

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

EUROFAMCARE

**National Background Report
for Spain**

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Objective

As a participant in the EUROFAMCARE project and responsible for the national report in Spain, my intention is to offer a comprehensive view of the situation of family carers of the dependent elderly in Spain, following the model established by the project itself.

Method for seeking and selecting documentation

There has not been much research into social services in Spain and even less so into carers and care.

The following strategy was used to seek information on the Internet: (1) Institutional information from the central government (Ministry of Employment and Social Affairs, and the Imserso independent body) and autonomous governments (Departments of Social Welfare of the Autonomous Communities) through their respective websites. All pertinent documents were recovered and analysed; (2) Statistical data of the National Institute of Statistics and the Basque Statistics Institute (the institute that is qualified to gather statistics in the Autonomous Community of the Basque Country); (3) Search for relevant social information produced by the two main research centres working with the Imserso: Centre for Sociological Investigation (CIS) and the Higher Centre for Scientific Investigation (CSIC). Both represent the highest level of social research in Spain; (4) Search for relevant social information produced by the La Caixa Foundation (a private body deeply involved in investigating the area of the dependent elderly in Spain); (5) Search for scientific literature through Medline, using the following key words: a) Caregivers and Spain; b) Caregivers (language restriction = Spanish). A total of 69 articles were identified, of which only 43 were pertinent to the study. They were all collected and analysed (6) Additional search on the Internet using the Google and ISI-WOK (<http://isiknowledge.com>), search engines with the following key words: a) cuidado ancianos, b) familiares ancianos, c) extranjeros cuidadores, d) servicios sociales, e) ancianos dependientes, f) ancianos terminales, g) familiares alzheimer, f) estadísticas encuesta salud.

A hierarchy of the identified information was established as follows: first place was given to national information above autonomic, regional or local. Greater weight was given to institutional information in reports from the public administration. Then priority was given to national reports from public research institutes (CIS and CSIC) and private research institutes (La Caixa Foundation). In third place, information was used from specific studies. Finally, we resorted to journalistic information and opinions.

Summary of Main Findings

- In Spain there are carer organisations defined by the deficiency or incapacity of the person cared for and not by their age, and the one that covers most elderly people is the association of relatives of Alzheimer sufferers.
- Relatives of Alzheimer sufferers are gathered in more and more widely spread provincial associations, which are federated across the country. These are self-help associations subsidised publicly, which give their members services of information, training, psychological support, relief programmes, etc (www.afal.es; www.alzheimerzamora.com; www.alzheimersalamanca.com; etc...).
- On the other hand, most elderly people belong to associations for pensioners or those who have been widowed. These associations are also subsidised publicly or by non-profit making entities, and are intended to encourage the elderly to lead an active life and to offer them a medium for socialising.
- The main sanitary service providers are public administrations. The health service is universal and free at the point of entry. However, coverage is limited for certain services.
- Social services are a mixture of public and private services. The introduction and development of public social services varies from one autonomous community to another. These services are generally characterised by their limited cover and access.
- Private social services have arisen in response to the existence of a market not covered by the public sector. Furthermore, the private home service competes with a traditionally unregulated, illegal domestic service.
- Spain is divided into 17 autonomous regions. These regional autonomous governments are responsible for Social Welfare, Social Services and Health. The central government performs legislative functions in, amongst other things: Civil and Penal Law, Social Security and Employment. Therefore, the analysis of the regulations that affect dependency and its care requires that both central and regionally autonomous governments are examined.
- At central level, the institutions responsible for employment and social services are the Ministry of Employment and Social Affairs, and its autonomous institute Imserso (Institute of Migrations and Social Services) (www.seg-social.es/imserso). The essential jurisdictions of the said Institute concerning social assistance for the elderly are:

- The management of disability and retirement pensions in their non-contributive forms (transferred) and the services complementary to those of the Social Security system.
- The proposed basic regulations for the effect of recognising disability. And the proposal, management and follow-up of state social service plans.
- At autonomic level, Regional Social Welfare Departments are responsible for planning and managing social services.

Introduction – An Overview of Family Care

The CIS carried out the first nationwide study of carers (“Informal aid to the elderly”). The study indicates: that in 12.4% of Spanish homes there is a person who gives informal assistance to the elderly. This amounts to 5% of the population over 18 who give informal help to the elderly – an approximate total of 1,464,299 people, of which 83% are women (CIS 1996). The Health Survey of the Autonomous Community of Navarre in 2000 expands the above information. It indicates that 68% of the disabled population in Navarre receive some kind of help. 64% of these receive help from family members; the environment outside the family provide support to 24%; and finally, institutions give support to 11%. The remaining third do not receive help of any kind (Gobierno de Navarra 2000).

In Spain, the responsibility for caring lies with one person – the main, and often only, carer. This is usually an adult woman aged 45-64, generally with a low level of education whose main occupation is looking after the home (Imsero 2000).

According to the IMSERSO report, the large majority (75%) of the elderly have more than one child alive (the average number is close to three). Almost 24% share a home with one of their children and 43.5% live in the same town, although they do not share a home with them. Contact between the elderly and their children is frequent. They see each other several times a month even if they do not live in the same town, and telephone contact is usual. Approximately nine out of every ten elderly people are very or quite satisfied with their relationship with their children (Imsero 2000).

The report also indicates that eight out of every ten elderly people have grandchildren, whom they see and talk to on the telephone several times a month. Almost all the elderly (96%) have other relatives: brothers and sisters, cousins, etc., whom they also see and talk to on the telephone several times a month. The satisfaction levels of the elderly is very high (Imsero 2000).

In its “Barometer of November 2001” the CIS found that almost 28% of the population identified an elderly person in their family in need of care and spe-

cial attention, and almost 21% classified themselves as carers to some extent (CIS 2001).

In the event of help being necessary, the main carer usually begins caring on his/her own initiative. This is due to several reasons: moral responsibility (90%), the perception that caring is a dignified and socially accepted activity (47.5%) and due to the lack of alternative solutions (42%) (Imsero 2000).

The amount of public care given to the dependent elderly is minor, although it is increasing. According to Imsero data (Imsero 2000) in Spain:

Fewer than 2% of the over 65s had a Home Help Service (between less than 1% and less than 5% depending on the Autonomous Community), with an average of almost 3 hours of care per week (between 8.07 and 0.52 hours per week).

Teleassistance was given to less than 1% of the elderly and 0.11% had the services of a Day Centre for dependent people.

The number of residential places for the over 65s was 3.20%, of which 1.26% were public.

The percentage of public housing under care was 0.05% of the over 65s, and that of the public temporary stay service was 0.03% of the over 65s.

Access to these kinds of services is defined by a series of criteria set by the administration, which include income and family conditions. However, it can be seen that the fact of living alone, regardless of the existence of children, and serious dependency facilitate access (Casado et al., 2003).

The domestic service has traditionally covered the private care market, although with little weight (0.8%) (CIS 2001), and only recently have specific companies appeared, though this is not very widespread (Imsero 2000). The factors that are associated with contracting private care are living alone (which quadruples the chances of contracting private home help) and the absence of children. When there is no family that responds to a need for help, external contracting is sought (Casado et al., 2003). The elderly person having a high income and a high level of education also increases the likelihood of them contracting a private service.

The participation of volunteers or the church in caring for the elderly is almost anecdotal (0.1%), whereas friends and neighbours come in as part of the family caring network led by a daughter (Imsero 2000).

The INE Disability Survey of 1999 estimates that 32% of the elderly require caring to a lesser or greater extent (INE 2000).

The National Health Survey of 2003 indicates that 65% of the over 65s say that their health is fair, poor or very poor. For 27% of men, their health is poor and for 11% it is very poor. This perception worsens with age: it rises from 5% to 7% on passing the 75 year mark. The perception of poor health is more no-

ticeable among women, where 42% classify themselves as being in poor health and 14% in very poor health. This also increases with age: from 5% to 9.5% on reaching 75 years of age. Furthermore, 14% of men and 21.5% of women in the 65 to 79 age group recognise that they have difficulties with everyday activities. This figure rises to 34% and 49.5% respectively at 80 and above. The over 65s account for 27% of hospitalisations and 20% of the use of emergency services (INE 2003).

Spain is one of the countries of the European Union with low social expenditure and a lower index of home service coverage, which is a common cause of complaint to the government by the different social agents (Diario Médico 2002).

The social debate with respect to a possible dependency insurance plan is still in the academic medium (Programa Acción 2000) and the political medium with indications that lean towards the possibility of a mixed private-public solution (Diario Médico 2000). In a brilliant article, Casado analyses this situation in the following terms (Casado 2003):

Dependency is a private phenomenon, and must be resolved by the family. The administration is subsidiary to the inexistence, incapacity or ignorance of the family.

There is concern for the impact of ageing on pensions and health and the need to increase the role of the administration in care.

The idea of facing the risk of dependence with private insurance is relatively new in Spain.

Based on experiences in other countries, the academic community is in favour of public insurance, although the criteria of access to the services, or the type and intensity thereof have not yet been determined. Some propose considering the presence of dependency as a critical point for entitlement to services, which requires the adoption of reliable instruments for measuring dependence. They also propose devising a basic packet of services aimed at guaranteeing the maintenance of basic activities, leaving aside aspects of comfort or solitude. And finally, the method of payment that allows users greater freedom of action seems to be the one most mentioned, that of service cheques.

Casado proposes the creation of an insurance of minima linked to income tax that leaves space for private coverage. The autonomous communities would be responsible for directing the insurance.

Spain is a country with great populational imbalances between the centre and the periphery. Furthermore, the socio-economic characteristics of the Spanish population vary between autonomic regions, so there may be significant variations in the coverage and content of the services due to the decentralisation of the management of social services.

1 Profile of family carers of older people

The responsibility for giving health care generally falls upon: women, the unemployed, those with low income and the most elderly (La Parra 2001). The fact of giving an elderly person care negatively affects the health of the carer, who sees his / her physical and psychological quality of life reduced (Roca et al. 2000, López et al. 1999, Moral et al. 2003, Vallés et al. 1998, Segura et al. 1998).

1.1 Number of carers

In Spain, family relations are relatively broad. The first generation of grandparents relate to their spouses; their children and their spouses, their brothers and sisters and their spouses and respective children (Imsero 2000). However, the job of looking after a dependent elderly person seems basically to fall upon one person, the main carer, who may briefly be helped by other members of the family network. (Bermejo et al 1997).

1.2 Age of carers

The age of carers is over 45 in 70% of cases (CIS 1996). Women between 45 and 54 make up 40% of carers (Casado et al., 2003).

1.3 Gender of carers

There seems to be a trend to attribute the responsibility for caring or to select the main carer within the family. That is: in the first place is the spouse, and if incapable (physically, socially or psychosocially) or absent, the role falls upon the children, and particularly daughters (Rivera et al 1999, Imsero 2000). This is justified by the habit and preferences of the elderly themselves (Agulló 2001).

The perception concerning the gender of the carer, however, varies depending on the gender of the informant. The Barcelona health survey of the year 2000 provides very interesting data in this respect. When the informant is a man, he declares himself to be the single protagonist in almost 27% of cases and says that he shares the work with another person in 8% of cases, whereas he attributes 17% of the care of a dependent elderly person with whom they both live to his wife alone. When the informant is a woman, 58% say they care alone and 10.5% say they do so with another person, leaving it to their partner in 3% of cases (Institut Municipal de Salut Publica 2002).

1.4 Income of carers

According to Imserso data, carers are generally people with little education, normally 'housewives' (50%), and of a modest social background. In consonance with this, in 40% of the homes of the carers, income does not exceed 600 € a month (Imserso 2000).

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

More than half (56%) of the people who recognise themselves as carers are involved in caring every day and more than 22% every week, whereas nearly 14% are involved occasionally (CIS 2001). It seems that care is predominantly given either in modules of some two hours a day or during the whole day (Gobierno de Navarra 2000).

