0 %; 90 years old and above: 10 %) – but as to who is main carer in the case of couples, it remains unknown.

A quantitative study (N 569) shows that 48 % of patients suffering from dementia are cared for by a spouse aged 75 and above (Chardon).

1.3 Gender of carers

In 1985, the (UK) General Household Survey included a section which asked all adults about any help they provided, on an unpaid basis, to individual family members, friends or neighbours. One of the most surprising findings emerging was the high level of involvement of men in caring roles (Parker). It would be interesting to see from data collected in the French HID survey, how accurate the supposition is that the bulk of informal care is undertaken by women, but the report does not mention which tasks were taken into consideration in defining the informal carer; judging from the different criteria introduced in the HID survey, it apparently concentrated on 'typical female' tasks.

HID figures assess the predominance of female family carers, increasing with age: 56 % in the 50-59 age group, and 66 % amongst the nonagenarians (*inter alia* because of the male over-mortality). Again, it has to be considered that the published HID data do not cross-reference the age of the carer with that of the cared-for person; consequently, these figures include carers involved in care of children and younger adults (Goillot, Mormiche, 2002, table 271).

Bocquet et al. state that older men are mainly cared for by their wives, while older women, often widowed, are mainly cared for by a daughter (Bocquet et al., p XXXI). Due to longer female life expectancy, adults are likely to care for their mothers or mothers-in-law. As husbands, men can undertake any task concerned with women's genital area – sons (very fortunately) do not. Bocquet et al. underline that men are very far from avoiding care giving: husbands generally are the main carers within the couple, and sons and sons-in-law are often active co-carers (Bocquet et al., p XXXI). In fact, married sons' involvement depends on the constellation in the caring situation: if the cared-for person is their own mother, they are very likely to even undertake household tasks in their own homes to support their wives and to show gratitude for all they do for their mothers; on the contrary, if the cared-for person is their mother-in-law, the conjugal relationship tends to be in conflict – the 'you do everything for your mother and nothing for me!' type of scenario.

There are tremendous knowledge gaps concerning family care giving and family caregivers in France, and that is especially true for men. Knowledge gaps also concern the identity of family carers; are they wives, husbands, daughters, sons etc?

1.4 Income of carers

We did not find other data on this topic.

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

Bocquet et al. distinguish between three levels of help and support to older parents, but do not mention the distribution (N and / or %):

- 'simple' help: occasional, mutual exchange
- regular help and support in daily life: a 'border' area where mutual help progressively becomes unilateral, provided to the old parents
- help and support on an unilateral basis due to old age and loss of autonomy (Bocquet et al., p XXXI)

Considering need in the case of dependency, it is not surprising that household work is the main area of care provision, nor that these daily tasks are done by formal (51 %) as well as informal (42 %) caregivers. In France, the aim of formal home help initially was defined as preservation of autonomy, so that all these tasks were supposed to be carried out, as far as possible, together with the dependent person. Due to drastic cost cutting, this ideal objective has been gradually forgotten, and in general, the number of hours granted weekly, give barely enough time, and sometimes far less time than is necessary, to do the work of prime importance. e.g. at present time, helping the de-

pendent person to move outside the home is four times more frequently carried out by informal than by formal carers (28 % and 7 %), and shopping is also the 'private hunting ground' of informal carers (52 %; 15 % formal carers).

Figures show that family carers naturally take on any task they would normally undertake for themselves. Household work is the only task where informal help dominates, probably due to the relatively easy access to home help services, especially for older dependents with modest income.

Table 1: Type of help by type of carer (in % of carers). Results include all cared for persons disregarding their age

Type of help	Informal carer	Formal carer	average
personal hygiene	26	18	23
moving inside the home	5	3	5
moving outside the home	28	7	21
defence of the cared for persons interest	29	9	23
accompanying to medical visits; health management	36	10	27
budget running, administrative tasks	38	9	28
shopping, incl. at the chemist	52	15	40
household work	**42**	**51**	**45**
company, presence	40	8	29

Source: Goillot, Mormiche, 2002, table 275

Care giving to a person suffering from dementia is, doubtless, the most difficult task. Dysfunction of his / her brain means dysfunction of the relationship, the household, any organisation, and often of the carer himself. It means, at least in advanced stage of the illness, the need for constant vigilant supervision. What the carer does is often undone some minutes later.

A small quantitative study (N = 56 m,) carried out in 2000, within family members caring for a person suffering from dementia, show that 'the majority devote more than six hours a day to the cared-for person' (Chardon).

We did not find statistics on the number of hours; it is not difficult to imagine, though, that caring for a patient suffering from dementia is a 'round the clock' job where people are co-resident.

1.6 Level of education and / or profession / employment of family carer

We did not find statistics on these issues.

1.7 Generation of carer – relationship between the carer and the cared-for relative

Below the age of 70, both dependent older men and women, if they are a (married) couple, receive help from their spouses; later on, if both suffer some loss of autonomy or when one of them has died, spouse care is less important (in the age group ≥90 years, only 9 % are still cared for by their husband or wife). Progressively, spouse-care becomes care provided by adult children (35 % amongst the fifties, 55 % amongst the nonagenarians) and, in minor proportions, by grandchildren (respectively 0 % and 10 %). Other family members intervene too, with the exception of brothers and sisters; siblings rarely care for each other (3 % and 2 %) and if they do, the care relationship is comparable with that of older couples (Goillot, Mormiche, 2002).

A small minority, less than 5 % of the 50+ age group, gets care from an ascendant. One can assume that the dependent person has been mentally or physically handicapped since birth.

Table 2: Type of informal carer by age of the cared for person (in %*)

Type	50-59	60-69	70-79	80-89	≥90
spouse	50	51	34	14	7
child	35	31	43	56	55
grandchild	0	2	4	5	10
ascendant	4	1	0	1	3
brother or sister	3	4	4	2	2
other family member	3	5	7	11	14
friend, neighbour	5	8	8	11	9
subtenant	0	0	0	0	2
maid living in the same house	0	0	0	0	0
Total	100	100	100	100	100

* 0 % = ≤0.5 %
Source: Goillot, Mormiche, 2002, table 271

Mamou underlines that if the dependent person is the husband and if the dependency develops progressively, it can take years for the wife to realise that she has become the carer, especially if she is used to undertaking all household tasks. In the case of widowhood and especially where there is only one child, that child will naturally become the main carer, and often they become geographically nearer. The care situation can be more complicated when there are siblings: married children tend to feel free of caring obligations; sons (married or not) tend to take it for granted that 'by nature' their sister has to care, especially if she is unmarried (Mamou (2)).

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

The kind and degree of dependency determine where the individual lives.

- Intellectual or mental problems are experienced by:
  - more than 80 % of people aged 60 or less living in an institution; this percentage decreases with increasing age with 50 % amongst nonagenarians;
  - in a private household, they represent less than 20 % until the age of 70, and then the percentage increases up to 43 % amongst nonagenarians[20].
- Locomotive problems are experienced by:
  - about one in four residents aged 60 or less in an institution, and more than 60 % in the 80 and above age group;
  - 70 % of nonagenarians in a private household (Goillot and Mormiche, 2003, p 198).

There are important information gaps on co-residence patterns between carers and the cared-for person. Bocquet et al. argue that two types, of equal importance[21], have to be distinguished.

- Permanent co-residence, mainly related to the transmission of property (agricultural and commercial); this is mainly the case in rural areas. Unmarried sons and daughters who never decided to live on their own or who are disabled and consequently unable to live alone constitute a minority.
- Re-cohabitation, most often to care for an old parent; this category is more frequent in urban areas (Bocquet et al., p XXVIII). The main tendency seem to be that in the case of heavy dependency, re-cohabitation is increasing because caring at distance becomes inappropriate for the health and safety of the cared-for person, or is too difficult to manage.

The 1999 census provides data on co-residence, but disregards possible dependency as a reason for it, not really providing much reliable information on the subject (see table 3).

[20] Sheltered housing (*logements-foyers*) by administrative definition is considered as private households. Official statistics follow the same definition

[21] Percentage and number not specified

Table 3: Population of the households by 2 age groups, type of co-habitation (in %*)

	60-74 years	≥80 ears.
living in a couple without children	60	32
living in a couple with children	12	2
living with an ascendant or descendent	4	4
living with a person not belonging to the family	4	12
others	1	–
living alone	21	50
Total	100	100

* N = 27.8 million households
Source: Census 1999. INSEE, anonymous, 2001, table MEN3

The high frequency of households consisting of a couple without children, (nearly two in three within the age group 60 to 74, one in three at the age of 80+) and of people living alone (21 % and 50 %) is not surprising. However, the percentage in the category 'living in a couple with children' is increasing. Probably these figures can be accounted for by the delay in the last child moving out of the parents' home to live on his own, and possibly a more detailed age profile would show some 're-cohabitation' between an adult child and his / her old parent.

Furthermore, there is also a clear lack of information on intergenerational relationships other than those of co-residence. Bocquet et al., refer to a survey carried out in 1992 with centenarians belonging to a family with three adult generations. It is reported that amongst old parents, 50 % have one child living nearby (less than 1 km.), and 90 % have a child living at a distance of less than 50 km; 31 % live in the same village or town and 67 % in the same *Departement*. Other (regional) survey results confirm the geographical closeness between adult children and their old parents (Bocquet et al., p XXVIII).

1.9 Working and caring

We did not find relevant data on this topic.

As a result of the real average retirement age being 57, in addition to the fact that dependency is progressively being delayed until more advanced age, people involved in eldercare are no longer engaged in full-time employment.

Unquestionably, working and caring is a difficult combination, particularly for those who work full-time, and may be so particularly for men. At the tenth anniversary conference of the UK National Carers' Association (London[22]), we participated in the working group devoted to male carers. Those who were working reported negative reactions amongst their colleagues and friends from

[22] We do not remember the year.

work or sporting activities or in pubs: being carers of their wives discredits them and leads to social rejection because a 'real man' does not engage in care activities. If this is the case in the UK, why then should analogous convictions and behaviour not exist elsewhere, in France, for instance?

1.10 General employment rates by age

The real average retirement age is 57 (2001), three years less than the legal age. About half of the French population stop working when they are 50 years old or older. The proportion of working people in the age group 55 to 59 is 54 %, while 15 % are in retirement. In the 55+ age group, nearly one in two do not work any longer. At 43 % [23], France has the lowest employment rate in the 50 to 64 age group in the whole of the developed world (Seniorscopie).

Gauté underlines that the focus on employment in young people being high on the agenda, has lead to its discussion with regards older workers taking a back seat, irrespective of the fact that the growth of unemployment in young people has appeared together with that of the over 50s. Despite a recent increase in employment rate in the 55 to 64 age group, it remains very low compared to that of other OECD countries. For years, the public and political debate on retirement has been focused mainly on the demographic relation between the active and inactive and on the necessity of lengthening people's working lives. The French reform of the pension system (2003) has promoted this lengthening, following European objectives to reach an employment rate of 50 % within the 50-64 age group by 2010 (resolution of the European Council, Stockholm, March 2001), and to raise the legal pension age progressively (European Council, Barcelona, March 2002) (Gauté).

The unemployment rate within the 50+ age group is 7.3 % (March 2003 and March 2004). The employment rate is 32 % in the group aged 55 to 64 (INSEE Conjoncture).

1.11 Positive and negative aspects of care-giving

Positive aspects

Findings from research from the late eighties, carried out for the European Foundation, led to the observation of a strong link between the positive aspects of and motivation for caring: a balance between the objectives and the results is essential. Nevertheless, the findings also show a clear predominance of negative aspects, that enriching and 'good' moments are rare (Jani-Le Bris, 1993). We did not find any indication that this has changed over the years.

