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

EUROFAMCARE

National Background Report for Greece

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Content

Main Findings and Recommendations

Family Carers

As the findings from this report indicate, family care is still not on the public agenda. However the substantive demographic and socio-economic changes occurring in Greece suggest that if family carers are to continue to take on the responsibility for older family members, the state must offer some forms of support, if increasing levels of abandonment of older people, hospital bed-blocking and declining health status amongst family carers are to be avoided. For those family carers on a low income, this support is likely to take the form of pension and insurance rights and economic recognition, while for all family carers there is an evident need for information, respite care, day care centers and reliable home social and health care services for the older person.

The setting up of any kind of group to support family carers is a phenomenon of the past five years in Greece, and such groups are few numerically. Some of the models for family care support organizations e.g. Alzheimer Association, have been developed in collaboration and with the encouragement of similar bodies in Europe and the U.S.A. Older people are rarely organized into advocacy groups with the exception of some pensioners rights groups who are almost entirely focused on pension issues.

Recommendations:

- The *voice of carers* can best be heard in national support organizations for family carers. The few existing family care organizations in Greece need to cooperate and develop a common campaign to to extend their activities and to inform bodies such as the KAPIs, Pensioners' organizations, public, religious and NGO social-welfare organizations, of the need for appropriate ways to support family carers.
- Few family carers are aware of the existence of self help organizations; existing organizations should consider developing a common 'advertising strategy' setting out the goals and help provided by the existing bodies. In addition it would be useful if they provided *information* for family carers.
- The *development of a common European policy* towards the support of family carers, with the stated need to increase participation (especially women's) in the labour force, should be seen as an opportunity for family carers to press for some forms of support and sensitivity in existing and developing public services. The success of family carers' organizations in other Member State's countries in putting family care on the policy agenda and sensitizing policy makers to the issues, should be used to back Greek national efforts and local organizations.

- The *findings of the EUROFAMCARE Greek research* will be of particular importance in sensitizing family carers and older people's organizations to the need to support family carers. Consideration needs to be given to how best to conduct *a publicity campaign* to make the main findings of the research known, combined with the development of family carer support groups.

Service Providers

The report and limited initial research on service providers by students at the National School for Public Health, indicates that few service providers are aware of the needs of family carers and what forms of support can best help them. Health professionals need to consider the kind of information and technical knowledge that would ease the burden of caring for older people with high levels of dependency and chronic illnesses and would help preserve and maintain the health of family carers themselves. Social care providers should consider how to use existing and newly developing services to provide family carers with support in parallel with the services provided to older people themselves

Recognition of the value of care provided to older people by their informal family carers can be acknowledged by professional care providers by including carers in evaluation and support plans for the older people they serve, as well as respecting and advising on their own needs for care, if this is requested.

Recommendations:

- All professional providers of services to older people need sensitization to the needs of family carers and *training in the evaluation of these needs*. This needs to be incorporated into medical training, training in other health professions and in social work and social care courses. Given the lack of specialized gerontological services, all service providers need to be aware of the issues associated with ageing and family care.
- Integrated care teams providing services to older people should include family carers as valued members of the team.
- The development of support groups for family carers should be encouraged as part of the normal service offered by the main health and social care providers e.g. KAPI, Help-at-Home, General Hospitals, IKA polyclinics, Centres for Mental Health etc.
- Residential care facilities (Elderly Care Units) should be actively encouraged and subsidised to provide short term respite care packages for dependent older people, so that their family carers can be assured of high quality care when they take a break from their caring responsibilities.

Policy Makers

The demographic developments in Greece and all the European Union, including the ageing of the population, the rise of employment rates amongst women over 45 years of age (those most likely to be involved in the care of family relatives of an older generation), the rise in single person households, in divorce, in small families and geographical mobility, make the issue of the health and social support of older people a key policy issue for Greece for the coming decades. While spouses and families are still predominant in the care of dependent older family members, this is often at tremendous cost to their own health and well being. Given the high cost of institutional care and the preference for older people to stay in their own environments, full consideration needs to be given to how best to support Greek family carers. If such measures are not taken there will be an increase in the abandonment of older people, increases in physical and mental health problems amongst family carers, longer stays in acute hospitals and the associated increase in costs.