The main carer spends an average of seven hours a day caring, and may receive help for one hour a day. This person is responsible for the care, whereas the rest of the network work subsidiarily and when explicitly required (Agulló 2001). The person takes on the care of the elderly person and the home, which takes up almost the whole day at an intense rhythm and with jobs superimposed. These jobs cover the following areas: 1) Physical (washing, dressing, etc.), 2) Emotional (affection, company), 3) Other (vigilance, jobs, etc.), 4) Household (cleaning, ironing, ...).

In the Navarre health survey (Gobierno de Navarra 2000), 76% of the disabled receive help from people in the household, and at least half of those receive it from the surrounding environment, receiving several kinds of help.

1.6 Level of education and / or Profession / Employment of family carer

The CIS indicates that the education of the main carer is fairly low. 87% say they have "no studies, primary or secondary education", as opposed to 11% who have "professional or higher" studies. This is explained by bearing in mind the age of the carers and the educational trends in Spain for their age group. Only 22% say they are employed, 15% are pensioners, 13% indicate other situations, and the majority, 50%, housewives. Of those who say they are employed, 36% have part-time work and 64% full-time (CIS 1996).

12% of carers say they have had to stop work to be able to deal with caring. Women without studies or with primary education have a greater tendency to give up paid work to care. The severity of the dependency is another variable that explains why carers leave their jobs (Casado et al., 2003).

1.7 Generation of carer, Relationship of carer to OP

According to data from the CIS, the relationship between the carer (not necessarily the main carer) and the cared-for person is established approximately as follows: spouse in 12.4% of cases, daughter in 26%, son in 15%, sister in 1.4%, brother in 0.4%, granddaughter in 8%, grandson in 5.4%, daughter-in-law in 5.6%, son-in-law in 6%, other relatives 14%, neighbours and / or care-takers 5.6%, friends 4%, household employees under 1%. In other words, nearly 53% of the caring is carried out within the family unit by a partner and children. (CIS 2001).

1.8 Residence patterns

In its Plan of Action for the Elderly (Imserso 2003), the Imserso indicates that the majority of housing is owned (82% of the over 65s), although with some differences between autonomous communities, urban or rural medium, age and sex. Most elderly people - eight out of every ten - live in their own homes, although the proportion falls with age. Moreover, six out of every ten elderly people, with variations by age and sex, live with their partner. In these homes, there are often children: 28.5% between the ages of 65 to 69, and 17.4% from 70 to 74. The elderly living alone are a growing group, which in the 2001 census accounted for 20.1% of the over 65s, women being in the majority (INE 2004).

In this respect, it is important to highlight the rapid social evolution of recent years, which has made living trends change greatly from a more or less rural situation to one in the city. A sign of this is Barcelona, where 32.6% of women and 10.4% of men over 65 live alone (Institut Municipal de Salut Publica 2002).

The relationship of coexistence between the carer and the cared-for person may be described in the following terms: 59% live together permanently, 16% live together temporarily, 26% live in separate dwellings or in other types of residence (CIS 1996).

When the dependent person is married, the spouse generally cares for them in their own home. If the person is single or widowed they receive care from the family, and if the person is highly dependent, they go to live in a relative's home, although they might also live at home accompanied by another relative, an option that is given more amongst the younger dependent person. (Casado et al., 2003).

1.9 Working and caring

There is not much information available on this subject, although if we note the results of a study on carers of elderly people with dementia, it seems that the fact of working out of the home is decisive in the content of the care. There-

fore, in comparison with housewives, women working out of the home are those who more largely deal with entertaining the elderly person, asking for outside help and participating in caring shifts organised by others. Workers with flexible working hours are those who seem to least use such strategies, maybe based on the belief of having greater availability to care for the dependent person and believing in their own capacity to organise the caring activities (Abengonzar & Serra 1997). Furthermore, it seems that participation in caring shifts particularly occurs with workers with flexible timetables rather than with workers with a fixed timetable, and finally housewives (Abengonzar & Serra 1999).

Artacoz indicates that the combination of care in the home and working out of the home has a negative effect on the health of caring women. It increases their morbidity, worsens their perception of health status, and increases the use of the health services. No differences are noted with respect to the time conditions of paid work (Artacoz et al. 2004).

1.10 General employment rates by age (part-time / full-time / self-employed) for general population

The characteristics of the Spanish job market are described in the following tables (INE 2003):

Table 1: Men and women in the jobs market. 2002 (INE 2003)

	People in thousands			Percent	
	Both sexes	Male	Female	Male	Female
16-64 years	27,169.0	13,635.1	13,533.9	50.19	49.81
Inactive	15,624.5	5,460.9	10,163.6	34.95	65.05
Active	18,340.5	11,034.6	7,305.9	60.17	39.83
Employed	16,257.6	10,146.6	6,111.0	62.41	37.59
Unemployed	2,082.9	887.9	1,195.0	42.63	57.37
Employment rate	54.0	66.9	41.8	–	–
Unemployment rate	11.4	8.0	16.4	–	–
Part time employed	1,277.8	258.0	1,019.8	20.19	79.81
Full time employed	14,979.8	9,888.6	5,091.2	66.01	33.99

Source: INE 2003

Table 2: Percentage distribution of women of 16 or over according to economic activity. 2002

Employed	Unemployed	Inactive	Student	Pensioners	Housewives	Other
35.0 %	6.8 %	58.2 %	8.4 %	16.9 %	29.3 %	3.5 %

Source: INE 2003

The job market is deeply affected by the gender variable: There are more men in the "Active" and "Occupied" categories and more women in the "Inactive" and "Unemployed" categories. There are significantly more women occupied part-time (79.8%) whereas the majority of those occupied full-time are men (66%).

The activity rates of men have evolved steadily in the last decade. The evolutionary profile of women is entirely different. In the last decade, the rates of female activity have presented rising tendencies to different degrees in all age groups, except for the youngest, from 16 to 24, where the tendency is falling. The activity rates are lower as the women's age rises from 25 to 64. On the one hand, this shows the gradual, rising inclusion of women in the job market, the feminisation of activity (a feminisation that is unequal by sectors of activity and categories of occupation) and, on the other hand, that a substantial part of the group leaves professional work when, due to marriage or the birth of the first child, they come to deal mainly with the family private life. In such cases, these women do not usually return to work.

It is suggested that this labour behaviour of many women affects family care. The low activity rates of women with dependent elderly people have made it possible for them to cover the caring needs in the family (Casado et al., 2003).

Table 3: Unemployment rates by sex and age group. 2002 (INE 2003)

Age	Male	Female
Overall	8.05	16.36
From 45 to 49 years	4.65	12.60
From 50 to 54 years	5.35	11.99
From 55 to 59 years	6.10	10.40
From 60 to 64 years	5.52	8.49
From 65 to 69 years	0.96	1.79
From 70 years	0.16	0.66

Source: INE, Active Population Survey

Female unemployment rates are higher than male both in general and in specific areas for all age groups.

1.11 Positive and negative aspects of care-giving

The overload of responsibilities falling on the carer make her a victim of "domestic stress". In other words, deteriorating physical and psychic health, character disorders, depression, etc., and many of the physical consequences are the result of somatisations (Agulló 2001).

More specifically, according to CIS data (CIS 1996), 64% of main carers indicate that they have had to reduce their leisure time, 51% are tired, 48% can not go on holiday, 39% do not have time to visit their friends, 32% feel de-

pressed, 29% think their health has deteriorated, 27% cannot think of working out of the home, 26% do not have time to look after other people as they would like, 23% do not have time to look after themselves, 21% have financial problems, 12% have had to reduce their working day, 12% have had to give up work altogether and 9% have had conflicts with their partner.

One person can suffer several negative effects at the same time. Therefore, 71.4% of main carers are seen to be in a state of psychological ill-being (Gálvez et al 2003). There are data that suggest that the care of elderly people with dementia places a greater load on the carer than other types of dependency; although in almost all cases, symptoms of depression are generated, as well as the use of active and passive confrontation strategies and requirements of more formal support (Aranburu et al 2001).

Religion and the emotional support of the family seem to play an important role in the mental health of the carers. Religion is a resource used basically by spouse carers, which seems to give protection against depression. High degrees of religiousness among daughters, however, seems to be associated with the stress caused by caring, and in this case is associated with greater signs of depression (Zunzunegui et al. 1999).

If at the beginning of care-giving, the carers are able to express positive feelings, with time, the weight of the negative experiences is overwhelming, maybe due to the lack of outside support. In general, more negative effects are seen than positive (Agulló 2001).

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

It is necessary to bear in mind two recent demographic trends that are changing the structure of the Spanish population: on the one side is the ageing population and on the other, the arrival of large numbers of immigrants. In this context, the role of immigrants in caring for the dependent elderly corresponds to the following parameters (Imsero 2003):

- Formal social resources are insufficient, so more and more families resort to contracting immigrants to cover caring needs. Initially, outside help is sought for a few hours, and as the dependency increases, a person is sought to stay in the home of the elderly person.
- The immigrants are usually illegal and remain in this sector until their situation is legalised. Contact is made between the family and the immigrant through informal routes (relatives and friends) or through NGOs turned towards the elderly or immigrants.
- The negative aspects of this situation are the immigrants' lack of suitable knowledge to deal with the caring needs and their own labour situation. The most frequent problems are: excessively long working days, domestic

activities beyond caring for the person, low wages, illegal situation. Their future prospects are not always bright, and when they legalise their situation, they seek other work (Ariza 2003).

- The balance is generally positive for the families and for the immigrant carers. Both positively value the relationships they establish with the elderly.

1.13 Other relevant data or information

No other relevant data or information provided.

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

The general policy states that the care of dependent elderly people is the family's responsibility. This is something established legally and socially accepted. Social services try to keep the elderly person at home for as long as possible. Attention for the carer is something that has only begun to be considered very recently.

For the moment, access to social services is not considered a citizen's right. The extension of the coverage in social services therefore responds discretionally to the political objectives of the relevant administrations. Behind this situation is the non-existence of a general national law that recognises the right to social services and basic regulations dealing with the later autonomic development. Therefore, although all the autonomous regions have developed their own autonomic social service laws, each one is independent of the others. On the other hand, access to health assistance is a citizen's right covered by the General Health Law of 1986.

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

The data on expectations of health in the event of need indicate that only 8% of the population would wish to be attended only by the public social services, and 12% would wish to be attended by the family and the social services together. The rest prefer the family to act as a source of support. Of the most desired services, the majority of the population (57%) prefer to receive economic aid from the Administration in the form of a monthly payment, and in second place (20%) a home help service (CIS 2001).

According to one study, the perception of the quality of residential services among carers is very low. This poor image is associated with the consideration that the institutionalisation of a relative reflects the failure of the family to look after the elder. The feeling of blame if the person is put in a home is particularly strong among women, who have internalised the role of carer more than men. This idea is gradually changing in the sense that residential care is being considered more and more as a further resource (Rivera 1999).

Agulló indicates that carers show great dissatisfaction with the formal support services, due to their insufficiency in numbers, their deficiency - poor quality, discontinuous - and their inaccessibility - they exclude those with medium or high incomes, but they do not reach those with low income (Agulló 2001).

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

The CIS indicates that 87% of the population agrees or strongly agrees with the phrase "the care of elderly parents is a problem mainly of the children", and the same percentage also agrees with the phrase "the care of elderly parents is not a problem exclusive to the children, but also affects society and the state". It would seem that society attributes this responsibility to the children to the same extent as it asks for help from the state (CIS 2001). However, the situation is changing rapidly, and only 24% of the population believe that children will continue to take on this task in the future (Consumer 2001) The situation concerning the elderly is also changing, with an increase in the number of elderly people isolated in their homes (Diario Médico 2003, Diario Médico 2002).

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

In Spain, from adulthood to death, it is considered that all people have equal rights and capacities. If there are solid reasons to suspect a person's incapacity, it is necessary to promote their declaration as such, according to the procedure legally established in the Spanish Civil Code. This indicates that nobody may be declared incapable if not by judicial sentence by virtue of the causes established by Law: illness or persistent physical or psychical shortcomings that prevent the person from controlling themselves. In the event of incapacity, a legal guardian is appointed to be responsible for ensuring the well-being of the incapacitated person. The functions of the guardian are a duty and will be performed to the benefit of the guarded person and will remain under the safeguard of the judicial authority (Spanish Civil Code. Book I).