Positive aspects are still:

[23] Sweden: 80%; USA: 68%; UK: 64%.

- the satisfaction of doing one's duty
- the satisfaction of giving back what one has received at a former time
- the satisfaction of feeling that the cared-for parent is satisfied
- the satisfaction of accompanying a beloved person through an illness to their death
- the satisfaction of being useful to somebody – a feeling which makes life meaningful
- the process of maturation of the carer
- the process of facing former problems in the relationship and sorting them out, enabling the carer to finally build a relationship between two adults, overcoming the notion of child / parent
- taking pride in facing and overcoming huge difficulties

Any care situation is first and foremost a relationship, with not only all the emotions, both positive and negative, evolving from the history of that relationship; but all the problems, whether they have been sorted out or not, from childhood, if the carer is the child, or from marital life, if the carer is the spouse – emotions or problems, all of which are exacerbated by the caring situation.

Irrespective of the age of the cared-for person, Goillot and Mormiche assess that contacts within the family are generally not affected by the caring situation as far as parents, spouses, children and siblings are concerned. They put this down to the fact that the family constitutes the hard core of any relationship, able to withstand the difficulties which accompany any carer situation. On the contrary, relationships with further-away family members, friends, colleagues or neighbours are affected by the situation; the greater is the handicap or dependency, the more they retreat from the cared-for person: about 40 % of bedridden, non-demented persons have no contact with them (Goillot and Mormiche, 2002, p 206).

These findings are contradicted by a former research project carried out by Ross and Eynard, and it is highly unlikely that time has changed the problems. According to their typology of carers, they report that the typical care situation is characterised by conflicts and rivalry between family members living together with the cared-for person (Ross and Eynard).

Negative aspects

Negative aspects are (in alphabetic order):

- burden and over-burden
- the desire for or waiting for the death of the cared-for person, leading to shame and feelings of guilt

- fears of not being able to care until the end: fear of collapsing, of dying before the cared-for person, of falling seriously ill, of becoming depressed or of becoming dependent oneself
- feelings of guilt
- feelings of helplessness
- feelings of hopelessness and despair
- feelings of isolation and loneliness
- the fear of social exclusion (oneself and the cared-for person)
- the impossibility of carrying out old projects conceived for the retirement period, and making plans for the future (only to be undertaken on the tomb of the cared-for person)
- the lack of understanding amongst friends, relatives and other people about the situation
- the loss of enjoyment of life and joie de vivre, of humour and laughter
- the loss of freedom
- the loss of identity
- the loss of social environment, sometimes of the partner (divorce)
- the mirror effect of and unconsciously identifying with advanced age and dying
- the steady confrontation with the negative aspects of aging and old age, with dying and death
- steady sadness
- uncertainty of the development of the situation and of one's mental faculties and physical ability to care and to go all the way to the end

Other powerful emotions linked to the caring relationship are e.g. the search for love or forgiveness, which often provides the motivation for caring.

A small quantitative study (N 569) carried out in 2000, aims to clarify the daily pressure on carers of Alzheimer patients, and their needs for and expectations of facing the situation. According to the findings, the major risk is that the carers themselves sink into madness because of their vulnerability from the daily erosion of their mental health (Chardon).

Mamou insists particularly on the 'trap syndrome' particular to family carers who are confronted with the carer situation all alone, and want to combine family life and filial obligation, resulting in them experiencing permanent feelings of guilt for not succeeding in either domain (Mamou (3)).

Aquino (geriatrician) underlines that the risk of depression is twice as high amongst family carers than in the general population. Factors making things worse are the absence of diagnosis and consequently the absence of treatment and the isolation of the carer (Quoted from Hunsinger).

Elderly abuse

Elderly abuse is still a taboo subject, although for years there have been hotlines and associations to support both victims and perpetrators[24]. The associations (sometimes associated with the local authority) process information on abuse they receive and, where appropriate, bring it to court.

It is significant that the first and only French survey on abuse (2002) focuses on younger women.

Nevertheless:

- There are several laws to protect the old population against abuse.
- The former Secretary of State for the old population, Mme P. Guinchard-Kunstler (former government socialist (Jospin) set up a plan to combat elderly abuse, aiming at better knowledge on the subject and to introduce into the basic programme of medical studies a compulsory section devoted to elderly abuse (Le Quotidien du Médecin, 23.01.02).

The association AFPAP, according to 2,500 calls received on their hotline during the last six months, and concerned with abuse in institutions, reports that 'profit-thinking' is the main reason for abuse: trying to economise can lead to certain kinds of abuse such as: lack of appropriate medical care, not employing necessary help, malnutrition, and all kinds of negligence. The main victims are the most vulnerable, i.e. those suffering from dementia (AFPAP).

Abuse carried out by family carers is far less apparent and more unknown because of the inherent difficulty of control and the issue of policing. In cases of denunciation, callers to the hotline are required to give their consent for legal action to be taken, thus resulting in the carer (daughter, son husband, etc.) being charged. The difficulty of this system is that it is equivalent to the cared-for person breaking off the relationship and ending the caring situation – and then what happens to them?

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

There are vast information and research gaps on this issue.

[24] E.g. ALMA – *Allô maltraitance des personnes âgées* (http://www.almafrance.org); AFPAP – *Association française de protection et d'assistance aux personnes âgées* (http://www.afpap.org/maltraitancepersonnesagees.htm).

1.13 Other relevant data or information

50 % of all cared-for people have exclusively informal carers, 29 % receive mixed care – professional and informal, and 21 % receive exclusively professional care (Aliaga et al., 2002 / 03 p 635).

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

French socio-gerontological policy does not focus on eldercare in the family nor does family policy (which is quite central in childcare policy). This does not mean that socio-gerontological policy in the sectors of community and residential care does not indirectly support family carers. This is especially the case of the National Dependency Allowance APA.

Policy and society give priority to the principle of keeping the old at home, in the environment and day-to-day routine they are familiar with. Entry into an institution is associated with negative representations and notions of failure, guilt, abandonment, boredom, loneliness, dying and death – the final solution when nothing else is possible. Numerous family carers therefore adopt the hard-line attitude of not giving up caring even when they are completely exhausted. Obviously, the public image of old people's homes is worse than the reality: in the last few decades, different government programmes have introduced significant changes, so that there are many 'good' homes and many 'good' directors, but they co-exist with the terrifying spectre of the former *hospice*: asylum, Christian charity houses surviving from the middle-ages that were later overtaken by the public sector, and were organised more like prisons than homes. Often with 1,000 beds, these institutions had the legal obligation to offer refuge to alcoholics, the old, the homeless, the disabled and the mentally ill, who all 'lived' together in huge dormitories (Ennuyer; Jani-Le Bris, 1979). In spite of the law that required them to be turned into homes for the elderly by 1975, in the beginning of the eighties there were still *hospices* in France.

Inter alter due to this negative association, moving into a home for the old or a nursing home is rarely takes place from a deliberate choice having been made.

All available services for dependent older people directly or indirectly support carers.

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

The family is expected, at least morally, to care – an expectation which policymakers and society, as well as potential and active family carers share,

based on the concept of moral obligation to one's spouse and one's old parents. Often – especially when the need for care is in its early stages, and even more amongst older couples – becoming a carer is an insidious process that happens over several years, during which time carers rarely identify themselves as such (Jani-Le Bris, 1993). Adult children and older husbands and wives still espouse widely the traditional model of duty and normality, considering that they have to face the situation when fate decides it.

It is significant that when the law on dependency allowance was passed (PSD), the French government replaced the expression 'family carer' with 'natural carer', and that there was almost no criticism of this change.

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?

The legal definition of autonomy / dependency is based on the need for care and is stated by law, by the National Allowance of Dependency (APA). Related to the APA, the legal French instrument for measuring the degree of autonomy / dependency (law 24.01.1997) is the scale AGGIR.[25] (Other scales used in France are e.g. the *Indicateur Colvez*, *Indicateur EHPA*, and the scale of Katz, mainly applied to research work.[26])

APA and its scale consider physical and mental dependency. APA is a legal entitlement.

Basic regulations of APA

- There are the following basic requirements of age (60+), dependency (from the AGGIR scale), and residence (main residence must be France, APA cannot be received abroad).
- There is no means test, but nevertheless income is taken into account: the higher the income, the more the beneficiary may have to contribute[27] to financing[28].
- There is no condition of nationality.
- Caring spouses are expressively excluded
- An allowance is paid for domiciliary and residential care.
- In kind allowance: the amount is established on the basis of the compulsory 'help plan' set up individually by the regional government (*Conseil general*[29]).

[25] AGGIR: Autonomie Gérontologique – Groupes Iso-Ressources.
[26] For details, see Goillot, Mormiche, 2001, p 29-34.
[27] Financial participation = 0 % if the income does not exceed 914.52 euro/month – = 80 % if ≥3048.41 euro/month (2001; Secrétariat d'État aux personnes âgées).
[28] 70 % of the beneficiaries have been exempt from financial participation in 2002.

The allowance is based on national price setting (national government).

The AGGIR Scale

The scale includes ten criteria:

- coherence (language and behaviour)
- orientation (time and space)
- personal hygiene (being able to wash oneself)
- dressing und undressing
- urinary and faecal elimination
- physical transfer (to get up, sit down, go to bed)
- moving inside the house (with or without technical help)
- moving outside
- communication at distance (to use a telephone, an alarm system, etc.)

Criteria **not** taken into account:

- managing one's own budget, goods, officialdom
- preparation of food, cooking
- household work
- transportation: using public or private transportation, ordering a taxi
- shopping: direct purchase, buying by mail order, telephone shopping
- follow-up of treatments: the ability to follow medical prescriptions
- leisure activities: the ability to practice sports, to have cultural, social and leisure activities

According to their answers, the individuals are categorised in one of the 6 complex *"iso-ressource"* groups. APA is granted to people belonging to GIR groups 1 to 4.

Group 1: loss of mental, physical, locomotive, and social autonomy

Group 2: bedridden individuals without mental disorder, and demented individuals without physical disorder

Group 3: no mental loss, but partial loss of physical autonomy

Group 4: individuals unable to get up alone, but able to move indoors and conduct activities such as eating but needing help with the WC, personal hygiene and dressing; people without locomotive prob-

[29] Elected government of the département.

lems but needing help with physical activities like personal hygiene and eating

Group 5: physical autonomy inside the home, but need for regular assistance and overseeing several times / week, and help for personal hygiene, cooking and housecleaning (typical tasks for the home-helper)

Group 6: autonomy in daily life

Group 5 and 6 take into consideration in how far the person depends on help to be safe at home. APA is excluded from these groups.

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 or similar)?

There is a general legal obligation for any citizen to assist any person in danger (article 223-6, *Code Pénal*).

According to the national allowance APA (see above) the state has a legal obligation to provide care.

According to French civil code, children are obliged to undertake the maintenance of their mother, father and other ascendants[30] (article 205); article 203[31] obliges children to indicate their income to the *Aide social* when an ascendant gets financial support from this institution (which then decides if the children have to contribute or not, and for what amount). *Aide social*-receivers of APA, and of home help are exempt from having to contribute. Nevertheless, this improvement might be abolished for financial reasons – it has appeared sporadically in government debates since the law was passed through Parliament.