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)?

Spanish civil regulations assign the responsibility for attending and caring for the dependent elder to the spouse and children (Spanish Civil Code. Book I). In this way:

- Maintenance is understood as everything that is essential for sustenance, shelter, clothing and medical assistance. Spouses and all ascendants and descendants are reciprocally obliged to maintain the older person to the fullest extent. Brothers and sisters only owe each other the necessary help during their lifetimes. When the obligation for maintenance falls upon two or more people, the payment of the older person's pension will be divided between them in proportion to their income.

- The amount of maintenance will be proportionate to the means of the provider and the needs of the older person. The obligation to give maintenance will cease with the provider's death or when their wealth has fallen to such a point that maintenance cannot be satisfied without neglecting their own needs and those of their family.

Any infringement of the above mandate is punished by the Penal Code. Whoever might fail to fulfil legal duties of assistance will be punished with imprisonment from between eight to twenty weekends (Spanish Penal Code).

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

As has been made clear in the previous point, Spanish law obliges the family to deal with the dependent elder person to the limit of the wealth of the family. On the other hand, there is no legal aside referring to the rights of carers either before the elderly person or before the State.

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

In Spain, there is no legal definition of elderly, however social service regulations sometimes indicate 65 years as the minimum age for access.

However, Social Security legal regulations establish that the entitlement to retirement and pension allowance shall be exercised from sixty-five years of age (Royal Decree 1 / 1994 of the Social Security).

2.2 Currently existing national policies

2.2.1 Family carers?

The policies aimed at family carers, though largely requested from different areas (carers, researches, health sector, etc.) are fairly testimonial.

On its website, the *Imsero* offers the 'Portal Mayores' with information concerning, amongst other things, programmes for carers: There are programmes that give economic subsidies for families in the Balearic Islands, Valencia, Castilla León and Madrid. In Galicia they use the "assistance cheque" form. In Andalusia there is a programme aimed at training the carers of dependent elderly people. In Gipuzkoa, Castilla León, Canary Islands and Catalonia, there are programmes of training and psychosocial support, together with some economic aid for carers (*Imsero* 2004).

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

In the Plan of Action for the Elderly (*Imsero* 2003), the Ministry of Employment and Social Affairs establishes different areas of action, particularly the Area I, "equal opportunities", which includes the aim of "developing policies of protection of the elderly in situation of dependence" (Objective 2). The strategy designed by the Ministry is as follows: to establish means of support for the dependent with the existing programmes, to develop co-ordination between health and social services, to develop the law on bioethics in order to safeguard the dignity of the elderly, to promote specialised attention to dementia. To put this strategy into practice, it is necessary to have the collaboration of the Autonomous Communities.

As an example of regional policies, the autonomous community of Extremadura establishes specialised social services for attending the elderly, in order to ensure that all citizens might find their place and avoid marginality by promoting social integration. It proposes budgetary measures (aiming to reach a coverage of 8% of the dependent over 65s) and administrative measures (management and financing measures for new forms of home help, including regulations for the economic contribution of the beneficiaries). Finally, together with the town councils, it establishes criteria to standardise Home Help cover (Law 5 / 1987 of Social Services Autonomous Community of Extremadura).

In the different autonomous communities, it is possible to identify two types of programs present in all communities (*Imsero* 2004). The first group is gathered under the title of residential alternatives. This includes information on residences, dwellings and programmes of shared housing. This section usually includes public residences, subsidised residences, temporary stays in residences and, in some cases, family reception of the elderly person.

The second block is constituted by programmes that are gathered under the title of aid for remaining at home. This basically includes home help and teleassistance. Day centres can also be included, economic aid for paying for day centres, economic aid for restructuring the home, and less frequently: programmes of shared housing among the elderly and students, a programme of volunteers to help the families of those ill with Alzheimer's disease and two meals programmes.

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)?

The legal regulations on the protection and rights and duties of employed workers until recently did not contemplate the support to the carers of dependent elderly persons. A later revision of the legal ordinance (Law 39 / 1999, Conciliation of family and working life) contemplates the right to a reduction in the working day with a proportional reduction of salary, and / or leave for a

time not exceeding one year to look after a relative who, for reasons of age, is unable to look after him / herself.

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

The Imsero (Imsero 2000) describes the legal situation as follows: In Spain, the legal regulations concerning citizenship, work, labour protection, entitlement to health services and the social protection regarding pensions are national, therefore a carer or a dependent elder concerning these issues are in the same situation regardless of where they are geographically. However, there are regional inequalities concerning the provision of health services, which limit the full realisation of the recognised right to health care.

The legal structure for the dependent elderly and carers is the same throughout the country, although the content and extent of social services to which they have access vary from one autonomous community to another. The autonomous communities are responsible for social protection via social services (Imsero 2004). In each autonomous community, there is a department of social welfare which contains a section aimed at the attention of the elderly whether or not they be dependent. The regulations of the communities as regards the type of services are subject to local criteria. In all communities, there is a home help service in order to keep the elderly in their homes, and attention in residences is far less widespread. The carer support programmes are secondary (programmes have been identified, all secondary, in seven of the seventeen autonomous communities).

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

The Imsero identifies some problems in the introduction of social services (Imsero 2000):

- Bureaucratic barriers: the multiplicity of programmes or organisers, administrations, etc. can make it difficult to organise care, and discourage the elderly person.
- Inequalities in the geographic distribution: especially in rural areas, it is difficult to compensate the greater dispersion of the elderly with needs.
- Barriers on transport and mobility (both on public transport and architectural barriers).

There are also large differences in offer and coverage of services through the autonomous communities. The public offer of places in residential homes is higher in Castilla León, the Basque Country and Catalonia (with ratios of over 1.5 of the over 65s). The lowest coverage is in Galicia and the Balearic Islands

(with ratios of 0.7). The offer of public home help is highest in Extremadura (with a ratio of 4.7 of the elderly) and the lowest in Valencia (with a ratio of 0.8) (Imsero 2000).

3 Services for family carers

In recent times, the figure of the informal carer has gained attention and specific programmes are gradually emerging, albeit in a very limited manner (the Community of Madrid established the programme of aid to carers in the year 2003, and Valencia, Balearic Islands and Galicia in 2002). The services for family carers reach a very small proportion of the population. These are basically economic aid for the cared for person. Taking the example of the autonomous community of Madrid, in its programme of aid to carers (CAM Order 1049 / 2003) it establishes the following criteria for accessing help: annual income of the family of under 9,286 € and the presence of great disability. The maximum amount of aid is 2,710 € a year.

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

3.1 Examples

3.1.1 Good practices

In the autonomous community of the Canary Islands, within its “Programme of attention for the Elderly in Primary Attention”, a programme has been established of support to carers which promotes offering training activities to 100% of carers and plans for community support (self-help groups, associations) (Gobierno de Canarias 2002).

3.1.2 Innovative practices

Guipúzcoa county hall (autonomous community of the Basque Country) offers the Sendian programme in support of carers, which accesses different resources: family training, psychological support, self-help groups, weekend breaks, long term breaks, technical help, volunteer programs, economic aid, tax exemptions. The programme is structured as a co-operation agreement between San Sebastian city hall and the provincial council, and is offered to all caring families. (Diputación Foral de Gipuzkoa 2004).

Galicia is the only autonomous community where the “Assistential Cheque” has been used (Galicia Government, 2001). It intends to help the dependent elderly cope with the cost of their caring. The programme requires great dependency on the activities of daily life, together with scarce economic resources. It presents different forms of help: residence cheque, day attention cheque (day centres), cheque for attention in the home, cheque for temporary stay and programmes of family rest.

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

The role played by the social services in caring for the weak elderly, as already said, is very scarce (Imsero 2000, Casado 2003).

The National Health Service, through the Autonomic Health Services that are the responsibility of the autonomous communities, is responsible for providing health care.

4.1 Health and Social Care Services

As a result of the diminishing dedication of the family to caring for the dependent elderly, and specifically the gradual inclusion of women in the working world, the increase in the number of the elderly living away from their children and the growth in the number of years of dependency, has resulted in an increase of the intensity of the consumption of health and formal social resources by the dependant elderly. Almost 90% of the amount of health and social resources consumed are concentrated in the last 7 or 8 years of life of a person, a time that coincides with the duration of the dependency (Montserrat et al. 2001).

The use of services varies depending on the elder's illness or health problem. People with dementia seem to use the disability preventive services less than other elderly people, but they make more use of the hospital services, medical surgeries, nurses at home and third party consultation. The coverage of the social services in aid of family carers is very low (Zunzunegui et al. 2003).

4.1.1 Health services

The Imsero describes the health service coverage in the following terms: In the Spanish health system, health offer and health coverage are practically universal and free at the point of entry, and demand is only conditioned by the health status of users, their social and cultural characteristics and by geographical limitations. On the whole, the large majority of users are elderly (one in four) and women (almost three in ten), who, in addition to being out of the job market and having more free time, generally are in a poorer state of health and therefore make greater demands for attention (Imsero 2000).

The large majority of the population is covered by the public health care system (99.7%), the National Health System, and somewhat more than 10% also have some private insurance. The generalisation of public coverage and the rise of private insurance have both occurred in recent years.

The health services generally have a sufficiently well-developed base of primary care, which includes programmes of home health visits, and a second

level of hospital care. However, the co-ordination between social and health services is still a pending subject.

Little by little, the health services introduce new criteria with regards to the care for the dependent elderly. It is beginning to be considered from three pillars: a) the programme for the elderly, b) measures of action for family carers (such as information on the problem, on the therapeutic programme, training in dealing with contingencies, in respiratory relaxation techniques), and c) measures in the environment (home adaptations etc.) (Caballero et al. 2000).

However, there are still problems that question the effectiveness of the system. Mention is made as to the scarce level of co-ordination between primary and hospital care for both the long-term treatment of chronic and terminal patients and the care after hospital discharge. These types of care are not suitably covered due largely to the lack of specific resources for home health care but also to the under use of existing resources in the social services area (Casado 2002).

4.1.1.1 Primary health care

Primary health care in Spain lies with the National Health Care system. The primary health care level undertakes home health visits for the dependent.

Some of the problems noted in evaluations of home health care suggest that: the frequency of home visits, relatively high in the past, fell to very low levels in the 1990s in almost all autonomous communities (under 2% of all visits) and the role of primary care nurses is still very limited (Casado 2002). The ATDOM group (Home Health Care Group) in a study on home health care in Catalonia, indicated that home health care programmes have been introduced in 90% of the primary care centres. Among the functions performed by the Home Health Care Groups, more than 75% of the teams offer carer training and almost 69% specific "caring for the carer" programmes.

On identifying the problems that impede the introduction of the home health care programme, they indicate: firstly high assistential pressure at the health care centre, insufficient social resources and the lack of co-ordination with other assistential levels (ATDOM 2003).

According to the Survey of Satisfaction with Primary Care (ESAP 2001, INS 2002), home health care is a service that is often requested and well appreciated by the users. Visits are made whenever requested and the immense majority of users tend to be satisfied with them. This type of attention was requested "urgently" in the majority of cases, although in more than a quarter of the requests it was related to long-term illnesses that should have been attended in a programmed manner within the programmes of home health care for the chronically ill. Requests for "urgent" home health visits are growing in number and in the past year have increased by two percentage points.

However, Prieto finds complaints about: the lack of Home Health care coverage outside the working hours of the Health Centre, the difficulty of contacting the centre in the event of need, the delay in dealing with urgent calls and the fact that attention for oncological patients does not form part of the programmes for chronic conditions of primary care (oncological care is covered by hospital services which do not tend to provide home health care programmes), therefore these patients only receive home health services on demand (or urgently) (Prieto et al. 2003).