National health insurance is legally obliged to provide access to medical support and treatment as well as hospitalisation and medical transportation, though preventative health care is excluded. This insurance has to bear at least part of the costs. For uninsured individuals, in 1999 the CMU Act was passed[32] which guarantees underprivileged people[33] access to free medical treatment, hospitalisation, etc.[34]

[30] Law of 17.03.1803, law of 1891, number 72-3, 03.01 1972 establishes that children are obliged to maintenance.
[31] Article L123-6, law nº 2004-1, 02.01.04, art. 18.
[32] CMU: *Couverture maladie universelle*, medical universal coverage.
[33] Two main conditions: living in France and small income (≤562 euro/month/person in 2002) (Boisguérin).
[34] The CMU counts more than 4 million beneficiaries (beginning of 2004), amongst whom the age group ≥60 years is clearly under-represented. As in retirement, they are in general covered by the basic system of the *Sécurité sociale* and their *caisses complémentaires*. There are very few beneficiaries aged ≥65 years.

Access to a home-helper and other domiciliary services (nursing excluded) is not a legal right. Access to medical treatment and APA is.

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

See above, chapter 2.1.3.

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

The legal definition of old age varies according to the institution and kind of benefit.

- Old age pension
  - For the national pension fund (the basic system for employees in the private sector), special systems and pension funds for agricultural workers, craftsmen, and shopkeepers, the age is 60, for both men and women: full pension rights are accorded on payment of social contributions for 150 to 160 trimesters (the exact number of trimesters depends on the year of birth). Other special pension funds may have different practices.
  - For civil servants, the age is 60, with the right to a full pension after social contributions have been paid for 37.5 years.

Other specific pension funds practice lower age limits (e.g. workers in the underground mining or blast furnace sector).

- Allowance in the case of widowhood is granted up to 55 years of age (basic pension system; the special and complementary systems may stipulate other age limits).
- *Pension de réversion*[35] (pension paid to the survivor of a married couple) is granted for people 55 years of age and above, but in July 2004, the age stipulation was abolished.
- *Minimum vieillesse*[36]: This is paid for the 65 and over age group, or 60 in the case of inability to work.
- APA: This starts to apply at 60 years of age.

[35] Before the abolition of the age condition this pension replaced the allowance in case of widowhood which stops at the age of 55 years.
[36] The so-called *minimum vieillesse* (old age minimum, crated by law in the late fifties) is paid by the National pension fund, provided that the person has very low income, is aged ≥65 years (or 60, see above), and is living in France. It is a complicated combination of two allowances. Since the 1st January 2004, the amount of both together is 6, 511.06 euro/year/person living alone.

The reform of the national retirement system aims at raising the average retirement age so that the different instruments for early retirement tend to vanish. Nevertheless, since the reform, older workers who entered the labour market at a very young age are entitled to retirement with full rights between the ages of 56 and 59 if they have paid 168 trimesters of social contributions.

2.2 Currently existing national policies

2.2.1 Family carers

There is no real 'care for carer' policy in France.

However, since 2001, APA has relieved family carers (if they accept help from outside) from the load. APA is a financial source for family carers, too: the beneficiary can choose the care provider he will employ: a home service or an individual, excluding spouses. Whoever is employed, payment has to be made in the form of a declared salary (Secrétariat d'État aux personnes âgées) so that social contributions (health and old age etc.) are paid for the family carer, too.

If a real government policy in favour of family carers is a long time coming – or as a result of the delay – there are numerous claims from different associations and the media, for due consideration to be given to carers' responsibilities. Huguette Drera, president of *France Alzheimer* e.g. declared: 'The role of the family is essential and needs to be recognised by society. The family cannot continue working like that, bringing their jobs and their own health into play, for zero francs.' (quoted from Chardon) UNASSAD[37] stresses that the new government policy to prevent future possible high over-mortality rates due to high summer temperatures is forgetting the homecare sector; both professional and family care.

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

The French state set up its geronto-social policy in the beginning of the sixties[38], based on the key objectives of informing the older population of their rights and improving: social integration, social autonomy, living and housing conditions, as well as income. Since the beginning, the home-helper has been considered to be the cornerstone of this policy. At the end of the seventies,

[37] UNASSAD – Union Nationale des Associations de Soins et Services à Domicile: national union of homecare associations.

[38] Policy for the older population has been initiated by the government in 1958, creating the *Commission Laroque* (presidency: Pierre Laroque), which worked out a report on the problems of the population ≥65 years (social and material conditions of life), which showed that the situation of the old population was disastrous and worse than presumed. This report constitutes the pillar of France's policy for old/er people (Commission Laroque).

metropolitan France was geographically well-covered with home-helpers, though due to public financing problems all needs were not covered. In conjunction, paramedical home services were developed, and the first policy was set up to improve elderly people's homes. Until the late eighties, nobody took into account the basic pillar, the family, which had been systematically ignored by all policy makers and accepted as 'normal' by the public, including family carers themselves (Jani-Le Bris, 19). In the mid-eighties the first congresses[39] and publications on family care appeared.

Unlike Germany, France did not manage to set up a long-term care insurance programme as the fifth pillar of its social protection system. Nevertheless, in 1997, a special public benefit (PSD) was created for dependent people aged 60 and above with modest income.[40] Access to this was, however, considered to be too restrictive, and in 2001 it was enlarged and replaced by an analogous benefit (APA). Even in its first year, APA registered four times as many beneficiaries (605,000 on 31.12.2001) as PDS (143,000 on 31.12.2001) (Secrétariat d'État aux personnes âgées) (See above, chapter 2.1.2).

For years now, and particularly since Germany created its dependency insurance scheme, there have been sporadic political debates on setting up an analogous 5th pillar of the social protection system. As there has been, and still is, no concrete evidence to think that such a system will be implemented, over the last decade private dependency insurance schemes have been developed.[41] In the case of dependency, monthly private payments are made, supplementing income.[42] As these schemes are quite recent, only a few dependent older people are benefiting from them; consequently, they have not yet had any statistical influence on the financial cost to the family (Mamou (1), 2002).

An important topic on the socio-political agenda after the heat wave of August 2003, that led to an additional 15,000 deaths in the general older population, was prevention of over-mortality if hot summers occur amongst the very old and frail. This is an issue which is still being reported by the mass-media and has led to high public expectations that immediate government action will be taken. To avert a repetition of 2003, the Minister for Health and Social Protection published his plan in May 2004, based on the admission that wrong government decisions were made in 2003. As a result of the minister's official declaration, the government is setting up a political intervention plan involving all political authorities and NGOs; the idea is to set up coordination between different ministries, and all public and private institutions, on national, regional and local levels. Amongst general fears for very frail older people there is also some hope in sight. E.g. the *département Hauts-de-Seine* (near Paris).

[39] E.g. a conference organised in Paris in October 1987 (Fondation de France).

[40] December 1999: 110,000 beneficiaries.

[41] 850,000 subscriptions in 1999, 1 million in 2000, and 1.2 million in 2001(Sénat, 2004).

[42] Premium, according to the insurance company: 7 to 30€/month until the insured state of dependency arrives. Then the insurance finances ≤2,440€/month. Example: paid from 50 to 80 years, the costs over 30 years are 4,880€, and the insurance will pay e.g. for 3 years dependency 90,000€.

The political debate on the older population in need of support generates lot of criticism.
Jacquat, in his report to the National Assembly, underlines the inadequacy of the budget to sufficiently finance the loss of autonomy faced by the aging population (Jacquat, p 9).

The independent and very critical French consumer revue, *Que choisir*, based on three official reports concerned with the critical situation in the elder-care sector, points out to the general public that recent government plans and strategies cannot make up for the enormous eldercare gaps which the summer disaster of 2003 brought out (Moran).

Moran reports that

- according to IGAS[43], 15 % of residential care institutions have to be totally renovated[44] and 30 % need partial renovation, involving 200,000 beds which represents one third of the total capacity;
- according to a ministerial circular from 2003, as a result of the high-mortality of August 2003, the government required all homes for the elderly *inter alia* to have a room with air-conditioning by June 2004; how this was supposed to be financed was not mentioned, but would normally fall under the responsibility of regional governments (*Conseils généraux*); some of which decided to initially absorb the cost, only later to pass it onto the residents by way of an increased daily rate[45]. Once again, the family is affected financially – perhaps a measure designed to encourage the family to take on eldercare (Moran, p 40, 41).

Ozaram points out with respect to APA that

- as it depends on regional government, there are enormous differences from one *département* to the other;
- costs have been underestimated due to the number of beneficiaries being underestimated: 500,000 to 550,000 in 2002 and 2003 with costs: 2.5 billion €, and 800,000 at the end of 2004, but the latter number already had been reached in 2003 – the real costs are estimated at 3.9 billion in 2003 and 4 billion in 2004 (Ozaram).

LEEM points out the saturation of home nursing services and the uncertainty of their future development: they have reached 100 % of their capacity, and the government has limited the creation of new places to 20,000 supplementary beds, while the capacity of places in residential care has decreased (-23 % between 1994 and 2001) (LEEM).

[43] Inspection générale des Affaires sociale.
[44] Access to wheelchairs, safety in case of fire, adequate care for persons suffering from dementia, etc.
[45] The average daily rate is 1,300 euro (2004), the average income of pensioners 1,440/month for men and 894/month for women.

In 2000, the so-called "CLIC"[46] were created, a new attempt to coordinate domiciliary services as well as the grey area between them and residential care.

The need for community care in 2004 is not being met due to lack of financing. To limit public expenditure, the number of hours needed tends to be systematically underestimated in the individual 'intervention plans' worked out individually for each APA receiver.

Many services are income-related, favouring the poorest, so that, in particular those whose income approaches the upper limit for (nearly) free assistance cannot afford the amount they have to pay themselves. E.g. for the home-helper, the beneficiary's contribution varies, according to their income, from between 1.62 and 11.96 euro per hour. Well-off pensioners often prefer to employ a traditional maid, which is less expensive.

A special service exists to make administrative tasks easier for the individual employer of a cleaning lady and to reduce black employment: the *chèque emploi service*[47] which is particularly helpful for older people. The salary can be paid in this way if the weekly work does not exceed eight hours.

In 1975, a special type of institution was developed in France for older people suffering from dementia: the *"Cantou"* (See chapter 7.2). The total number of these 'small units' and the population they serve is unknown.

Not surprising: for demographic reasons, the population in residential care is mainly female with a clear predominance of widows (62 % plus 29 % single and divorced women). Their social integration *extra muros* is quite passive: less than 4 % go out to meet their family at least once the week, less than 10 % once a month, and only 7 % go on holiday every year. 70 % report regular family contact and visits. They receive visits from friends, former neighbours and colleagues, too. Amongst those (30 %) who do not have any contact with their family, two in three declare that they do not have children or that all family members are dead. The population in institutional care is very old due to the average age at the time of entry: at the end of 1999, it was 79 for men, and 84 for women (Mormiche).

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)?

We did not find data on this issue.

[46] *Centre local d'information et de coordination gérontologique* (Local centre for gerontological information and coordination).
[47] These cheques are edited by any bank in collaboration with the national office for collection the social contributions. This free service exempts the employer from all administrative formalities (monthly declaration and payment to the abovementioned office, monthly pay slip, calculation of the social contributions).

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

The application of the national socio-gerontological policy largely falls under the general and financial responsibility of regional government (*Conseils généraux*). E.g. the *Aide sociale*, financing the national allowance of dependency as well as several other socio-gerontological services for older and disabled people, depends on the *Conseils généraux*. These local authorities are quite free in their decisions, programmes and applications.

Furthermore, many cities pursue their own socio-gerontological policy, like the City of Paris.