Also problematic is the poor introduction of protocols for common health problems of the elderly (such as pressure ulcers, attention for bed-ridden patients, treatment of pain and attention for terminal patients), and the scarce participation of medical professionals in this kind of care (representing only 8% of their time). Also indicated is the need for greater internal communication between health services, and for external communication with the social services (Benítez 2003).

On the other hand, although the coverage of health care is universal, usually, no type of disability testing or any other comprehensive evaluation of the loss of autonomy on the population, are performed. In this situation, the delivery of care is a function only of the demand for services, which is based on the criteria and resources of the carer, on the one hand, and the health of the elderly person on the other. Some determining factors of demand are: the existence of physical problems in the carer, the fact of supporting a greater caring load, having cared for a long time and having had to reduce leisure activities. Great religiousness and great emotional and instrumental support work in the opposite way (Llacer et al. 1999).

4.1.1.2 Acute hospital and Tertiary care

According to the National Catalogue of Hospitals (Ministry of Health and Consumer Affairs 2003) in Spain there are 783 hospitals with 158,500 beds. The population coverage ratios vary between Autonomous Communities as follows: Catalonia 5 beds per 1000 inhabitants, Cantabria 4.8 per 1000, Aragon and Canary Islands both with 4.7 per 1000. In contrast, the ratio is lower in other communities: Valencia 3 per 1000; Andalusia and Castilla la Mancha both with 3.1 per 1000, and Murcia with 3.4 per 1000 inhabitants. With respect to ownership, private centres represent 58% of the total, as compared with public centres, at 42%. However, the majority of beds are in the public network (68%) (La Caixa 2001).

In recent decades (1986-1998) hospital visits have increased by almost 27%. More than one third (10%) are due to the ageing population and the more frequent visits from this age group (the over 74s visit three times more often than the under 65s). This leans towards a change in the morbidity pattern of hospitals towards a fundamentally gerontological profile. Finally, patients of 65 and

over are more complex, generally more costly and are at a higher risk of being readmitted than the rest of the population (Castells et al. 2002).

However, the increase in health expenditure is not merely based on demographic factors but rather on a greater perception of morbidity, increased users' expectations of obtaining benefits from the health interventions and an increase in the offer of services (Gornemann et al. 2002).

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

Medium and long-term care is not highly developed in Spain. In 1999, somatic long-term care beds represented less than 10% of the total. This figure has been stable since 1976 despite increasing needs. However, there have been declines in some regions. An example of this evolution is the autonomous community of the Basque Country (EUSTAT 2001), where the number of beds has fallen by 7% in recent years. This fall is higher in medium-long term hospitals (16%) than in the acute (7%). For their part, the availability of psychiatric beds fell sharply following the mental health reform started in 1983, which gave priority to community mental care. Finally, though alongside this, day centres and short-stay hospital resources have increased, though slowly and not equally distributed (Casado 2002).

There is a great difference between the provision of geriatric and long-term hospitals among the different autonomous communities. Whereas Catalonia has more than half of the long-term hospitals and 45% of the beds in the State (for 15% of the population), there are communities such as Castilla-La Mancha, Rioja and Navarra where there is no hospital of this type (INE 2002). This inter-territorial imbalance is due to an uneven, uncoordinated evolution of the social welfare systems in the autonomous communities.

The Catalan programme "Vida als Anys", created in 1986, the most ambitious and most widely implemented programme in the State in offering medium and long-term services, has become a reference for the rest of the autonomous communities. Centres offering a mix of social and health care, with beds for long-term care, convalescence and palliative care, are the cornerstone of the programme. Half-way between assisted-residences and acute hospitals, they offer treatments of lower intensity than acute hospitals and include social services. At the same time, they involve greater medical care than the residential homes and shorter length of stay. On the other hand, day-hospitals, aimed at maintaining the functional capacity of those who have overcome the acute phase of illness and do not require admittance, complete the network of resources of the programme. Finally, in order to support the provision of geriatric care at the primary care level, two types of teams have been set up: The Socio-sanitary Interdisciplinary Functional Units at hospital level, in order to collaborate in geriatric care and plan hospital discharges, and the Teams of Evaluation and Home Health care (PADES), located at primary care level to

play a co-ordinating role with other socio-sanitary and social resources for the care of geriatric patients. No formal evaluations of the programme Vida als Anys are known. However, in the opinion of experts, it seems that by attracting the dependent elderly, the socio-sanitary centres have contributed to a greater specialisation of the system. Furthermore, there is empirical evidence that shows that the PADES have contributed to improving the care received by some patients, although instead of fully performing the role of case managers, they rather focus on providing information on social services (Casado 2002).

4.1.1.4 Are there hospice / palliative / terminal care facilities?

It is difficult to obtain statistical information on the extent of the palliative care, although there is more information on some aspects of functioning or specific treatments. According to a study by Tortosa Chuliá (Tortosa Chuliá 1999), palliative care in Spain presents the following panorama:

There are few palliative care units in the acute hospitals, and those that there are do not deal with terminal patients but rather acute. Moreover, given the small number of long-stay hospitals, there are few units in these centres. Nor are there many home health programmes dependent on hospital palliative care services. The palliative care for terminal patients by the primary care teams follows the existence of specific protocols at each health centre; a decision that pertains to the health centre. However, the frequency of these protocols and their content is generally very limited. The residences for the elderly generally have no staff with knowledge of palliative care. Although terminal patients and their relatives in principle can receive attention from the social services in their homes, access to this is also highly restricted in practice.

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

Formally, the personal care and hygiene of hospitalised patients is a duty of the hospital staff. However, it is a fairly common practice that the relatives of weak patients, including the elderly, accompany them during their hospital stay and help them to maintain their hygiene in addition to offering them moral support and assuring the general supervision of their needs. Normally visiting hours are limited to a few hours a day. However, hospital staff are generally fairly flexible and allow relatives a lot of time, particularly with the weaker patients. The accompanying relatives generally act as informal carers.

4.1.2 Social services

Citizens' right to social services is not established on a national legal basis, but rather on the discretionary action of the Autonomous Administration. The criteria that establish the condition of right are regulated in the legislation of the autonomous communities.

The main criterion of the social service network is to keep the elderly in their own environment for as long as possible. The main social services are therefore aimed at maintenance in the home. There is also a residential type network. These services generally concentrate on attending the dependent elderly who live alone. The need is also recognised to help subjects with few resources.

4.1.2.1 Residential care (long-term, respite)

Residential care is intended for people with serious disabilities. The autonomous community of the Basque Country (CAV Decree 41 / 1998), defines it as an establishment that provides accommodation and care for the over 65s. They are classified into: a) guarded apartment, with collective services, intended for the elderly in a situation that does not require more intensive care, b) community home intended for people able to deal with themselves to a certain extent, c) residence, intended as a permanent, common home for people who require continuous comprehensive care.

In recent years there has been a tremendous increase in the number of residential places, reaching a coverage index in January 2002 of 3.4% for the over 65s (Imsero 2003). The coverage of the public service in temporary stays was 0.03% in 1999, focused almost entirely on the community of Madrid (0.17%) and in the Basque Country (0.09%) (Imsero 2000). Furthermore, there are 4,280 guarded housing places in the country distributed around 396 houses (Imsero 2000).

The most frequent situation is that the dependent elderly are taken care of by a relative who assumes the care-giving role. However, on occasion, the elderly and / or the carer decide to seek residential care. Among the reasons that lead a carer to seek a place in a residential facility are low income of the carer, being a woman without her own income, depression, conflictive behaviour of the dependent elder and, above all, having little emotional support. In the absence of a caregiver, residential homes are a valuable option. The general image of the homes is, nevertheless, fairly negative and entry into one is also seen as something negative (LLacer et al.1999).

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

The people who live in residential homes are more often very elderly women. The absence of children to take on the caring tasks is one of the most determining factors behind entry into a residential facility. Together with this, the greater probability of them suffering from problems of dependency and solitude due to widowhood increases the chance of going into residential care. The entry of widows into residential care significantly aggravates the loss of economic income experienced by such women (Casado 2003) (a widow's

pension in Spain is generally less than 50% of the pension of the person entitled).

Table 4: Percentage of people living in residential care in relation to the whole group of over 65s (public and private). 1998

Age	Male	Female
65-69	0.94	1.25
70-74	1.22	1.95
75-79	1.78	3.29
80-84	3.74	6.95
85+	7.76	13.97
Total	1.93	4.00

Sources: Imserso 2001 and INE 2001

As can be seen in the table below, the age structure of people accommodated in residential homes in the autonomous community of the Basque Country supports the general profile. The age group of the 80-90s is over-represented in both the public and private networks. In other words, when dependency is greatest. However, the age profile is significantly younger (6.2 percentage-points) in the private network. This can be explained by the stricter criteria on access to the public network, which requires high dependency and little wealth, while the criteria of the private network are exclusively financial (in the contrary sense). In other words, they do not require scarce wealth and favour less dependence. It would seem that the behaviour adopted by families with sufficient economic means consists of going to the private network until the wealth of the elderly person has been consumed, which is when they are liable to be able to access the public service.

Table 5: Percent of elderly in private and public residences in the Autonomous Community of the Basque Country. 2001

Age	Private	Public
< 75	16.0	22.2
75-79	15.8	17.3
80-84	23.7	20.6
85-89	26.4	22.8
> 89	18.0	17.1

Source: EUSTAT 2001

We do not have data broken down by type of residential care.

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

In the absence of general regulations, the relevant administrations of the Autonomous Communities set the criteria of access to the public residential places. Taking the operation of certain communities as an example, it is possi-

ble to establish typical behaviour. In the autonomous community of the Basque Country, the Department of Social Action decides on the residential admission of particular individuals following the report of a qualified informative body created ex-profeso for deliberation and support in decision-taking (autonomous community of the Basque Country, Regional Law no. 4564 / 2001). The elderly person's situation is judged through certain parameters, for instance the community of Madrid evaluates entry according to: the social and family situation of the candidate (38% of importance), the degree of physical and psychological incapacity of the applicant (21%), their economic situation (13%), their housing situation (14%) and their age (12%) (CAM Order 368 / 2003). When the residential unit is of the Guarded Flat type, one of the basic requirements is that they should be independent in the basic and instrumental activities of daily life and also lack suitable, stable accommodation or be in a risk situation because they live alone.

4.1.2.1.3 Public / private / NGO status

According to 2002 data, 58.8% of residential places are financed wholly by the user, and the rest totally or partially by the public sector. However, there are large regional differences: Catalonia, Andalusia, Castilla Leon and Madrid have a stronger concentration of private places (Imserso 2000, 2003).

The financing of public places may be public or mixed. For instance, the autonomous community of Madrid (CAM Order 1377 / 1998) distinguishes: Places wholly financed by the community (without prejudice to a discretionary public price). Places financed in part - by the community of Madrid and the users. The price the user pays will be 700 € a month. If the person occupying the place has a personal net income of over 750 € a month, their contribution will be raised by 36 € for every 60 € that their personal income exceeds this.

According to data of the autonomous community of the Basque Country (EUSTAT 2001), in recent years the residential market has seen the entry of a business sector attracted by the opportunities arising from the ageing population.

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

The residential regulations do not establish any working or caring requirement specifically aimed at the carers (CAV Decree 41 / 1998, CAM Order 1377 / 1998).

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

The social services in Spain reach a small part of the collective of elderly dependent, and few use the home help services. According to data from the CIS

(CIS 1996), the Home Help service is used by 7% of those who need it, the provision of wheelchairs reaches 13%, levered beds in the home reach 5%, accompanied visits of volunteers and help to adapt the home 3%; and finally, day care in a centre for the elderly, teleassistance, hot meals on wheels and home laundry services reach only 2%.

The existence of non-residential social services is unknown by a large sector of the population in need (25% of the over 65s know nothing of the home help programme and this lack of knowledge is even greater in other programmes). Awareness of the service offer is associated with better education, youth and dependence (Casado et al., 2003).

4.1.2.2.1 Home-help

In Imserso data for January 2002, throughout the country 2.8% of the over 65s were attended by the Home Help service. The people attended were mainly women (over 60%) and 53% were over 80 years old. The average number of hours of attention was 3.5-4 hours a week. The service is given with a mean hourly cost of 9.5 € . 1.48% of the over 65s receive public teleassistance service.

The demand for services has increased sharply in the past three years: The Home Help service has increased by 75% and the Teleassistance service by 114.75%. The hourly cost of the Home Help service has risen by 5.9% (Imserso 2003).

The people receiving home help generally live alone, although they may have children, and also present serious dependence. The reception of the home help does not seem to be related to the economic income of the elderly person. Consideration is given more to the insufficiency of the family to provide care (Casado et al., 2003).

The impact of the Home Help service on users living alone is very positive. However, there is a contradictory effect among informal carers. It is viewed as very positive when it is very short (three or fewer days a week). On the other hand, when the service is given every day or nearly every day, the impact among carers is negative, as their expectations of resting from the daily caring work seem to grow but are not fulfilled (Medina et al. 1998).

4.1.2.2.2 Personal care

The administrations perceive personal care as part of the Home Help service and generally little weight is given in the job distribution, with the exception of certain autonomous communities: Asturias, Catalonia, Navarre and the Basque Country, where they account for 59 to 80% of the work done (Imserso 2003).

It seems that there is a connection between the low importance given by home help services to the personal care tasks and the preferences of the elderly

themselves. The elderly largely consider that this work is the responsibility of the family, an opinion that is also shared by the carers, who would rather receive more domestic work from the formal help services (Valderrama et al. 1997).

4.1.2.2.3 Meals service

This programme is only available in the cities of Malaga and Cordoba in Andalusia, and in the city of Lerida in Catalonia (Imserso 2004).

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

There is help aimed at adapting the home to the needs of the dependent person under a variety of names in the communities of Andalusia, Castilla-Leon, Valencia, Extremadura and Navarre. Of the seventeen autonomous communities, at least ten offer teleassistance or telealarm services. Laundry, shopping etc. services are included in the home help service (Imserso 2004).

4.1.2.2.5 Community care centres

38% of the population of 65 or over go to the Homes and Clubs for the elderly, and more than half of these users (54.7%) are women. In practically all municipal areas there is at least one, and several where they are large municipalities (Imserso 2003), and in many cases they have the private financing of the social work of financial entities (La Caixa 2004, Caja Madrid 2004). These are centres engaged in promoting the leisure and social and cultural participation of the over 65s.

4.1.2.2.6 Day care ("protective" care)

In January 2002 in Spain there were 18,639 places in 956 Day Centres. 55% are public, of which 39% are managed by public entities and 16% by private entities in agreement. Catalonia has the largest offer of psycho-geriatric places (Imserso 2003). The coverage achieved with this service is 0.27%, nearly 0.15% in public places. Most of the users (67%) are over 80 and approximately 63% are women.

4.1.2.3 Other social care services

There are no more caring social services, except for the subsidies to carer self-help associations (Alzheimer). This is a fairly widespread programme, but there are no precise data.

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

The social services are not evaluated systematically. In general there is no knowledge of the quality of the social services.

However, it would seem that some of the problems related to doubtful quality are: The profile of the professionals, which is not always suitable for the work, especially work concerning supervision and management; the scarce interest of the workers in jobs concerning the hygiene and personal attention of the elderly; the frequently scarce connection between the workers and the users; the scarce mechanisms of co-ordination between services; the general scarcity of the service and the high levels of co-payment (Peinado 2003).

4.2.1 Who manages and supervises home care services?

Home help services are the responsibility of the Town Halls. Different management formulae have been drawn up: 1) Direct management through their own personnel, 2) Indirect management through agencies, 3) Direct assignment of help to families (Peinado 2003).

Formulae 1 and 3 are of doubtful effectiveness at least. In the first case, due to the high cost of personnel (the hourly service costs more than 17€) and finally, due to the complication of the relatives of the elderly person managing the help. In this case, the person concerned receives financing to contract outside help for caring or help with daily activities. They generally resort to irregular contracts by the hour, without assuming the corresponding labour costs, so the municipal money contributes to nurturing the submerged economy.

Indirect management through specialised agencies is the option gaining greatest importance for reasons of competence, efficiency, effectiveness and quality. These agencies are structured in a simple manner. At the head, there is usually a social worker performing the functions of a Manager/Co-ordinator, who directs a team of home helpers. The team is co-ordinated with the Municipal Social Services by means of follow-up meetings and the necessary contacts between the Head of the Municipal Programme and the Co-ordinator of the Agency.

The Town Hall is basically responsible for: a) attracting family units and individuals eligible to receive home help; b) evaluating needs and the financial contribution; c) proposing services and times; d) resolving inclusion/exclusion; e) follow-up of cases; f) monitoring the agency's performance.

The service agency must carry out: a) service provision; b) assignment of professionals, c) follow-up of cases; d) incident control and evaluation; e) fast reply to emergencies; f) report to the Municipal Social Services.

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?

As has been said, jurisdiction is autonomic and the regulations in each case render the area administration responsible for the work of authorisation, registration, approval and inspection of residential and day centres (CAV Decree 202 / 2000, CAV Decree 41 / 1998, CAM Order 1377 / 1998). This control is based on the fulfilment of the requirements established by the regulations from the structural point of view (location, internal distribution, facilities, services, etc.) and the functional (internal regulations, prices, fire prevention, programming).

In the home help service, the body responsible for monitoring the quality is the town hall itself, as mentioned before.

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

Professionals working in the social services are mainly social workers and home helpers or nursing auxiliaries with specific training in home help. The co-ordination is done by a social worker. The personal care work is covered by home helpers. Although the presence of psychologists, nurses, chiropodists, physiotherapists and other professionals is recommended, this does not happen very often and is not regulated (Peinado 2003). Care in dependent or assisted elderly residences is provided by clinical auxiliaries, where these constitute up to 55% of the personnel (EUSTAT 2001).

There is regulated professional certification for home help and Assisted Residence Auxiliaries. Professionals are defined as those who give help to individuals in their own home or in residences, when they are incapacitated temporarily or permanently for physical, psychological and/or social reasons (Ministry of Education, Culture and Sport 2004).

The training programmes vary from between 720 hours (six months) and 1,800 hours (eighteen months) in accordance with which each Autonomous Community establishes for the different modalities. Teaching is structured in three modules: a) Care and attention for the user, b) Domestic organisation, c) Training in work centres.

Training includes:

- Caring for the personal hygiene of the user: body hygiene, feeding, user mobilisation, provision of first aid.
- Basic domestic work: cleaning different kinds of surfaces, clothes hygiene and cleaning, ironing and sewing clothes, elementary and basic cooking.

- Activities of support to daily life: mobilisation inside and out of the home, accompaniment on medical visits, elementary bank dealings, leisure activities, etc. small domestic repairs.

The qualifications of social worker and nurse correspond to medium grade university training and last three years.

4.2.4 Is training compulsory?

By way of example, the regulations of the autonomous community of the Basque Country (CAV Order no. 4564 / 2001) and (Decree 202 / 2000) in the area of residential attention and day centres establish that professionals must have a technical qualification that corresponds to their professional level without specifying what it is, except for residencies with assisted places, which must have a nursing service. However, it is specified that all services must have a permanent personnel training programme.

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

There is no information concerning the existence of problems in this sense.

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

The integration of health and social care in terms of case-management, is very scarce. The different legal situation of both types of service has already been discussed, and is a severe obstacle for their co-ordination.

Apart from the “Vida als Anys” programme already discussed, there is the case in the Canary Islands and in Cantabria concerning attention for the vulnerable elderly from a single responsible body that co-ordinates the health and social services. The key element lies in the fact that in the two areas, the health and the social, the same instrument is used to evaluate needs. In the second instance, this model provides a central role to the “case manager” in determining the services required. Having made the evaluation, a social and health commission decides on the suitability of the resources available. The case manager has specific spokespersons in the health services and may choose the right resource from the range of health and social resources available (Casado 2002).

The remaining existing cases are very small scale.

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

We have no documentary evidence on this subject, however, it is not common practice in the public services to ask for the opinion of relatives.

5 The Cost – Benefits of Caring

The GDP for the country? (Will be obtained from OECD and others cccentrally)

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

Montserrat (Montserrat et al 2001) found that the expenditure on health and social services attributable to dependent people is 9.01 thousand euros per individual per year. Including pharmaceutical expenditure, individual expense per year is 9.62 thousand euros. This overall expense breaks down into 33% health services, 60% social services, 6% pharmaceutical products and around 1% in technical help. An elderly dependent person incurs a health and social cost ten times larger than a non-dependent elderly person. The degree of dependence is a determining factor of the expense. The passage from slight dependence to severe dependence means multiplying the means cost in health and social services by three and a half.

According to data from 1999, the most important section of social expenditure in Spain is that of pensions, which accounts for more than half (Imsero 2003). The percentage of the expenditure for the social protection of the aged (pensions plus social services) was 8.2% of GDP in 1999. This cost throughout the 1990s grew constantly by over 40% in the decade accounting for 41.9% of the total expenditure by social services.

In the year 2002, health expenditure was the second programme in the social charter (excluding education) and in the whole of the economy it absorbed 7% of GDP with an elasticity of over one unit. The nominal public health expenditure has grown in recent years, basically due to the type of services (increase in the use of technology), followed by the expansion of coverage towards universalisation and the increased price of health services. In 1997, health expenditure corresponding for the over 65s accounted for 40.3% of the total health expenditure (Barea 2002).

Taking the example of the autonomous community of the Basque Country in 2001, the expenditure in social services reached 1.8% of GDP (789 million euros) (retirement pensions are the responsibility of the national government through the Social Security). This expenditure is divided into three sections. Therefore, 587.3 million euros of current expenditure is aimed at covering the provision of services (74%). The second item referring to financial transfers to families reached the figure of 164.6 million euros (21%). This section mainly includes the funds intended to finance the Plan for the Fight against Poverty, and the pensions that do not belong to the Social Security (Non-Contributive Pensions, allowances of the Law of Social Integration of the Disabled and Social Welfare Funds). Finally, the third item of 37.2 million euros was aimed at investment (5%) (EUSTAT 2001).

62% of the expenditure was made in the public network and the remaining 38% in the private.

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

It is estimated that the users of public home help and residence services hardly even account for 7% of all dependent elderly people. Furthermore, users of long-term private services, either in guarded homes or residences, represent approximately 15% of all dependent elderly (Casado et al., 2003).

Table 6: Total estimated cost of long duration car in Spain. 1998

	EUROS	%
Public expenditure	5,234,814.5	27.1
Home help	1,690,286.1	8.7
Day centres	67,313.34	0.3
Residences	3,332,731.7	18.0
Private expenditure	14,098,599	72.9
Home help	5,635,268.8	29.1
Day centres	72,662.35	0.4
Residences	8,390,668.4	43.4
Total expenditure	19,333,474	100

Source: Casado et al., 2003

The total volume of public resources engaged in providing long-term care for the dependent elderly accounted for 0.6% of the GDP generated in Spain in 1998 (Casado et al. 2003). This situation is explained by the relatively greater importance that informal care still has in our country. Moreover, most of the formal care is seen to be given in the private sector. More than 70% of the total cost of care is generated by private agents (residences, home help agencies etc.) that do not receive public funds. As a result, the said cost is financed by the users of private services. Despite playing an essentially subsidiary role, in 1998 the public sector devoted 5,234,814.5 € to providing long term care. Despite the expansion of the Home Help Services in recent years, nearly 70% of the public cost is taken up by residential services. They are estimated to have transferred nearly 1,733,859.5 € in 1998 to the public sector residence service (sum of the 'net' cost and the contributions, as the 3,332,731.7 € aimed at residential places includes the contributions of the users).

In the expenditure of the autonomous community of the Basque Country in 2001, the home help service accounted for 5% of the total expenditure, and the resources intended for the elderly accounted for 30%, which includes 26.25% corresponding to residential centres for the elderly (EUSTAT 2001). The current expenditure per place in residences for the elderly was 16,107 eu-

ros. This ratio varies significantly depending on the type of residence, and increases by 48% in residences for the assisted elderly (30,557 euros) and falls by 68% in residences for the valid elderly (6,583 euros). The expenditure per place in public centres was 74% higher than in the private centres. The residences for the elderly were financed with a public contribution of 56% and the contribution of families, basically in the form of sales and provisions, was 37%.