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

As a consequence of the above-mentioned political involvement of regional government, there are important differences from one *département* to the other. This is true for all social care services and for any policy and public initiatives in favour of family carers, and even for the attribution of APA, namely because the *Aide sociale* depends on this government. For rich *départements'* socio-gerontological policy generally is better than poor(er) ones, and beneficiaries of APA living in a rich *département* get more home-help hours than those in a poor *département*. This system of financing inexorably leads to important social differences and injustice.

Two examples:

- Numerous *Conseils généraux* choose and subsidise a home-alarm-system, but often their choice is based on other criteria than quality; generally, users can only benefit from financial support for this if they choose the same system. Consequently, the access to a home-alarm system is not equal, and the access to a system of high quality is even less equal.
- The development of private initiatives (e.g. from associations) often depends on local financing. Some are in better position in relation to the *Conseil général* or are more combative than others; in the general climate of cost-cutting, lot of associations have to reduce their activities or at least cannot develop them.

3 Services for family carers

- Publishing brochures dealing with different topics

For decades, numerous books, brochures, magazines and guides have been published and are available to the public. To list some of them:

- *Bayars Presse* has for more than 30 years produced the magazine *Notre Temps* for the 50+, based on the principle of active retirement, including special sections: advice, new laws and reforms, rights and obligations concerned with older people, nutrition, health, memory gym, recipes, information on taxes, the transmission of goods to heirs, how to make one's will, different kinds of information for the old as well as for informal carers, etc. *Notre Temps* also publishes special practical guides on different subjects, including some for family carers.
- Some years ago *Bayars Presse* also created a magazine for informal carers, which, after a number of issues, disappeared.
- The *Fondation Médéric Alzheimer*[48] recently published the first French national directory of all operations providing support for people suffering from dementia and their carers.
- *Alzheimer France* publishes newsletters at both national and local level (information; advice).
- All *caisses de retraite complémentaire* produce and distribute newsletters or magazines (information; advice) to their members.
- Local authorities publish and distribute broad information brochures.
- Since June 2004, the ministry of Health and many local authorities have produced and distributed guides on how to cope during a heat wave (the ministry itself has sent out three million copies).

There are numerous websites on or for the older population, providing a great deal of information and advice on numerous topics.

In light of the huge amount of information sources, it is difficult to understand that many older people and, to an even greater degree, many family carers still remain quite uninformed. This fact may be accounted for by their retreat into social isolation.

[48] The foundation has been initiated (1999) by and depends on the *caisse de retraite complémentaire* Médéric. It mainly aims at research, advice and information. (See below, chapter 3.1.1. The foundation's website is available in French and English: http://www.fondation-mederic-alzheimer.org/page0.php?c=0&selection=2&lang=2.

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	X	X	X
Self-help support groups[49]		X				X	X	X
"Granny-sitting"		X						X
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X				X	X	X
Weekend breaks		X						X
Respite care services		X				X	X	X
Monetary transfers		X						X
Management of crises		X		X	X	X	X	X
Integrated planning of care for elderly and families (in hospital or at home)								
Special services for family carers of different ethnic groups		X						X
Other								

3.1 Examples

3.1.1 Good practice

- Accueil familial
- Jalmalv
- Cantou

See description in chapter 7.2.

3.1.2 Innovative practices

- CLIC

[49] Answers depend on the definition „self-help groups. Above "X" means: organised support groups

- Association française des aidants de personnes malades, dépendantes ou handicapées – AIDANTS
- Fondation Médéric Alzheimer (see chapter 7.2)
- The municipality of the City of Paris has instituted the 'Prize for good treatment' in socio-gerontological sports and culture. In 2004, the public hospital Bretonneau won the prize with their programme "Taï Chi Chuan" for family carers who are invited to join the weekly group to relax.
- Rich information helpful for carers and the old on the Internet developed by associations specialised in community care, residential care, in gathering information, or in special health issues (such as osteoporosis, incontinence).

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

«On vit de plus en plus vieux. Les statistiques le montrent!
Mais cette longévité entraîne quelques problèmes.»[50]
(Serge RUCHAUD, Benoît Chauveau)

4.1 Health and Social Care Services

In total, approximately 800,000 people aged 60 or more are in need of help, representing 7 % of the 60+ population. 524,000 (66 %[51]) are living in private households, mainly cared for by a relative. The type and the amount of help obviously changes with the age of the cared-for person: they constitute 15 % of those needing care amongst the 60+ group, 85 % amongst the nonagenarians (Goillot, Mormiche, 2002, p 246).

Dress[52] elaborated projections for the older dependent population in need of help, and their potential carers until 2040. The part devoted to the elderly concerns dependent people aged 60 and over. It is based on the HID survey (1998 / 99), takes into account the increasing better health of older people[53], and includes three hypotheses: optimistic, central and pessimistic. 'The ageing of the French population will probably lead to an increase in the number of dependent people aged 60+. Two sharp increases will probably appear around 2010 and 2030: the increase between 2000 and 2020 is estimated at 16 % (optimistic hypothesis), 25 % (central) and 32 % (pessimistic); during the following decade, the proportions might be slightly higher. From 2000 to 2040, the increase might be, in total, between 35 % (optimistic) and 80 % (pessimistic). The increase will mainly concern the 80+ age group.' (Bontout et al., p 1) The second part is based on demographic projections from the National Office for Statistics (INSEE). 'It is close family, friends and neighbours who mainly provide eldercare. However, the age group 50 to 79, which is the main source of carers, will probably increase by about 10 % between 2000 and 2040 (…), an increment clearly less important than that of the old dependent population. This demographic development might be amplified by an increased female participation in the labour market. Other, individual factors might also intervene leading to an increase or decrease of the potential carers.' (ibidem)

[50] "We are becoming more and more old. Statistics show it! However, this longevity causes some problems."
[51] 800,000 = 100% (population ≥60 years).
[52] DRESS: Direction de la Recherche, des Études de l'Évaluation et des Statistiques, Ministry for Employment and Solidarity.
[53] Physical and intellectual disorders are taken into account. The authors underline the difficulty to calculate the number of people suffering in the future from dementia, because of the lack of knowledge and diagnosis up to now.

In the French socio-gerontological landscape, there is no concept of user empowerment, by neither old dependent people nor of informal carers. Alan Walker's 'message of autonomy' (Walker et al.) is unknown or ignored. Caring is consequently a question of struggle for and exercise of power by carers, be they professional or informal. In our opinion, this fact is one of the essential negative phenomena in the caregiver system in France and elsewhere.

4.1.1 Health services

The primary health care sector is widely developed with doctors, therapists, professional nursing services as well as social and medico-social services, but the geographical distribution especially of GPs and specialists is unequal. (Sokolsky) Nevertheless, this sector is in a critical situation leading to serious repercussions *inter alia* on the health care of the old population. Hospitals (as well as the residential care sector) mainly belong to the public sector. There is a concentration in cities.

The organisation LEEM[54] criticises several medical abnormalities concerning the older population due to age discrimination; some examples:

- Latrogenic accidents are twice as high after the age of 64 than before.
- The practice of insufficient medical treatment due to age, contrary to the official position condemning age discrimination: e.g. in the case of colorectal cancer 50 % of under 65s receive radiotherapy but only 25 % of the over 70s, and 86 % of the first group have access to chemotherapy but only 24 % of patients aged 75 and over.
- Depression is not sufficiently taken into consideration amongst the older population: France has the highest rate of suicide of older people in Europe (nearly 3,000 in 1999) (LEEM).

4.1.1.1 Primary health care

GPs play a crucial role, although their geriatric knowledge is often limited. The majority of older people never get to see a geriatrician, and the majority of those suffering from any form of dementia or depression are only followed-up by their GPs. The geographical distribution of GPs and specialists is unequal: despite some government fiscal initiatives, rural areas in particular are not attractive to doctors (Sokolsky). The ratio of geriatricians is 1: 12,000 in the *dé*partement Creuse, and 1: 7000 in Île-de-France (the greater Paris) (LEEM).

Nursing home care: see below, chapter 4.1.2.2.2.

If the patient is bedridden or housebound, doctors and all paramedical professions do home visits.

[54] Les enterprises du medicament.

Due to the lack of co-ordination in community care, teamwork seems not to be the general rule.

A special out-reach hospital service has to be mentioned: the HAD – *Hospitalisation à domicile* 'hospitalisation at home' – which has existed in France since 1955. HAD aims to keep patients (any age) suffering from chronic pathologies or in the terminal phase of life, at home. Generally, HAD is practiced after a period of hospitalisation or between hospitalisations. A specialised medical team takes over responsibility for different kinds of medical treatment and reports back to the hospital. Home help and night care can be organised in addition. Most of the patients are in very bad health, often in the last phase of their lives; good medical teams are trained in accompanying terminal patients to their deaths (Circulaire du 30 mai 2000). Although very efficient and appreciated by both patients and the medical profession, HAD is still underdeveloped with only 4,739 places in 2002.[1] There are huge deficiencies in geographical distribution: 33 *départements* do not have any places (Circulaire, 4 février 2004). The French government recently declared its intention to increase the number of places by the end of 2005 (8000 places) (Le Monde, 12.02.04).

4.1.1.2 Acute hospital and Tertiary care

There are about 1,058 public hospitals amounting to 320,000 beds. We have ignored the number and capacity of private hospitals and clinics.

There are geriatric public and private hospitals and clinics as well as geriatric units within public hospitals. There are specialised institutions, such as the public *Hôpital Braca* in Paris, which specialises in neurogeriatrics (in-patients, out-patients, scientific diagnostic of dementia, research, day-centre), or the Clinique verte in Versailles specialised in all-around-check-up for older people.

As public nursing homes depend on public hospitals, they are considered to be the training ground for geriatricians.

Geriatric day or night clinics exist, but this sector is under-developed, as is the whole day-care sector for the elderly. (We did not find statistics.)

4.1.1.3 Are there long-term health care facilities (including public and private clinics)?

See below, chapter 4.1.2.1.

4.1.1.4 Are there hospice / palliative / terminal care facilities?

Despite high engagement and efforts of many associations and public hospitals, palliative care in 2004 remains quite underdeveloped – at home, in hospitals, in homes for elderly, in nursing homes, in HAD, so that needs are not covered at all – again, for financial reasons: it requires specially trained multidisciplinary staff and lot of personnel[55] (Sebag-Lanoë, p 46). According to Sebag-Lanoë, palliative care provided for the very old has its specificities, which need to be taken into consideration (ibidem).

Madame Montchamp (*secrétaire d'État* for the disabled), suggested, in May 2004, launching a vast communication campaign on dying. She underlined the necessity for harmonisation of professional praxis, creating good practices, training health sector professionals, and developing palliative care.

In this domain, JALMALV is the oldest non-profit association (created in 1983) carrying out end-of life accompaniment, and bereavement counselling for family members (See chapter 7.2).

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

In general, institutions for the old are expected to take on all responsibilities and tasks, and these expectations meet demand. Former family carers in particular tend to be demanding and to moan about anything they consider is going wrong.[56]

As nursing homes belong to the hospital sector and are organised like hospitals, in general they do not practice integration of the family; however, this population includes a high percentage of patients who do not have children. The family's tasks are mainly limited to visits. The very negative image (sometimes a reality) of nursing homes leads to the situation that often families feel guilty so they use strategies of self-protection and keep away from visiting.

To what extent the family is involved in the work inside homes for the elderly is difficult to say; involvement in tasks such as laundry, personal care, nursing, and eating are *a priori* excluded because they are generally done by staff. If family members and friends – as well as volunteers – are integrated into the work, it is likely to be with the purpose of livening up the afternoons and weekends; they offer different activities battling against boredom.