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

In Spain, access to the health services is universal and free. However, there are limitations in the coverage of some services not considered essential, the users of which must acquire them in the private sector (dental attention is an example). For users of the social services, there are public prices established in the regulations dealing with each specific programme.

The user's contribution to the cost of public residential places lies at around 75% of their pension. In a day centre, they must contribute 25% of their pension (Casado et al., 2003).

I have only seen one study that analyses the cost of caring, including the cost assumed by the family. Boada indicates that the health services give families little release, that the direct costs incurred by patients only represent 23% of the overall costs of caring, whereas the indirect costs, the main component of which is the cost attributed to the main carer (average price per hour of 3 € , assigned by the author) represents 77% of the total cost of caring for the most severely dependent patients, 78% for moderate patients and 82% for the least severely dependent patients (Boada et al 1999).

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

There are no data concerning the national distribution. The example of the autonomous community of the Basque Country is the following: In 2001 (EUSTAT 2001), the large part of the expense was financed through public money (70%). The main sources of financing were the County Halls of the three historical territories (provinces) (39%), followed by the City Halls (15%) and the Basque Government (14%). Private financing covered the remaining 30%. Users contributed 14%, other outside sources 12% and finally, the net contribution of private institutions accounted for 4%.

The network of public centres is mainly financed through the County Halls (49%), City Halls (22%) and the Basque Government (20%). Public financing represents a total of 91% and the income from private sources, the remaining 9%, received almost entirely from the sale of services, though with territorial variations.

The private centres were financed 35% with subsidies and agreements with the administration, and private contributions covered the remaining 65%. Depending on the nature of the income, 50% comes from the sale of services, 37% arises from subsidies and agreements, almost entirely from the public administration, donations made by individuals account for 5%, other income 1% and the funds from the institutions themselves the remaining 7%.

Hospitals were fundamentally publicly financed (89% of hospital expenditure), and the remaining 11% was private (EUSTAT 2001).

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

We have not broken down data of the costs of residential care throughout the country. The prices of the residential homes depend on many factors: the ownership (private, approved or public), the degree of dependence and type of attention required by the elder (valid or assisted), the quality of the room and, in the public financed centres, the economic capacity of the resident. In the year 2000, the monthly price in private centres was almost 900 € . However, it is necessary to distinguish between profit-making institutions (some charge 1052 € a month) and the rest, normally religious, which charge around half of the others. A reference pricing is the most typical thing in public residential homes, which in the year 2000 was 702 € (Consumer 2000).

The average price of a residential place takes up 42% of the highest average salary in the country and 63% of the lowest average salary. It is also equivalent to twice the minimum interprofessional salary (451.20 euros per month) (ROYAL DECREE 1426 / 2002).

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?

As has already been indicated (Casado et al., 2003), the public resources used for giving long term care for the dependent elderly represent 0.6% of the GDP in Spain in 1998, moreover, a large part of formal care is given in the private sector and more than 70% of the total cost of the care is generated by private agents that do not receive public funds.

The financing of the Spanish health service is based on transfers from general taxation. The social services are financed on the basis of the general budget.

5.7 Funding of family carers

In Spain, carers bear the brunt of the cost of caring. Only very marginally is it possible to talk of public financing. As has already been said, there is no dependence 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	Carers´ allowance	Care leave
Restrictions	Family income Dependency level		
Who is paid?	The carer		
Taxable	?		
Who pays?	Autonomous Gov- ernment		
Pension credits			
Levels of payment / month	220 €		
Number of recipients in 2002	?		

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

There is no information available.

5.7.3 Are there tax benefits and allowances for family carers?

The government participates in financing care for the elderly with an income deduction on carers (Roncero 2003). Taxpayers of over sixty-five may reduce the base by 800 €, and for each ascendant living with the taxpayer who is over sixty-five or disabled, there may be a reduction of 800 €. A reduction is also programmed of 1,000 € a year for expenses associated with the assistance of the elderly or disabled when the taxpayer is over sixty-five.

In some communities (Madrid, Balearic Islands) help has been established for families attending elderly people in a situation of dependence in their own homes. These are characterised as having very demanding requirements for access and a very limited budget. In the case of the autonomous community of Madrid (CAM Order 1049 / 2003), the credit assigned was 2,877,246 euros in 2003 (in relation to the disability data for 1999 this is 14.54 € person / year). The annual amount of the aid is 2,710 euros per elderly person.

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

We do not have many data on this question, however, according to the CIS study on informal help, 63% of carers indicate that the elderly person they care for does not usually give them an economic reward, whereas nearly 23% regularly receive compensation and 13% do from time to time (CIS 1996).

The perception of the impact of caring for an elder on the family economy is fairly negative. The dependent person is not only perceived as someone who does not make any contribution from the economic viewpoint, but one who also supposes an expense, above all in families with a medium-low economic status, and although they do in fact contribute with their pension, this is generally low and does not cover the costs they incur (Agulló 2001).

In cases where the carer of the elderly person is the legal guardian, there is legally established economic compensation, provided the wealth of the elderly person so allows. The courts set the retribution in such cases, ensuring that it does not fall below 4% nor rise above 20% of the yield of the goods (Camino 2003).

A special case is that of Catalonia, where there is the figure of “self-guardianship”. The Catalan Family Code (CAT Law 9 / 98 of 15th July) establishes that the cared-for person, as well as being able to appoint their guardian, replacements and people excluded, can also establish the functioning, remuneration and content of their care, especially concerning personal care.

5.7.5 Carers' or Users' contribution to elderly care costs (check list of services and costs to user)

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

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care / old people's home				X		
Temporary admission into residential care / old people's home in order to relieve the family carer				X		
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)				X		
Laundry service						
Special transport services	X					
Hairdresser at home						
Meals at home						
Chiropodist / Podologist						
Telerecue / Tele-alarm (connection with the central first-aid station)				X		
Care aids						
Home modifications				X		
Company for the elderly						
Social worker	X					
Day care (public or private) in community center or old people's home	X					
Night care (public or private) at home or old people's home						
Private cohabitant assistant ("paid carer")			X			
Daily private home care for hygiene and personal care			X			
Social home care for help and cleaning services / "Home help"				X		
Social home care for hygiene and personal care				X		
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:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring		X				
Telephone service offered by associations for family members		X				
Internet Services		X				
Support or self-help groups for family members		X				
Counselling services for family carers						
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?

Carers criticise the pension system due to its low purchasing level, and particularly against the high price of the private services both in residential homes and at home (Agulló 2001). They also ask for more home help public services.

A second current aspect is that of dependence insurance and its future public-private articulation (Diario Medico, Casado 2002).

With respect to ill-treatment, although this is a subject for which there is an academic and political concern, there is no social echo behind it so that it is effectively foreseen and analysed (Caballero et al. 2000).

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?

The integration of the health system, the over-riding role that the hospitals are acquiring in attending the elderly and the lack of co-ordination with the social services cause practical problems that must be solved in the future (Casado 2002).

In favour of this is the fact that since 2001 the autonomous communities have had social and health jurisdiction. However the unequal coverage in both networks does not favour co-ordination. To this we add the lack of recognition of the right to social services, and their financing system. In this sense, a future dependence insurance might be a possible solution.

Other problems that must be solved from the health sector are: to strengthen and redefine the role of the primary care centres in attending the elderly in the community, to facilitate the participation and access of the general practitioners in hospital admission and diagnosis, and the creation of specialities more in line with the attention requirements presented by the elderly, such as geriatric nursing.

Finally, there is a great challenge facing all assistential services in Spain, which is that of considering the family a valid spokesperson when considering the care offered to the dependent elder (Biurrun 2001).

Furthermore, women who are now between 30 and 45 years of age are following lives that are very different from those of their mothers: they have fewer children and have them later, and the majority do not leave the labour market.

In short, a large part of the new generations of women have opted for a smaller family model in which they bring in their working life. Therefore, in the coming years, the collective of women prepared to work as informal carers is likely to be smaller, or they will have to combine it to a greater extent with formal work (Casado et al., 2003).

I believe that the evolution of Spanish society in the sense mentioned above will rapidly cause an increase in the demand for formal support services. The likelihood of relative economic prosperity will play a decisive role in this change, which will enable the above challenges to be overcome.

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

As has already been said, there are hardly any groups of carers not related to Alzheimer's disease. These associations are mainly self-help groups and only scarcely have any capacity to press those responsible for the social services, although they do have capacity to claim financial aid for their work.

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

Due to the generational and labour change of Spanish women, there is a feeling of uncertainty among current carers. They perceive a lack of reciprocity with respect to the coming generations of carers, and uncertainty as regards the future of those receiving care. The discourse becomes more acute among the older carers and those that are more alone (Agulló 2001).

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

In Spain, research concerning subjects relative to dependence, ageing and informal care has not been excessively developed. However, the National Plan of Scientific Research, Development and Technological Innovation (2000-2003) contemplates the area of ageing as a priority. State administration institutions have made clear the idea of facilitating and nurturing the area of the study of ageing.

Of the subjects of interest, it is necessary to indicate the study of the factors determining the differences noted in the awareness of the public services and its impact on use (Casado et al., 2003).

A dependence insurance and its expression in the public sector is another important challenge where the need is established for analysing the evaluation of dependence, the suitable degree of coverage, the type of insurance and fi-

ancing, the price and the criteria of determining the right to coverage (Camps 2000).

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

In Spain, as well as in other places, the Internet is becoming a means of spreading information. There are therefore more and more places where carers are able to obtain general information, self-help recommendations, contacts, resources, research or bibliography. Imsero offers the "Portal Mayores", and Fundación La Caixa, Obra Social Caja Madrid, Fundación Matia, Asociación Española de Geriátría y Gerontología, are other resources that offer interesting information via internet to the elderly and their carers.

"The Experts Centre" is an Internet application experiment to resolve problems in caring for the elderly. It is sponsored by the Red Cross and the Obra Social de Caja Madrid (Cruz Roja. 2004). It is a website that offers a consulting service to a group of experts. Users are able to find free professional advice on questions that affect daily life: health, meals, advice on legal and business matters, volunteer force, addiction etc.

6.7 Comments and recommendations from the authors

No comments and recommendations provided.

7 Appendix to the National Background Report for Spain

7.1 Socio-demographic data

In the year 2000, with a figure of nearly 17% of the population over 65, Spain is one of the oldest countries in the European Union, behind Italy, Sweden and Greece and practically on the same level as Germany and Belgium. Current projections of the population (updated in 2001) indicate continuance in the tendency to greater ageing. If in the year 2000, it was calculated that there were 6.8 million people of 65 or more, in 2020 this figure will reach 8.6 million. In the year 2050 there will be 12.8 million (Cantalapiedra 2002).

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

The Spanish population has undergone a profound change in the past century. It has multiplied by 2.3 and its structure has varied with increased weight to the elderly. There has been a general ageing process throughout the 20th century. The percentage of young men under 20 fell from 37.30% in 1970 to 21.57% in 2001. The evolution is similar in women, falling from 34.21% in 1970 to 19.53% in 2001. On the other hand, the population of over 65 increased from 8.90% for men in 1970 to 14.60% in 2001 (18.71% in 2025 and 27.28% in 2050). Women increased from 11.10% in 1970 to 19.45% in 2001 (24.50% in 2025 and 34.67% in 2050).