The family can be involved in all tasks in sheltered housing – often as much as when the relative is living at home. Being defined as private households, help is provided from outside (home care services, family, neighbours, etc.).

The Cantou (see below, chapter 4.2.1) is an exception: the family forms the central pillar of the concept.

[55] 6 hours/day in average (Sebag-Lannoë, p 47).

[56] From qualitative interviews we learnt that e.g. family members criticise the way their mother is dressed, nothing fitting together; actually, the staff invites the cared-for person, especially if demented, to chose her clothes, disregarding if the result is lovely or ugly.

4.1.2 Social services

The municipalities' social service is generally where people go to or phone to get information, advice and relevant addresses. Local agencies of the National Pension Fund and the National Health Insurance as well as all *caisses complémentaires* and lot of hospitals also have their own social service.

The 'CLIC' (see chapter 2.2.2) is supposed to be / become the local public service for the old and family carers.

4.1.2.1 Residential care (long-term, respite)

In 2003, there were about 650,000 beds in:

- 6,500 traditional homes for old people – public, private non-profit and commercial -, of different sizes with an average number of places as follows (1996): 60 in private non-profit institutions, 75 in public homes, 86 in public homes depending on a public hospital, 48 in private commercial homes. Some of these homes have a nursing section called 'medical cure'[57] and some don't.
- 3,000 in sheltered housing (*logements-foyers)*; average number of places (1996): about 50.
- 1,100 nursing homes, generally depending on public hospitals; average number of places (1996): non-indicated, but they often have hundreds of beds (Anguis et al.).

Residents of sheltered housing (*logements-foyers)* tend or are supposed to be autonomous: *a priori*, dependent residents are not accepted in 90 % of these institutions, but in recent years they have adapted to be able to deal with dependent residents and have a nursing section, if not to admit new dependent residents at least to maintain those who become dependent in the institution.

40 % of public homes for old persons accept highly dependent persons, even if bedridden: 90 % have a nursing section. This percentage is less dominant in private non-profit homes due to financing problems; and it is low in commercial institutions. The latter often refuse entrance as well as *a fortiori* maintenance of persons suffering from dementia (ibidem).

The new minister of state for older people, Hubert Falco, recently declared in a public speech on elderly abuse that one third of the beds in traditional homes for the old 'are unworthy of our elderly'.[58]

[57] The section «medical cure» is a special unit inside a traditional home for old persons, granted by the national health insurance. Its objectives are: accommodation and medical support for residents in need of help and support in daily life. That is to say that these homes got the official agreement to employ nurses and nursing auxiliaries. Costs for accommodation are paid by the resident (or the *Aide sociale*). Costs for medical care are paid by the National health insurance *via* the "medical fixed daily rate/person" (*forfait soins*).

[58] AFPAP; http://www.afpap.org/maltraitancedomicile.htm.

In addition, the *Accueil familial*[59] accommodates about 20,000 people (2002) (FAMIDAC). This is a special form of family co-residence set up in France by law in 1989 (see chapter 7.2).

Since 1975, a special type of institution has been developed in France for older people suffering from dementia: the '*Cantou'*. Twelve people live together; each having their own room with individual bathroom and WC and they move in with their own furniture. Residents share daily life in a spacious room with a big table and the cooking area in the middle. Their main occupation is cooking together for lunch and dinner, or baking in the afternoon. A professional housekeeper – like any family carer – has the key position, supported by nurses, night carers, cleaners etc. Unlike homes for older people, in the *Cantou* the moral responsibility for the resident is not overtaken, but remains in the hands of the family: all important decisions are taken by the families in monthly meetings. Furthermore, family members are invited to spend as much time as possible within the group, participating in and generating all sorts of indoor and outdoor activities. A main advantage is that the family member (very often the former main carer) doesn't have to endure unbearable face-to-face confrontation with the demented mother, father, husband or wife.

Analogous experiences exist, but in general the family is less responsible and integrated, and the residents are not involved in cooking.

The number of 'small units' and their population are unknown.

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)

According to HID results 471,000 people aged ≥60 years (figures for ≥65 are not available) are in an institution for old people, psychiatric hospitals excluded. Following figures in % of the residents (Goillot, Mormiche, 2001):

7 %	private (non-profit and profit making) nursing homes
12 %	private (non-profit and profit making) homes for the elderly, including 10-50 % beds in 'medical cure' section
10 %	private non-profit making traditional homes for old people, without 'medical cure'
12 %	private profit making homes without 'medical cure'
16 %	public nursing homes
17 %	other public homes than nursing homes, including 10-50 % beds in 'medical cure' section

[59] Translation impossible; see definition

20 % other public homes than nursing homes, including > 50 % beds in 'medical cure' section

7 % other public homes than nursing homes without 'medical cure'

Not surprising: for demographic reasons, the population in the different institutions is mainly female with a clear predominance of widows: 62 %, plus 29 % single and divorced women. This population is very old due to the average age of entrance: at the end of 1999, 79 for men, and 84 for women. The social integration *extra muros* is quite passive: less than 4 % go out to meet their family at least once a week, less than 10 % once a month, and only 7 % go on holiday every year. 70 % report regular family contact and visits. They receive visits from friends, former neighbours and colleagues as well. Amongst those (30 %) who do not have any contact with their family, two in three declare that they do not have children or that all family members are dead (Mormiche).

Institutional short-term-care

Numerous institutions like sheltered housing and traditional homes for the old offer short-term-care if their institution has room, for some days, some weeks, some months. Some institutions specialise in short-term-care for older people.

It is considered to be a good solution because:

- it provides a release from care for the family carer;
- older people willing to live in the institution can try it out;
- it provides post-hospitalisation care for people living alone.

Nevertheless, many family carers do not take advantage of this facility because they have a negative attitude towards it; sometimes a negative reality and / or a negative experience leads to the conviction that their cared-for person will not be well during their stay, and they cannot cope with the egoistic idea of having 'a nice holiday' while their father or mother is suffering because of their absence. This is especially true for older couples.

Furthermore, there is enormous lack of short-term beds.

Holidays for the dependent old

Without any doubt, this is a better solution for both parties involved. Both carer and cared-for person separately have good time, the separation regenerates the relationship, they have new subjects to talk about, etc. Older couples who do not want to be separated can go on holiday together; the caring spouse takes advantage of leisure opportunities, knowing that their partner is well, too, and provided with adequate care and activities.

Unfortunately, there is little on offer. The association *Les petits frères des Pauvres* has experienced this, every summer for decades, in its own holiday homes all over France.

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

As far as we know, there is no criterion for admission other than age: ≥60 years.

There are some exceptions: e.g. homes owned by the *caisses complémentaire de retraite* give priority – if not exclusivity – to their members. (If the local authority co-financed the construction or the owns the land, in return, a number of rooms are set aside for older people from the locality.)

4.1.2.1.3 Public / private / NGO status

Due to French social policy, the public sector predominates with 55 % of institutional care; 28 % belong to the private non-profit sector, and 17 % are commercial institutions.

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

As nursing homes belong to the hospital sector and are organised like hospitals, in general they do not practice the integration of the family; however, their populations includes a high percentages of patients who do not have children. The family's tasks are mainly limited to visits and relationship-building. The very negative image (and, this is, in part, a reality) of nursing homes leads to the situation that often the family feels guilty and use strategies of self-protection with the result that they keep away from visits.

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

'A combination of several factors determines whether a dependent person can be maintained at home or not: health estate, kind of dependency, family environment, income, costs to adapt the flat / house.' (Simon, Fronteau)

Institutional measures aiming at the maintenance of old people at home include the provision of a multitude of services organised by a multitude of private and public organisations, based on different financial sources (public and private), using more or less trained professionals. Until recently, and in spite of several government and private efforts, co-ordination between the different services has been absent (Ankri).[60]

The French domiciliary services for older people include a wide variety of help and support such as:

- accompanying for walk, for medical visits, shopping etc.

[60] In numerous cases e.g. the home help service ignored that conjointly a nursing service helped a same person.

- adaptation of the flat / house
- administrative help
- day or night care at home
- delivery of drugs (especially in rural areas)
- taking them to eat in a centre
- granny-sitting
- HAD – hospitalisation at home
- home alarm service
- household-help (cleaning, cooking, shopping, washing, ironing, cleaning windows, etc.)
- keeping company (talking, reading aloud, etc.)
- meals-on-wheels
- mobile library
- night and day care at home or in an institution
- paramedical service (nursing, personal hygiene, physiotherapy, etc.)
- repair service (all 'little things' for which a craftsman would be too expensive)
- respite care
- shopping
- social nocturnal emergency services (e.g. buying drugs or food)
- technical help (hospital beds, crutches, etc.)
- transportation (special mini-busses from the local authority; informal transportation)
- tutelage
- etc.

Nursing and other paramedical community services are financed by the National health insurance; in the case of higher income the receiver can be asked for co-financing.

- Home help is financed from numerous private and public sources (mainly National pension fund, *Aide sociale*, and the *caisses complémentaires de retraite*[61]).
- Other services e.g. house alarm systems or meal-on-wheels are often financed by the regional government with varying degrees of participation by the recipient.

Anyone – including family carer, home-helper and nursing auxiliary – is allowed by law to administer prescribed medicines to the cared-for person (Circulaire DGS / PS3 / DAS 99320, 04.06.1999). This is a powerful measure to keep at home those people whose health depends on drugs taken regularly, but who are unable to do so on their own.

Generally, community services are concerned with old / er people and the adult handicapped, living alone or in a couple. The compulsory individual 'intervention plan' of APA takes into account the hours provided by the family carer, whose help and support are taken for granted: home-helper hours are more numerous if the cared-for person does not live together with the family carer. This is not a consideration in paramedical services.

Many services are provided free by volunteers, but many have to be paid for, sometimes they are income-related (home-helper), favouring the poorest so that especially those with an income near the income ceiling for (nearly) free assistance cannot afford the amount they have to pay themselves. E.g. for the home-helper client's cost sharing varies in order to the income between 1.62 and 11.96€ / hour. Well-off pensioners often prefer to employ a traditional cleaner which is less expensive.

A special public service exists to facilitate administrative tasks to individual employers of a cleaning lady, and to reduce black employment: the *chèque emploi service*[62] particularly helpful for older and disabled people. The salary can be paid with if the weekly work does not exceed eight hours. This service exists also on the Internet.

Like former years, the needs in 2004 for community care are not covered due to the lack of financing. The needed number of hours tends to be systematically underestimated in the individual 'intervention plan' elaborated individually for each APA receiver, to limit public expenditure.

[61] Private, compulsory old age and health insurances for employees. They have the legal obligation to use 1% of the contributions they receive for social actions to the benefit of their members (e.g. for domiciliary and residential care).

[62] These cheques are edited by any bank in collaboration with the national office for collection the social contributions. This free service exempts the employer from all administrative formalities (monthly declaration and payment to the abovementioned office, monthly pay slip, calculation of the social contributions).

4.1.2.2.1 Home-help

Home help is financed by numerous private and public sources (mainly National pension fund, *Aide sociale*, and the *caisses complémentaires de retraite*[63]).

Home-helpers remain the pillar of the system, although their social task (social integration of the user[64]) has lost its priority due to chronic cost-cutting. Their tasks are cleaning, cooking, 'light' support for personal care and going to the toilet, hairdressing, 'light' administrative support (excluding finances), laundry, ironing, shopping, etc.– all housework, spring-cleaning excluded. Often home-helper services are not run on Saturday, Sunday and bank holidays. Several associations employ volunteers who take on tasks that the home-helpers don't do or when the weekly number of hours is too limited (conversation, going out for a walk, reading aloud, administrative tasks, etc.).

Access to this for older people depends on their age and degree of need for home-help: firstly, they must be more than 65 years old (60 in the case of them being unfit to work, secondly, if, for health reasons, they are not able to do the different household tasks deemed necessary for living in a private household (extended to sheltered housing). Access to a home-helper is not a right, except when the cared-for person gets the dependency allowance (APA).

4.1.2.2.2 Personal care

Nursing and other paramedical services are various and spread over the whole territory.

They are financed by the National health insurance, the *Aide sociale* and the *caisses complémentaires*; financially disadvantaged users are exempt from personal co-financing.

Access to this service is a legal right; it has to be prescribed by a doctor.

Nursing – including personal care – is provided by services (associations and municipalities) or by nurses working in their own practice for out-patients; they are widely involved in home services (all age groups). They engage in – but only on prescription by a doctor – administering injections, bandaging, taking blood, urinary and faecal samples, giving vaccinations, etc. Nurses cannot prescribe anything themselves. Nursing services tend to send an auxiliary nurse for minor tasks (personal care etc.); private nurses do it themselves.

[63] Private, compulsory old age and health insurances for employees. They have the legal obligation to use 1% of the contributions they receive for social actions to the benefit of their members (e.g. for domiciliary and residential care).

[64] Initially the home-helper, as far as possible, had to do the work together with the user, taking over only tasks the user could not do on his own, including shopping. The high costs of time of this procedure are incompatible with cost cutting so that the number of hours/user/week of a home-helper has decreased.

4.1.2.2.3 Meals service

Meals-on-wheels is less developed in France than in other countries because it is generally associated with leading to or reinforcing social isolation; on the contrary, preparing food together with the home-helper, combined with chatting, generates good relationships. Furthermore, many dependent old people are keen on cooking and are able to do it, but unable to go out to buy food, so the shopping is done by the home-helper or any other person. Supermarkets and many grocers, caterers and delicatessens offer (free or payable) delivery service.

On the contrary, the concept and reality of a 'dinner service' is quite developed, where older people are invited to go out and meet other people. Many institutions such as homes for the elderly and sheltered housing open their restaurants to older people living at home; others are organised as an independent dining clubs by the municipality or an association. After lunch, indoor leisure activities are often offered to extend the period in which the older person is with others over the afternoon.

Many take-away restaurants in cities provide food delivery at home, such as Asian food; established in urban areas with a high percentage of Asian people, who thus benefit from a kind of meals-on-wheels with food they are used to and meals of their own choice. The same service is provided by other little restaurants (pizzeria etc.).

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

This issue has not been treated.

4.1.2.2.5 Community care centres

Big cities generally have community care centres. The CLIC are expected to take over their functions, but their development is slow due to limited public financing.

4.1.2.2.6 Day care ('protective' care)

We know that there are day-care centres in France, we know that they are insufficiently developed, but our search on this topic (on the Internet) has been fruitless.

4.1.2.3 Other social care services

This issue has not been treated.

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

This chapter has not been dealt with *inter alia* because our search on the Internet on this issue has not been successful.

It seems that quality control – except control of security (e.g. fire) and hygiene in institutions – is more the subject of individual initiatives than of legal framework. We did not find either any official definition of 'quality' in any sector.

The text of the reform of price setting (homes for the old) includes a 'quality engagement' (we did not find precision).

There is no control of family care.

4.2.1 Who manages and supervises home care services?

The regional authority (*Conseil Général*) is responsible for the management and supervision of all services provided in the framework of the APA programme.

More generally, quality control and supervision are reliant on ambition or idealism and ethic rules, on the engagement and professional education of the director and the members of the board. Special computer programmes have been developed for quality control (also for residential care), but there is no information available as to how far they are used.

Associations draw up, together with the staff, individual quality plans, based on their own definitions, aims and expectations; the plans are under their own control.

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?

Outside the APA programme there seems to be no legal basis for quality control. Nevertheless, home services working in the framework of APA also have non-APA clients, and it is unlikely that control staff neglects quality gaps in the Non-APA area.

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

4.2.3.1 Home-helper

In 1999, there were about 194,000 home-helpers (more than 90 % are women, average age 43) generally with a low professional level:

- 48 % don't have any diploma or any training
- 18 % have a professional qualification
- 9 % have the CAFAD[65]
- 23 % have received some training to enable them to do their work.

The new diploma DEAVS, replacing the CAFAD, is not specialised in elder-care. It requires 500 hours of theoretical training courses and 560 hours of experience practical work during three separated periods.

As on the one hand, even unskilled home-helpers quite easily find a working place, and on the other, having the qualification generally does not affect salary, this professional training does not elicit great enthusiasm amongst those who want to work in this area. Nevertheless, several associations demand the certification.

4.2.4 Is training compulsory?

Not for home-helper, yes (of course) for nurses, other paramedical professions, and social workers.

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

There is a shortage of nurses in France, especially in hospitals. As far as we know, there is no shortage in the other sectors (except of qualified home-helpers, but many services easily recruit unskilled home-helpers).

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

Case management is compulsory in the APA framework. Providing help is based on a tailored intervention plan setting up the type and frequency of help, in principle according to the person's need for help. The CLIC aim at case management beyond APA.

[65] CAFAD, *certification of ability to the home-help functions*. It has been created in 1988 and modified in 1993, and replaced since 2002 with the DEAVS: diploma "social auxiliary".

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

This issue has not been treated.

5 The Cost – Benefits of Caring

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

This issue has not been treated.

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

This issue has not been treated.

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

This issue has not been treated.

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

This issue has not been treated.

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

This issue has not been treated.

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 / and social contributions?

Care for the old is funded through taxation and social contributions. It falls under the state's budget[66] and of that of the local authorities[67].

5.7 Funding of family carers

Payment of family carers is limited to the APA programme, which relies on the *Aide sociale* and, thus, is financed by the local authority (*Conseil general*). Family carers have to bear a lot of costs in relation to care-giving if the cared-for person cannot cover the costs.

[66] E.g. *Aide sociale* under the responsibility of the *Conseils généraux.*
[67] E.g. National pension fund, National health insurance.

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

	Attendance allowance APA	Carers´ allowance	Care leave
Restrictions	spouses excluded		
Who is paid?	number of hours according to the intervention plan hourly rate of pay determined on national level		
Taxable	employees paid with APA money have to pay income tax		
Who pays?	*Aide sociale départementale*		
Pension credits	?		
Levels of payment / month	457.26 € (GIR4) to 1,066.94 €(GIR1)		
Number of recipients at 31.12.01	650,000		

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

Not as far as we know, but we did not search for the answer.

5.7.3 Are there tax benefits and allowances for family carers?

Not especially for family carers, but there are tax benefits in the case of payment for parents living in an institution.

5.7.4 Does inheritance or transfers of property play a role in care-giving situation? If yes, how?

Probably. There is a significant lack of research on this issue.

5.7.5 Carers' or users' contribution to elderly care costs

The issue on costs has not been treated.

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
General practitioner	depends on income[68]	depends on the agreement of the GP	no			
Specialist doctor	idem	idem	possible[69]			
Psychologist	rarely	idem	idem			
Acute Hospital	generally[70]					
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)[71]						
Day hospital	depends on income	depends on income and the insurance				
Home care for terminal patients	idem	depends on income and the insurance				

[68] Beneficiaries of the "CMU" (universal health coverage) do not pay anything. Older people, whose income is under the income ceiling, don't either.
Generally, there are at least two health insurances, which reimburse (idem treatments, drugs, etc.): the National Health insurance and the *caisse complémentaire*. Reimbursements of the latter depend on the contract the employer signed with "his" complementary health insurance, and consequently on the social contributions employer and employees paid/pay.

[69] If the specialist does not have the official agreement of the National Health insurance. Usually visits to and treatment of specialists (as well as GPs) require quite low personal financial contribution and are free for patients under an income ceiling.

[70] If in public hospitals or clinics with the official agreement from the National health insurance: National and complementary health insurances share the costs. Free for CMU beneficiaries.

[71] Costs, funding, paying authority or person are an extremely complex context, which would need pages to be explained.

Rehabilitation at home	idem	de-pends on in-come and the insur-ance				
Nursing care at home (Day / Night)						
Laboratory tests or other diagnostic tests at home						
Telemedicine for monitoring						
Other, specify						

b. Social-care services	**General access:**			**Access based on:**		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Permanent admission into residential care / old people's home						
Temporary admission into residential care / old people's home in order to relieve the family carer						
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)						
Laundry service						
Special transport services						
Hairdresser at home						
Meals at home						
Chiropodist / Podologist						
Telerescue / Tele-alarm (connection with the cen-tral first-aid station)						
Care aids						
Home modifications						
Company for the elderly						
Social worker						
Day care (public or private) in community centre or old people's home						
Night care (public or private) at home or old peo-ple's home						
Private cohabitant assistant ("paid carer")						
Daily private home care for hygiene and personal care						
Social home care for help and cleaning services / "Home help"						
Social home care for hygiene and personal care						
Telephone service offered by associations for the elderly (friend-phone, etc.)						
Counselling and advice services for the elderly						
Social recreational centre						
Other, specify						

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

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?

Without any doubt political and public debate in the area of socio-gerontology is focused on the problems of finance (drastic reduction of public expenditure, budget cutting, budget and cost shifting). As decreasing public financing of the community and residential care sector inexorably leads to increasing involvement of informal care-giving, family carers are directly involved with the debate but it is scarcely directly brought up. The main reason seems to be that there is no powerful pressure group of informal carers in France. Not surprising, there is an increasing number of voices in the parties belonging or near to the government, to abolish the article of APA law that does not allow the *Aide sociale* to reclaim money from the beneficiaries' relatives.

No doubt, the heat wave of August 2003 and its consequences on the mortality of old people, together with the government's failures – today publicly recognised – are driving the government to put socio-gerontological issues on their agenda once again.

Maltreatment of the elderly and the different kinds of abuse in institutions and at home, carried out by informal and professional carers is progressively coming into the debate. In particular, TV documentaries and discussions on incest committed by fathers, mothers and other relatives are also responsible for bringing out into the open abuse in other areas, but the taboo is apparently much more in existence when older people are the victims and when the abuser is a relative.

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?

There should indeed be some change, but at the current stage of the debates on the reform of the National Health insurance, on the steady downward revision of public expenditure, and on the government's search for financial sources, any kind of projection seems to be impossible to make and more might be revealed by consulting a crystal ball than anything else more grounded in reality.

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

Is there any pressure group working on behalf of informal carers? The young French carers' association, *Aidants*, is not yet powerful enough (if it ever does aim to become a pressure group). *France Alzheimer*, which champions the cause of family carers, contacts ministries, policy makers etc. but we have no knowledge about the impact it has.

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

This issue has not been treated.

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

Knowledge gaps on eldercare provided by the family are enormous. As family carers are expected to continue assiduously their devotion to their frail old spouses, parents and other relatives during future decades, the need for qualitative and quantitative surveys on all aspects and issues of family care is huge.

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

New technologies, such as mobile phones and the Internet, are increasingly used by the 50+ age group. Additionally, there are a lot of websites on socio-gerontological issues, including information and advice for family carers. But there is no information on carers using mobile phones or computers.

New technologies have had at least an indirect impact on family carers through the use of high-tech equipment in the field of home-alarm systems.