Table 7: Trends of Spanish population

Year	Total population (millions)	Males > 65 years (per cent)	Females > 65 years (per cent)
1900	18.62	2.47	3.18
1950	28.12	2.94	4.25
1991	39.43	5.59	8.02
2001	41.12	7.14	9.79

Source: INE. Population data. Own preparation (INE 2004)

Table 8: Projections of the weight of the elderly by age and sex in the total population. Years: 2004, 2010 and 2015

Age	2004		2010		2015	
	Male	Female	Male	Female	Male	Female
65-69	2.10	2.44	2.23	2.54	2.45	2.78
70-74	2.06	2.60	1.77	2.21	1.97	2.41
75-79	1.55	2.18	1.63	2.29	1.44	2.01
80-84	0.95	1.59	1.09	1.80	1.15	1.90
> 85	0.54	1.27	0.69	1.61	0.81	1.89
Total	7.20	10.06	7.43	10.45	7.82	10.99

Source: INE. Projections of population calculated on the basis of the 1991 census. Evaluation and revision. Own preparation (INE 2004)

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

Life expectancy has increased along with the age and is higher for women.

Table 9: Life expectancy by sex, at birth and at 65

Age	Male	Female
0 Years	75.25	82.16
65 Years	16.11	20.09

Source: INE Mortality Tables. Year taken as a base for the estimation 1998

The Health Survey of the Community of Navarre (Navarre Government 2000) brings in the concept of “quality adjusted life expectancy”, which reduces expectancy at 65 by almost three years for men and almost five for women.

Table 10: Life expectancy at 65 and adjusted by quality

Male		Female	
Life expectancy	Quality adjusted life expectancy	Life expectancy	Quality adjusted life expectancy
16.60	13.82	21.22	16.58

Source: Navarre Government. Health Survey 2000

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

The weight of the population over 65 by age groups (of 5 years) and sex in the general population is:

Table 11: Population over 65 by age and sex according to their weight in the general population

Age	Male	Female
65-69	4.86	5.34
70-74	4.10	4.87
75-79	2.96	3.97
80-84	1.57	2.57
85-89	0.73	1.47
90-94	0.24	0.58
95-99	0.04	0.12
100+	0.01	0.02

Source: INEBASE. Anticipated results of the Censuses of Population and Housing 2001. Own preparation (INEBASE 2003)

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

The data available are the following:

Table 12: Population of over 65, according to marital status, age and sex

Age	Gender	Single	Married	Widow / er	Seperated	Divorced
65-69	Male	8.05	83.82	5.89	1.45	0.79
	Female	7.23	66.29	24.29	1.35	0.82
70-74	Male	7.55	81.83	9.02	1.06	0.53
	Female	8.49	54.69	35.44	0.89	0.47
75-79	Male	6.10	78.17	14.70	0.72	0.30
	Female	9.49	40.26	49.37	0.58	0.29
80-84	Male	5.18	70.99	23.12	0.50	0.20
	Female	10.22	24.81	64.47	0.34	0.15
85-89	Male	5.00	59.20	35.22	0.43	0.14
	Female	10.48	12.67	76.53	0.21	0.11
90+	Male	5.33	39.51	54.65	0.35	0.16
	Female	10.38	4.79	84.63	0.13	0.07

Source: INEBASE. Anticipated results of the Censuses of Population and Housing 2001. Own preparation (INEBASE 2003)

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

Most of the elderly live with other people.

Table 13: Population over 65, by type of coexistence

Age	Single female	Single male	Couple	Other
65-69	8.39	3.99	41.59	46.03
70-74	13.19	4.34	46.66	35.80
75-79	18.92	4.84	45.78	30.45
80-84	24.08	5.41	39.46	31.05
85-89	25.62	6.01	31.95	36.42
90+	22.14	6.41	25.95	45.50
Total	15.35	4.64	42.46	37.55

Source: INEBASE. Anticipated results of the Censuses of Population and Housing 2001. Own preparation (INEBASE 2003)

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

The available data provide no specific classification between rural and urban. However, it is possible to try to estimate this categorisation on the basis of the size of the residence population. There is a considerable proportion of elderly who live in very small municipalities (probably rural), although most do so in medium or large cities. There do not seem to be very large differences as regards the age associated with the size of the municipality.

Table 14: Population of over 65 by size of the municipality where they live

Size of Municipality	65-69	70-74	75-79	80-84	85-89	90+	Total
< 500 Inhabitants	3.19	3.71	4.15	4.32	4.86	5.77	3.85
501-5,000 Inhabitants	16.59	17.51	18.21	18.72	23.16	20.53	17.73
5,001-20,000 Inhabitants	19.48	19.15	18.77	18.68	18.48	18.48	19.05
20,001-50,000 Inhabitants	12.31	11.96	11.52	11.03	10.41	9.82	11.69
50,001-100,000 Inhabitants	8.82	8.40	8.14	7.88	7.55	7.17	8.32
100,000-500,000 Inhabitants	21.17	20.40	20.10	19.90	19.68	18.97	20.42
> 500,000 Inhabitants	18.44	18.87	19.11	19.46	19.65	19.25	18.92

Source: INEBASE. Census of Population and Housing 2001. Definitive results (INEBASE 2003). Own preparation

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

In Spain, dependence is a subject that has been studied little and partially, and existing studies are generally small and are difficult to compare due to the differences in the dependence categories used and the characteristics of the populations.

The main comparative study that has been carried out finds that (Casado et al., 2003): Almost 35% of the elderly population need help with at least one daily activity, however, the level of help is different and also the impact of dependence in the activity of the life of the elderly person. Of those who declare difficulties in carrying out the Instrumental Activities of Daily Life, 20.8% of the over 65s, it is possible to establish three categories of elderly depending on the overall level of dependence: a light level, bringing together 76.7% of the dependent people; a moderate level with 14.6% of the group and severe, with the remaining 8.7%. In the group of people who say they have problems with the Instrumental Activities of Daily Life and with the Activities of Daily Life (13.4% of the elderly), the distribution varies with a fall in the weight of the light cases, in other words: 36.8% have light dependence, 33.6% have a moderate level and 29.6% are severely dependent.

Age is a determining factor in dependence. The immense majority of dependent subjects are over 80. Additionally, the poorer the health and the lower the educational level (and consequently poorer working conditions during their active life) the higher the level of dependence is.

In many cases, light dependence passes unnoticed until the person (normally the spouse) who was giving practically invisible support disappears.

Whereas there is a problem of dependence in 21% of married people, 38% of widows or widowers experience this problem. Obviously the larger number of widow / widowers is noticeable at higher ages, but it must not be forgotten that solitude and a lack of support affect the perception of one's own autonomy (Puga et al. 2002).

These data referring to the general population of the country change when the universe is focused on agricultural areas and medium-sized populations, where severity is higher, even though the incidence of a self-evaluated incapacity appears lower than the national average. In the autonomous community of Navarre, a mostly rural province, among the over 65s, disability reaches a rate of 287.7 per thousand. If we deal with the degree at which the presence of disability supposes that this disability is total for performing the task in question, the rate achieved is 220 per thousand, that is 77% of people complaining of some disability have it totally (Navarre Government 2000).

The national disability rate lies at 32.211% according to INE data (1999) (INE 2000) varying between 40.49% in the community of Murcia to 18.32% in the community of La Rioja.

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

The income of the over 65s in Spain comes from pensions (Herce, Perez-Diaz 1995). In fact, only 18% receive economic aid from their children, and only 4% consider they receive help that might be qualified as significant.

In 2002, the average pension in Spain (Imsero 2003) was 513 € , although 4.8% of pensioners received 240 € a month on average, with the lowest pension lying on 207.5 € . Specifically, the lowest pension is the widows pension, and it is the women who receive the lowest pensions, with an average 25% below the general average.

In the year 2000, two out of every three Spaniards of 65 or more (65.7%) received a contributory retirement pension, with variations in the geographical distribution (La Caixa 2004).

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

Current population studies in Spain do not cover the "ethnic group" concept as such. However, they do deal with the "nationality region". In any case, with the latest data available, the presence of foreigners of over 65 is testimonial.

Table 15: Population of over 65 according to the region of the world where they are national

Nationality	Total
European Union	99.61
Rest of Europe	0.9
Africa	0.6
Central America	0.03
North America	0.04
South America	0.13
Asia	0.03
Oceania	0.002

Source: INEBASE. Census of Population and Housing 2001. Definitive results (INEBASE 2003). Own preparation

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

The form of housing occupancy is largely ownership. It seems that with age, there is also a higher probability of there being options other than ownership.

Table 16: Population of over 65 by form of occupancy of their home

Age	Ownership	Rental	Cesion	Other
65-69	88.52	7.32	1.18	2.97
70-74	87.89	7.88	1.30	2.93
75-79	86.80	8.61	1.57	3.02
80-84	85.34	9.39	1.95	3.32
85-89	84.40	9.52	2.30	3.78
90+	84.74	8.82	2.41	4.03

Source: INEBASE. Census of Population and Housing 2001. Definitive results. Own preparation (INEBASE 2003)

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 provision of equipment in the homes of the elderly is fairly high, excluding lifts. Bath, hot water, refrigerator and televisions are found in more than 94% of the homes of the elderly; there is a telephone in 89.1% of homes and heating in 36.1% (Imsero 2003).

Table 17: Population of over 65 by lack of equipment in the home

Age	Lack of water	Lack of elevator	Lack of bathroom	Lack of heating	Lack of telephone
65-69	0.32	69.51	1.17	55.01	0.43
70-74	0.31	70.71	1.28	56.50	0.42
75-79	0.31	71.11	1.40	57.82	0.43
80-84	0.31	70.98	1.61	56.68	0.47
85-89	0.33	70.70	1.77	58.24	0.50
90+	0.36	71.22	1.91	57.23	0.37
Total	0.32	70.47	1.36	56.74	0.44

Source: INEBASE. Census of Population and Housing 2001. Definitive results (INEBASE 2003). Own preparation

7.2 Examples of good or innovative practices in support services

As has been said before, good practices are scarce bearing in mind the general scarcity of social services. However, there are more and more significant examples and this path is likely to continue. We must highlight the Vida als Anys programme in Catalonia, already referred to, as an example of management of assistential services and co-ordination between health and social services; the Assistential Cheque in Galicia and the Carer Subsidy in Madrid, as examples of help to families in financing care; Carer Training in Cantabria and the Canary Islands as examples of training carers and the Sendian pro-

gramme in Gipuzkoa as a good example of case- management. Though limited, these are examples that are setting a model to be followed.

8 References to the National Background Report for Spain

- Abengonzar MC, Serra E. 1997. Empleo de estrategias de afrontamiento en cuidadoras familiares de ancianos con demencia. *Rev Esp Geriatr Gerontol* 32, 257-269
- Abengonzar MC, Serra E. 1999. La sobre carga en las mujeres cuidadoras de familiares ancianos con demencia. *Psicogeriatría*. 15, 225-237
- Agulló T, M^a Silveria. 2001. Mujeres, cuidados y bienestar social el apoyo informal a la infancia y a la vejez. *Estudios* n° 74, Instituto de la Mujer
- Aranburu I, Izquierdo A, Romo I. 2001. Analisis compartativo de necesidades sociales de cuidadores informales de personas afectadas por Alzheimer y ancianos con patologia no invalidante. *Rev Mult Gerontol* 11, 64-71
- Ariza M. 2003. Obreras sirvientas y prostitutas. Globalización, Familia y mercados de trabajo en la República Dominicana, www.migracionydesarrollo.org. 11
- Artaco L, Artieda L, Borrell C, Cortes I, Benach J, Garcia V. 2004. Combining job and family demands and being healthy. *European J Pub Health* 14, 43-48
- Benitez del Rosario MA. 2003. Reflexiones sobre la realidad de la atención domiciliaria. *At Prim*; 31, 478-479
- Bermejo F, Rivera J, Trincado R, Olazabal J, Fernandez C, Gabriel R, Grupo Estudio NEDICES. 1997. Aspectos del cuidado sociofamiliar al paciente con demencia datos de un estudio poblacional de dos zonas de Madrid. *Rev Gerontol* 7, 92-99
- Biurrun A. 2001. La asistencia de los familiares cuidadores en la enfermedad de Alzheimer. *Rev Esp Geriatri Gerontol*. 36, 325-330
- Boada M, Peña-Casanova J, Bermejo F, Guillen F, Hart WM, Espinosa C, Rovira J. 1999. Costes de los recursos sanitarios de los pacientes en regimen ambulatorio diagnosticados de enfermedad Alzheimer en España. *Medicina Clinica* 113, 690-695
- Caballero JC, Remolar ML. 2000. Consideraciones sobre el maltrato al anciano. *Rev Mult Gerontol* 10 (3) 177-188
- Caballero JC Remolar ML Garcia R. 2000. Programa de intervención sobre el síndrome psicologico postcaída en el anciano. *Rev Mult Gerontologia* 10, 249-258
- Caja Madrid 2004. Servicios. www.obrasocialcajamadrid.org
- Camino Garrido V. 2003. La incapacitación de las personas mayores. Informe Imserso CSIC. www.imsersomayores.csic.es