6.7 Comments and recommendations from the authors

There is an enormous lack of data in the area of **Socio-gerontological research** – including publication – on informal, and especially family carers. Better knowledge is needed on the following issues, which should systematically take into account gender-related specificities:

- socio-demographic data
- motivation of spouses and descendants to care, not to care and to stop caring

- duration of family care-giving, carer 'careers' (caring simultaneously and / or successively for several persons)
- number of cared-for persons / carer
- male carers (spouses and descendants): gender-related specificities of male carers e.g. carer activities and tasks, self-perception, acceptance from the social environment, special problems generated by the care situation, specific needs
- carers in employment
- needs for help and support
- acceptance and refusal of help and support
- typology of family carers (according to Ross & Eynard)
- relationship between the carer and the cared-for person, its improvement / stagnation / deterioration through the caring situation
- relationship between the carer and the other family members (spouse, children, siblings): improvement / stagnation / deterioration through the caring situation
- advantages, enrichment (non financial), positive aspects of caring
- strategies to cope with the burden
- abuse and mistreatment emanating from informal and formal carers
- care situation and care relationship amongst the emigrant population

Political measures: there is need for:

- the creation of a real 'care for carers' policy with ongoing financing
- the creation of a dependency insurance as the 5th pillar of the social protection, disregarding age and including the disabled; this insurance should allow the family carer to be paid and exclude the clause on recovery of the paid compensations by the *Aide Social*
- in general: not to shift public financial problems over to family carers; in particular: maintain the exemption from reimbursement of funds received thanks to APA (*Aide sociale*)
- the development of day centres of good quality, especially for active dementia sufferers
- the development of the CLIC with the guarantee of ongoing financing, and including specific services for informal carers such as training, advice and support groups directed by specialists
- the development of measures that prevent carers from mistreating the cared-for person

- promoting and creating greater public awareness of abuse in family care, its causes and the moral burden it generates for the carer
- promoting the need for holidays for dependent old people, for carers and their cared-for relative together, including separate leisure activities for the dependent and the able-bodied as well as care for the first group – this recommendation also concerns NGOs and *caisses de retraite complémentaire*
- promoting specific measures for persons who combine working and caring
- the development of compulsory quality evaluation including continual vigilance
- the development of more systematical diagnosis of dementia and campaign amongst GPs to encourage patients who lose their memory
- promoting the creation and development of a Carer's Charter

7 Appendix to the National Background Report for France

7.1 Socio-demographic data

7.1.1 Profile of the elderly population-past trends and future projections

9.8 million are aged 65 and more, representing 16 % of the metropolitan population (ibidem). The age group ≥85 counts 1.4 million (2.4 % of the total population). The most important increase has happened amongst the centenarians: 11.6 thousand (Census 1999).

7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

The life expectancy at birth (2003) for men is 75.9 years, 82.9 for women (ibidem). During the last decade, it has increased especially for men: +2.4 years for men, 1.5 years for women[72]; thus, the gender difference has decreased from 8.2 to 7.3 years between 1992 and 2002. The number of older married couples consequently is slightly increasing (Pison, 2003).

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

9.8 million are aged 65 years and more, representing 16 % of the metropolitan population (Pison, 2004). The age group ≥85 consists of 1.4 million (2.4 % of the total population). The most important increase has happened amongst the centenarians: 11.6 thousand (Census 1999).

[72] Nevertheless, life expectancy at birth stagnated in 2003: especially due to the exceptional heat in August, the mortality has drastically increased (+4% compared to 2002; about 15,000 more deaths in August 2003) (Pison, 2004).

Table 4: Total population ≥65 years, 1999 (Census) by age

Age	Men	Women	Total
65 - 69	1,272,868	1,484,985	2,757,853
70 - 74	1,085,926	1,403,212	2,489,138
75 - 79	876,122	1,290,561	2,166,683
80 - 84	333,659	581,025	914,684
85 - 89	285,186	636,632	921,818
90 - 94	96,168	294,221	390,389
95 - 99	19,289	80,455	99,744
≥100	1,476	10,117	11,593
Total	28,419,419	30,101,269	58,520,688

Source: Recensement de la population 1999 - Exploitation principale - Copyright INSEE, POP1 http://www.recensement.insee.fr/FR/ST_ANA/F2/POPTABPOP1APOP1A1F2FR.html

7.1.1.3 Marital status of >65 year-olds (by gender and age group)

Table 5: Population at different ages by gender and marital status (in %)

in % within each age group	Men				Women			
	single	married	divorced	widowed	single	married	divorced	widowed
<55	61,54	33,99	4,17	0,29	56,11	37,22	5,44	1,22
≥55	8,32	77,77	4,72	9,18	7,37	50,49	5,51	36,63
≥60		76,90		10,99		45,94		41,77
≥65+	7,88	75,18	3,28	13,64	7,74	39,64	4,19	48,42
≥70		72,23		17,61		31,73		56,58
≥75	6,83	66,91	2,31	23,94	8,02	22,19	3,33	66,44

Source: Les familles monoparentales, Portrait social, collection Contours et caractères, Insee, septembre 1994; Les Femmes – Portrait social, collection Contours et caractères, INSEE, février 1995

7.1.1.4 Living alone and co-residence of ≥65 year-olds by gender and 5-year age groups

See chapter 1.8, table 3.

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

This issue has not been treated.

7.1.1.6 Disability rates amongst >65 year-olds. Estimates of dependency and needs for care

The notion of 'need for care covers very different levels of needs. Therefore needs are not easy to define, and the old population in need of help is consequently difficult to identify (Collin et al.). Estimations are based on the HID survey[73], conducted by INSEE[74] on the one hand within the population living in an 'ordinary household'[75] (1999), and on the other within the population in institutions (1998). Both surveys include all age groups (0-9 years to ≥90). The individuals or their carer have been interviewed so that the answers do not correspond to an objective medical acknowledgement (Goillot, Mormiche, 2001, 2002, 2003).

The HID survey value the total number of persons aged ≥60 years and in need for help at 800,000, representing 7 % of the population ≥60 years.

524,000 (66 %[76]) among them are living in a private household who split into the following groups:

- 292,000 (56 %[77]) are heavily dependent:
  - 22,000 (4 %) have suffered a loss of mental, physical, locomotive, and social autonomy;
  - 133,000 (26 %) are bedridden without mental disorder; dementia without physical disorder;
  - 137,000 (26 %) have no dementia but have suffered loss of part of their physical autonomy.
- 232,000 (44 %) are less heavily dependent: unable to get up alone, but able to move inside the house, to have all kinds of indoor activities and generally to eat without help; or: full locomotive autonomy, but needing assistance for physical activities as personal hygiene and eating.

All are seriously in need of many and various assistance, household-help as well as nursing.

The HID study states that all 524 thousand individuals are cared-for by somebody: a member of their family, a friend or neighbour, or a professional.

346,000 (66 %[78]), although are less dependent thanks to their relatively good physical autonomy, need regular home help (cooking, housecleaning, etc.) as well as assistance with personal hygiene (bath / shower, etc.).

[73] HID: Handicaps–Incapacités–Dépendance (Handicaps–Incapacities–Dependency).
[74] INSEE: National Office for Statistics and Economy.
[75] Including sheltered housing (*logements-foyers*).
[76] 800,000 = 100% (population ≥60 years).
[77] 524,000 = 100% (total dependency).
[78] 800,000 = 100% (population ≥60 years).

Table 6: Number of dependents people aged ≥60 years based on "AGGIR scale"[79] (in 1000)

Level of dependency	In a private household[80]	In an institution for older people	In other institutions[81]	Total
Group 1	22	46	1	69
Group 2	133	125	4	262
Group 3	137	62	2	201
Total 1-3: heavy dependency	**292**	**233**	**7**	**532**
Group 4	232	31	1	264
Total dependency (1-4)	**524**	**264**	**8**	**796**
Group 5	346	43	1	390
Group 6	10,692	156	7	10,855
Unknown level	24	17	4	43
Total population ≥60 years	111,586	480	18	12,084

Source: Collin et al., table T03

The type and the amount of help evidently change with the age of the cared-for person: 15 % amongst the ≥60 years old, 85 % amongst the nonagenarians (Goillot, Mormiche, 2002, p 246).

[79] AGGIR (*Autonomie Gérontologique – Groupes Iso-Ressources*) is the official French instrument to measure the degree of autonomy (law 24.01.1997). It has been developed for the dependency benefits.
AGGIR includes 10 criteria: coherence, orientation (time and space), personal hygiene, dressing, eating, urinary and faecal elimination, transfer (to get up, to situation down etc.) moving indoor, moving outdoor, communication (to use a telephone, an alarm system, etc.). Following their answers, the individuals are put together in 6 complex "iso-ressource groups".
Group 1: Loss of mental, physic, locomotive, and social autonomy
Group 2: Bedridden persons without mental disorder, and dement persons without physical disorder
Group 3: No mental loss, but loss of part of their physical autonomy
Group 4: Persons unable to get up alone but able to indoor moving and activities as well as eating (need for help: WC, personal hygiene and dressing); persons without locomotive problems but needing help for physical activities as personal hygiene as well as eating
Group 5: Physical autonomy inside the home, but need for regular assistance and overseeing several times/week, and help for personal hygiene, cooking and housecleaning (typical tasks for the home-helper)
Group 6: Autonomy in daily life
Group 5 and 6 take into consideration in how far the person depends on help to be safe at home:
C: Confined at home
B: Need for sporadic overseeing and for occasional help
A: Without major, permanent problems to be safe (can go for shopping and call for help)

[80] Including sheltered housing (*logements-foyers*).

[81] Homes for adult handicapped people, psychiatric institutions.

Dress[82] elaborated projections for the older dependent population in need of help, and their potential carers until 2040. The part devoted to the elderly concerns dependent people aged 60 and over. It is based on the HID survey (1998 / 99), takes into account the increasing better health of older people[83], and includes three hypotheses: optimistic, central and pessimistic. 'The ageing of the French population will probably lead to an increase in the number of dependent people aged 60+. Two sharp increases will probably appear around 2010 and 2030: the increase between 2000 and 2020 is estimated at 16 % (optimistic hypothesis), 25 % (central) and 32 % (pessimistic); during the following decade, the proportions might be slightly higher. From 2000 to 2040, the increase might be, in total, between 35 % (optimistic) and 80 % (pessimistic). The increase will mainly concern the 80+ age group.' (Bontout et al., p 1) The second part is based on demographic projections from the National Office for Statistics (INSEE). 'It is close family, friends and neighbours who mainly provide eldercare. However, the age group 50 to 79, which is the main source of carers, will probably increase by about 10 % between 2000 and 2040 (…), an increment clearly less important than that of the old dependent population. This demographic development might be amplified by an increased female participation in the labour market. Other, individual factors might also intervene leading to an increase or decrease of the potential carers.' (ibidem)

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

This issue has not been treated.

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

The 1999 Census counted 3.2 million foreigners living in France, 7.4 % of the whole population. This percentage has been stable since 1974, although this area is quite active due to the acquisition of French citizenship. The foreign population is mainly concentrated in large cities, reaching 15 % in the region Île-de-France (Paris and surrounding suburbs). Traditionally, emigration to France has been a male phenomenon, but since the late nineties, there have been as many women as men. Due to France's history, there is a clear predomination of natives from the Maghreb (1.3 million, representing 41 %), and more precisely from Algeria and Morocco. Immigrants from the rest of the world represent a steadily increasing number: 15 % in 1982, 25 % in 1999, amongst the latter 16 % from Turkey, 32 % from other Asian countries, and 37 % from sub-Saharan Africa. 60 % of the Immigrants live in three regions:

[82] DRESS: Direction de la Recherche, des Études de l'Évaluation et des Statistiques, Ministry for Employment and Solidarity.

[83] Physical and intellectual disorders are taken into account. The authors underline the difficulty to calculate the number of people suffering in the future from dementia, because of the lack of knowledge and diagnosis up to now.

Île-de-France, Rhone-Alpes, Provence-Côte-d'Azur (Marseille) (Boëldieu et al.).

There is a clear increase of older immigrants who arrived during the sixties and the seventies, mainly Algerians and Moroccans who settled in France and have grown old (ibidem).

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

The data we found on housing are not broken down by age.[84]

- 56 % are owners; this percentage is higher amongst older people.
- 38 % rent their flat / house, about half of them in the social housing sector (lower rent).
- 2 % are sub-tenants.
- 4 % have free accommodation (Lincot et al., p 13).

Additional comments: 57 % are individual houses, 43 % flats (ibidem, p 12).

7.1.1.10 Housing standards / conditions if available by age group e.g. % without indoor plumbing, electricity, TV, telephone, lift (if above ground floor), etc.

The data we found on housing are not broken down by age.[85]

All flats and houses are equipped with electricity, nearly all with running (cold) water (99.9 %).

67 % are equipped with electricity, water, bathrooms and central heating. This percentage is lower in small farms (Lincot et al., p 12).

TV

About 95 % of the age group ≥60 years watch TV every day; this percentages indicates the minimum TV equipment rate (Dumartin et al., p 26).

Phone

Due to the government policy, from the late seventies onwards, to rapidly install the telephone in all older households, more than 90 % of the over 60s now have the telephone and have had it for the last twenty years. The percentage is much lower for mobiles.

We did not find data on the installation of lifts.

Additional comment: older people do not want to move house: only 6 % of the ≥70 years old since 1984 had actually moved (by comparison with other age groups: 60-69 years 13 % – <30 years 44 % – average 23 %) (ibidem, p 21).

[84] But they are available at INSEE.
[85] But they are available at INSEE.

7.2 Examples of good or innovative practices in support services

Association française des aidants de personnes malades, dépendantes ou handicapées – AIDANTS

The association AIDANTS[86] was recently created: December 2003.

It is based on values such as mutual aid and independency in relation to any pressure group.

Its objectives are: information; support and advice; access to services; recognition –, by public authorities, professional carers, and public opinion – of the role informal carers play, their importance, and the work they do. It aims to become a platform of information and expression for informal carers.

Activities: AIDANTS have been publishing a fortnightly Newsletter on the Internet since December 2003 (short informative articles on anything concerned with informal carer-givers and the persons they care for (sick, handicapped and other dependent people of any age). The association also offers phone contact e.g. to inform carers on how and where to get help and support in their locality.

Contact:

Association AIDANTS – 27, rue des Boulangers – 75005 Paris

Phone: +33 (0)1.43.26.57.88 – Fax:. +33 (0)143.26.04.16 – E-mail: information@aidant.org

Editor in chief: Caroline Lamorthe – e-mail: caroline.lamorthe@wanadoo.fr

Website: www.aidants.org

CLIC

CLIC[87] is a local agency for information, advice, and orientation of the old population and their carers. Each agency is provided with a consistent data bank. Due to the law, the agencies are expected to fulfil the following tasks: calculate individual estimates of needs, establishing an individual 'help plan' together with the client, co-ordination of the different services identified in the 'help plan', development of inter-service collaboration, training of professional staff, and systematic follow-up of each individual situation. Other important tasks are the provision of advice and support for informal carers, as well as the organisation of support groups for them. The agencies are mainly public funded (about 95 %).

In May 2004, the territory has not been covered: according to data from the social ministry, at that time, only 413 agencies had been put into service; in six

[86] Care-givers.
[87] *Centre local d'information et de coordination gérontologique* (Local centre for gerontological information and coordination).

départments there is still none. (Ministère des Affaires sociales, May 2004) The omni-present cost cutting considerably slows down the development of the CLIC. Only cities with a well-established socio-gerontological policy and an attitude of real concern for older people's situation have created CLICs and provided them with adequate financing.

Fondation Médéric Alzheimer

The foundation was created in 1999 by Médéric, the oldest *caisse de retraite complémentaire.* At its creation it was endowed with 76.225 million €, and has a yearly budget of about 2.3 million €, leading to an active role dealing with dementia in old age and carers. The foundation co-operates with associations and political authorities developing initiatives and programmes to support family carers. It identifies needs, encourages innovating initiatives and provides information on good practice. It distributes information concerned with dementia in old age collected by different specialists and organisations (paper version and Internet), to professionals, individuals, press.

Thanks to its publications and press reviews it sensitises a large public.

Workshops are organised with specialists to discuss and gather information on special subjects (e.g. support groups for carers).

The foundation finances social research, as well as local initiatives. On 01.09.2003, ninety-two projects have been supported. These projects are selected through a call to tender. Their support is not only financial, but also helps the team during the development period.

Contact:

Fondation Médéric Alzheimer – 30, rue de Prony – F75017 Paris

Phone: international +33 (0)1 56 79 17 91 – Fax: international +33 (0)1 56 79 17 90

E-mail: fondation@med-alz.org

Website: http://www.fondation-mederic-alzheimer.org

Cantou[88]

Cantou is a special housing and care concept for older people suffering from dementia. It was created in the early seventies by the director of a traditional home for elderly, confronted by an increasing number of residents suffering a loss of their intellectual capacities. He did not want them to move into nursing homes (because of possible inadequate social care, at least at that period), and so he found the *Cantou*. He first changed only one floor, but over the

[88] ***C**entre d'**A**ctivités **N**aturelles **T**irées d'**O**ccupations **U**tiles* (Centre of natural activities linked to utiles occupations). This complicated name is based on the fact that *Cantou* in the langue d'Oc (group of southern French medieval dialects) is the huge central fireplace in the farm where people come get together. The creator of the *Cantou* is originally from this region.

years, based on the success of the concept – for the residents, their family, and this kind of patient in general – the whole structure of all seven floors has been changed. The model is in continuous development to improve daily life and working conditions, to adapt to new needs, to take into account the wishes of the family and the results of regular quality evaluation.

Twelve people live together; each of them has their own room with bathroom and WC; they move in with their personal furniture and decoration. The residents share their daily life in a spacious room with a big table and the kitchen in the middle. Their main occupation is cooking together for lunch and dinner. A professional housekeeper has the key position, supported by nurses, night carers, cleaners etc.

Unlike traditional homes for older people, the *Cantou* does not undertake the moral responsibility for the resident, which remains in the hands of the family. The family has the key position on the decision level: all important decisions are taken by the families in monthly meetings. According to the director's definition, the *Cantou* is release care for the family and excludes the family's resignation.

The family is integrated in the social life, too: family members are invited (constraint in the initial concept) to spent as much time as possible within the group, participating in and offering any kind of indoor and outdoor activities. A main advantage is that the family member (very often the former main carer) doesn't have to endure the unbearable face-to-face confrontation with the demented mother, father, husband or wife. This does not exclude the family member withdrawing together with their relative into his / her room or that they go out alone for a walk. Lot of family members are integrated to such a degree that after the death of their relative they carry on with their habit of spending time in the *Cantou*.

In the case of acute illness, the resident can be hospitalised, but the director (still the same) is very strict about getting them 'home' as soon as possible. Residents die in the *Cantou*: the staff are trained for this, and the family is invited to assist them (and *vice-versa*); if wanted, they can stay overnight, as long as they want, until death occurs.

Staff and family members are followed-up by a psychologist who has been directly involved in the concept and development of the *Cantou.*

Analogous experiences exist, but in general, the family is less responsible and less integrated, and the residents not involved in the preparation of the food and cooking.

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Jalmalv[89]

This movement is devoted to accompanying dying persons, based on the experience gained from Anglo-Saxon countries. It was created in 1983 in Grenoble; in 2004, it comprises 61 local associations, all federated at regional and national level. It is a founder member and administrator of the European association EAPC and the French SFAP[90] (1988 / 89).

Since 1985, Jalmalv has published its quarterly Revue Jalmalv with information and reflection concerned with accompanying and palliative care.

The objectives are:

- accompanying dying persons of any age, wherever they are (at home, in a hospital or any other institution)
- contribution to the changing of mentality and attitudes
- support of formal and informal carers by volunteers
- support for bereavement
- promotion of the development of palliative care
- promotion of research on the physical, psychological, social, and spiritual needs of older people at the end of life

To reach the objectives, four basic activities are carried out:

- consciousness raising (conferences, public debates, information meetings, dissemination of brochures, books, revues, etc.), press conferences
- accompaniment and support
- training
- research

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[89] **J**usqu'**à l**a **m**ort **a**ccompagner **l**a **v**ie Accompanying life until death.
[90] Société française d'accompagnement et de soins palliatifs.

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Accueil familial

Accueil familial is private accommodation and care, regulated by law (1989) to legally control this traditional form, to prevent abuse and protect the cared-for persons. A family, or a person living alone, offers paid accommodation and care to one or a maximum of three people, aged 60 or more or a mentally or physically disabled adult aged >18 years. Temporary accommodation and care is authorised, offering thus places to dependent older people while their family carer goes on holiday, is ill, etc.

Accueil familial requires the agreement from the local authority (*Conseil général*), delivered under the following conditions:

- signature of an official contract between the hosting and the hosted person (form edited by the local authority); the contract has to be confirmed yearly
- offer of a single room inside the house of the host, minimum 9 m^2 (16 m^2 for a couple) and individual or familial toilets and bathroom
- guarantee of housing comfort and hygiene
- guarantee of security and safety of the hosted person and her goods, as well as of her well-being
- acceptance of regular social and socio-medical follow-up and regular control

The host must get a monthly payslip, pay the same social contributions as any employee, and is legally entitled to holiday. The income has to be declared to the fiscal administration. The remuneration is determined by the local authority. Example of one *département*: basic gross salary: 564 to 715 € / month, plus an indemnity of 265 to 442 € / month for caring (according to the degree of dependency), plus a rent 150 to 180 € / month (Conseil Général Saône-et-Loire).

A priori the hosted person cannot be a family member, but due to the national dependency insurance (APA) this has changed: the hosted person can benefit from APA, and can chose the carer he / she wants to remunerate for caring (spouse excluded), and that can be done under an *Accueil familial* contract Family carers rarely think about this possibility, generally they do not know that it exists, and the steps are complicated for them. The advantage for the family carer is the guarantee of being paid and being legally entitled to holidays; the advantage for the cared-for relative is the guarantee of quality control. There might be a snag: the initial law excludes the host from inheritance; we ignore if that has been changed when the hosting person is a relative.

Accueil familial has been particularly developed in villages, too small to build up a home for their old but wanting to maintain them within the village. – The mayor of a small village with 400 inhabitants created a special form: he built up two adjoining, identical houses connecting on the ground floor. Each house is divided in two parts: a flat on the first floor for the hosting family; three rooms, one bathroom, a kitchen, a living dining room on the ground floor for the hosted persons. The two hosting families are supposed to complement each other (e.g. watch-over when one of them is out).

There are two national federations[91] of the *Accueil familial* (Anguis et al.; FAMIDAC).

Several local authorities are opposed to *Accueil familial* and tend to impede it: they invest in traditional homes for the old or subsidise them and want them to be fulfilled.

[91] FNAF – Fédération Nationale de l'Accueil Familial. FAMIDAC – Familles d'accueil et leurs partenaires.

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