- Camps G. 2000. Seguro de dependencia 2000 Sala de Conferencias de Recoletos Compañía Editorial. www.recoletosconferencias.com
- Cantalapiedra M. 2002. El envejecimiento demográfico en España. Fuentes Estadísticas Españolas - Revista N° 68 - Septiembre-Octubre. www.ine.es
- Casado D, Rico A, Sabes R. 2002. Asistencia integrada a los ancianos dependientes en España CSIC. *Documentación Social* (127), 247-275
- Casado D. 2003. El futuro del seguro de dependencia. *Gac Sanit* 17, 1-3
- Casado Marin D, López i Casanovas G. 2003. Vejez, dependencia y cuidados de larga duracion en España. *Estudios Sociales*. N° 6. La Caixa
- Castells X, Mercade LI, Riu M. 2002. Envejecimiento y Utilización Hospitalaria. Informe SESPAS, 495-510
- CIS. 1996. Ayuda informal a las personas mayores. *Estudios de Opinion* 4. Estudio CIS 2117. www.cis.es
- CIS. 2001. Barometro de noviembre de 2001, Estudio n° 2.439. www.cis.es
- Código Civil: Libro I: Título IX De la incapacitación. <http://civil.udg.es/normacivil/estatal/CC/1T6.htm>
- Consellería de Asuntos Sociais, Emprego e Relacións Laborais. 2001. Programas E Servicios. Gobierno de Galicia. www.xunta.es
- Cruz Roja. 2004. Club de expertos. www.cruzroja.es, 37
- Decreto 202 / 2000, de 17 de octubre, sobre los centros de día para personas mayores dependientes. B.O.P.V. n° 214, miercoles 8 de noviembre de 2000
- Decreto 41 / 1998, de 10 de marzo, sobre los servicios sociales residenciales para la tercera edad. B.O.P.V. n° 66, martes 7 de abril de 1988
- Diario Médico. 2000. El Gobierno aborda el seguro de dependencia. 18 de mayo. www.diariomedico.com
- Diario Médico. 2002. La Sociedad Española de Geriátría reclama una estructura sanitaria y social prioritaria para los ancianos. 30 de julio. www.diariomedico.com
- Diario Médico. 2003. Los abuelos golondrina con la maleta a cuestas de casa en casa. 27 de octubre. www.diariomedico.com
- Diario Médico. 2002. La Sociedad Española de Geriátría reclama una estructura sanitaria y social prioritaria para los ancianos. 30 de julio. www.diariomedico.com
- Diputación Foral de Gipuzkoa. 2004. Sendian <http://www.gipuzkoa.net/gizartekintza/sendian/recursos.htm>
- EUSTAT. 2001. Estadística hospitalaria. Analisis de resultados. www.eustat.es

EUSTAT. 2001. Estadísticas de Servicios Sociales. Análisis de resultados. www.eustat.es

Galvez J, Ras E, Hospital I, Vila A. 2003. Perfil del cuidador principal y valoración de ansiedad y depresión. *At Prim* 31, 144-145

Gobierno de Canarias. 2002. "Programa de atención a las Personas Mayores en Atención Primaria" Departamento de Sanidad y Consumo. www.gobcan.es

Gobierno de Navarra. 2000. Encuesta de Salud. Departamento de Salud. www.cfnavarra.es/salud/docencia.investigacion/textos/encuesta_salud_2000

Gornemann I, Zunzunegui MV. 2002. El incremento de la utilización de servicios hospitalarios por las personas mayores de 55 años: envejecimiento poblacional y respuesta del sistema de servicios de salud. *Gaceta Sanitaria* 16, 156-159

Grupo ATDOM de la Societat Catalana de Medicina Familiar i Comunitaria. 2003. Aproximación a la atención domiciliaria. ¿Cómo trabaja la sanidad pública catalana la atención domiciliaria? *At Prim*:31, 473-479

Herce JA, Perez-Diaz V. 1995. La reforma del sistema público de pensiones en España. *Estudios económicos* nº 4. La Caixa

Imsero. 2003. Cuidado a la Dependencia e Inmigración. www.seg-social.es/imsero/biblioteca/docs/emay03-01.doc

Imsero. 2003. Plan de acción para las personas mayores 2003-2007. Ministerio de Trabajo y Asuntos Sociales. www.imersomayores.csisc.es

Imsero. 2000. Las personas mayores en España. Informe 2000. www.imersomayores.csic.es

Imsero. 2004. Portal Mayores. <http://imersomayores.csic.es/>

INE. 2000. Encuesta sobre Discapacidades, Deficiencias y Estado de Salud, 1999. Avance de Resultados. Datos Básicos. www.cermi.es/documentos/descargar/Encuesta_Discapacidades_1999.pdf

INE. 2002. El entorno económico y social en 2002. www.ine.es

INE. 2003. Mujeres y Hombres en España. Nota de Prensa 1 octubre. www.INE.ES

INE. 2004. INEBASE. Censo de Población y Viviendas 2001. Resultados definitivos. www.ine.es

INEBASE. 2003. Datos provisionales de la Encuesta nacional de Salud, 2º Trimestre 2003. <http://www.INE.es>. Elaboración propia

INS. 2002. Encuesta de satisfacción de los usuarios con los servicios de Atención Primaria 2001. www.msc.es

Institut Municipal de Salut Publica. 2002. Enquesta de Salut de Barcelona, Ajuntament de Barcelona. www.aspb.es/quefem/docs/resultats_principal.pdf

La Caixa. 2001. Anuario Social de España. Indicadores sociales Provinciales. www.anuarisoc.lacaixa.comunicacions.com

La Caixa. 2004. Servicios para los mayores. www.fundacio.lacaixa.es

La Parra D. 2001. Contribución de las mujeres y los hogares mas pobres a la producción de cuidados de salud informales. *Gac Sanit* 15, 498-505

LEY 39 / 1999, de 5 de noviembre, para promover la conciliación de la vida familiar y laboral de las personas trabajadoras. (BOE 6-11-1999)

Ley 5 / 1987 de Servicios Sociales de la Comunidad Autónoma de Extremadura. <http://www.juntaex.es/>

Ley Orgánica 10 / 1995, de 23 de noviembre, del Código Penal.

Llacer A, Zunzunegui MV, Beland F. 1999. Conocimiento, uso y previsión de servicios sanitarios y sociales de apoyo al cuidador de personas mayores con incapacidades. *Rev Esp Geriatr Gerontol*; 34, 34-43

Lopez O, Lorenzo A, Santiago P. 1999. Morbilidad en cuidadores de pacientes confinados en su domicilio. *Atención Primaria*, 24, 404-410

Medina M, Fernandez J, Fuentes M, Hernandez M, Perez R, Grupo Alumnos TS. 1998. Evaluación del impacto en cuidadores de usuarios del Servicio de Ayuda a Domicilio. *Anales de psicología* 14, 105-126

Ministerio de Educación, Cultura y Deporte. 2004. www.mec.es/

Montserrat J, Rodriguez G. 2001. Los costes asociados a la dependencia en las personas mayores: una aproximación. *Rev Mult Gerontol*; 11, 122-131

Montserrat J, Rodriguez G. 2001. Los costes asociados a la dependencia en las personas mayores: una aproximación. *Rev Mult Gerontol*; 11 (3):122-131

Moral MS, Juan J, Lopez MJ, Pellicer P. 2003. Perfil y morbilidad psíquica en cuidadores de pacientes ingresados en su domicilio. *Atención Primaria* 32, 77-87

Orden 1049 / 2003, de 29 de agosto, de la Consejería de Servicios Sociales, por la que se convocan ayudas a familias que atienden en su domicilio a personas mayores en situación de dependencia. (Boletín Oficial de la Comunidad de Madrid de 3 de septiembre de 2003)

Orden 1377 / 1998, de 13 de julio, por la que se regula la tramitación de solicitudes y adjudicación de plazas en Centros Residenciales de atención a Personas Mayores que integran la red pública de la Comunidad de Madrid. (Boletín Oficial de la Comunidad de Madrid de 15 de julio de 1998)

Orden 368 / 2003, de 1 de abril, de la Consejería de Servicios Sociales, por la que se regula la admisión de usuarios en los pisos tutelados para personas

mayores de la Comunidad de Madrid. (Boletín Oficial de la Comunidad de Madrid de 28 de abril de 2003)

Orden Foral nº 4564 / 2001, de 4 de junio, Departamento de Acción Social, por la que se crea y regula la Comisión Técnica de Valoración de Personas Mayores, BOB nº 127, de 3 de julio de 2001

Peinado Álvarez. 2003. Las agencias de cuidadores profesionales. Congreso Nacional de Enfermería de Salud Familiar y Comunitaria. www.faecap.com

Prieto MA, Gil E, Heierle C, Frias A. 2002. La perspectiva de los cuidadores informales sobre la atención domiciliaria. Un estudio cualitativo con la ayuda de un programa informático. Rev. Salud Publica; 76, nº 5:613-625

Programa Acción. 2000. El seguro de dependencia, a punto de ver la luz. Nº 2. <http://www.fundaciononce.es/graficos/programa-accion/programa-accion.asp>

Puga González MD, Abellán García A. 2002. La predicción de una vejez dependiente. Revista Fuentes Estadísticas. Fuentes Españolas - Revista Nº 68 - Septiembre-Octubre. www.ine.es

Real Decreto Legislativo 1 / 1994, de 20 de junio, por el que se aprueba el Texto Refundido de la Ley General de la Seguridad Social.(actualizado a fecha 27 / 01 / 03) (BOE 29.06.1994)

Revista Consumer. 2000. Residencias de ancianos. Dotación de personal: suficiente, con algunas excepciones. 30 Febrero. www.revista.consumer.es

Revista Consumer. 2001. Informe: Ancianos en casa. Febrero. www.revista.consumer.es

Rivera J, Rivera S, Zurdo A. 1999. El cuidado informal a ancianos con demencia: análisis del discurso. Rev Mult Gerontol; 9:225-232

Roca M, Ubeda I, Fuentesalz C, Lopez R, Pont A, Garcia L, Pedreny R. 2000. Impacto del hecho de cuidar en la salud de los cuidadores familiares. At Prim 26, 53-67

Segura JM, Bastida N, Marti N, Riba M. 1998. Los enfermos crónicos domiciliarios y su repercusión en los cuidadores principales. At Prim 21, 431-436

Tortosa Chuliá MA. 1999. La reorientación de los cuidados a enfermos terminales una perspectiva económica. Rev Mult Gerontol;9: 161-168

Valderrama E, Ruiz D, Adame JF, Garcia C, Garcia PA, Perez J. 1997. El cuidador principal del anciano dependiente. Rev Gerontol: 7, 229-233

Vallés MN, Gutierrez V, Luquin AM, Martin MA, Lopez F. 1998. Problemas de salud y sociales de los cuidadores de los pacientes con demencia. At Prim 22, 481-485

Zunzunegui MV, Del Ser T, Rodriguez A, Garcia MJ, Domingo J, Otero A. 2003. Demencia no detectada y utilización de los servicios sanitarios: implicaciones para la atención primaria. At Prim; 31, 581-586

Zunzunegui MV, Beland F, Llacer A, Keller I. 1999. Family, religion, and depressive symptoms in caregivers of disabled elderly. J. Epidemiol Community Health 53, 364-369