Recommendations:

- *Financial support* for family carers is critical since many of the problems revolve around finance and the considerable number of households with elderly members that live below the level of poverty. Grants to carers and recognition of the equivalence of care work for social insurance contribution purposes for family carers would help support their work.
- *Day-care* facilities that allow family carers to leave their older person with serious health problems e.g. memory, physical disability, while they go out to work full or part time, would support them and help achieve the goal of increasing employment rates. Such centres should also make provision for all family carers who need a break from constant care.
- *Home care and support.* Existing services provided through Local Authorities, Prefectures e.g. KAPIs and Help at Home, Centres for Mental Health, need to be strengthened and extended in order to specifically and purposefully include the support of family carers in their work agenda.
- *Elderly Care Units* for both short and long-term care of dependent older people need to be de-stigmatised, regulated and recognised as fulfilling a necessary social function, so that real choices can be made by older people and their families when making decisions about care.
- *Social Tourism* should be systematically extended to cover and target groups of family carers and their older people. This will require help with transport and infrastructure in the residential units / hotels used, but may provide a break and some relief to family carers with few resources. Facilities will need to be provided at the central level, opportunities given for family carers to meet and discuss their problems and solutions, and for older people to meet and socialize with one another, as currently occurs in the organized KAPI and Local Authority camps for older people. Once instituted this programme could be extended to the European level with the promotion of off peak holidays and relief care for family carers and their older dependent relatives.

EUROFAMCARE – National Background Report for Greece

Introduction – An Overview on Family Care

The family network available for caring for older people reflects past and current demographic changes, namely a progressively declining and low birth rate, greater longevity, earlier rural-urban migration and increasing female participation in the paid labour market. This will continue to impact on the availability of family carers over the next decades, as both available kin networks become smaller, with fewer children and siblings, and social and gender expectations change. In many rural areas dependent older people have no children living near them and the onset of dependency may require relocation to the urban homes of their children. Earlier patterns of substantial external migration have further reduced the availability and proximity of family carers. The past 12 years have also seen a significant inward migration from non EU Member States, (currently approximately 10 % of the local population), many being attracted by the availability of illegal and increasingly legalized work as paid carers of older people, mainly under the supervision of family carers.

Currently there are no signs that the birth rate is rising, while life expectancy, both at birth and at age 60 years, continues to increase, though more slowly than in other EU Member States.[1]

The family, though nuclear and based on the married couple and their children, tends to be part of and / or create and sustain a frequently extensive family and kin network, including grandparents, co-in-laws, “koumbaroi” (godparents, marriage witnesses) and others. This network is drawn on throughout life for all kinds of help and support, essential still in a society where welfare state provision is limited, and is activated through continuous exchanges of gifts, economic and practical support, information and personal contacts, as well as social exchanges. Older people who have ‘paid into’ such a family system can expect to draw on this network when they need help and many continue to contribute through their pensions to supporting younger family members at times of unemployment, further studies, or as payment for care. Exchanges are essentially unequal since those with more economic resources are able to provide more support for children and the wider family network, though other forms of practical support and personal relationships may counterbalance such economic inequalities in network strengths. Although poverty is still strongly associated with ageing, it is those poor with inadequate networks, few social resources and separated from children or other kin who are most at risk of having no family support when dependent.

The historically residual nature of the state in the field of welfare has not essentially changed, though increasing recognition and associated services are given to older people without adequate family care. Thus state and local

[1] Greece is now 9th in life expectancy, whereas 10 years ago it was in second/third position.

provision focuses on the socially isolated and economically deprived sections of the population and there is virtually no discussion on the extension of such limited and new facilities to those with family carers, except where the family carer is also elderly or absolutely unable to support the elderly person due to disablement or chronic ill health. The limited form of public support for family carers comes mainly through the use of the state medical services for the dependent elderly person. However there are enterprising and innovative examples of support in a few Local Authorities which have extended their social and community work with older people to include all those in need of care.

The real increase in per capita income at national level is very unequally distributed; families and older people with middle or higher than average incomes tend to purchase private personal care services through the employment of migrant care workers. Heavily drawn from the Eastern European ex-communist countries, they are often middle-aged women unable to find work in their own country or earn enough money to support their families. While there was for many years a legal market for private carers, drawn primarily from the Philippines, Santa Dominica, etc., and serving the wealthier section of Greek society, the availability of cheap labour in the past decade and the demand for such services created a large growth in the numbers acting as paid carers for older people. Such carers often substitute for family carers in terms of the practical tasks of care, though family carers usually remain in charge of their payment, supervision and management. In 1998-9 350,000 migrants were given residence / work permits, with attempts in 2002-3 to legalize a further 300,000. Many of the women seeking legalization are family carers, mainly for older people. The state provided the opportunity for families to pay reduced social insurance contributions (IKA) for such carers, helping to stimulate their legalization. Nonetheless an unknown number remain illegal.

Some Greeks, mainly poorer women, also act as paid carers and in low income neighbourhoods some neighbours may become regular substitute or additional carers in return for payment, but the extent of this is unknown. During the 1990s, the Greek Red Cross organised regular training courses for Home or Family Helpers for older people, but these courses were discontinued when state funding was withdrawn. There are now many organized agencies providing care workers but these are all in the private sector and there is no state supervision or regulation of how they function.

The numbers of volunteers are increasing in many areas of Greece and many are active in providing support for elderly people. How far they are also providing support for family carers is unknown. Friends and neighbours often support family carers by sitting with the dependent older person while the carer undertakes essential tasks. The Orthodox Church, to which most (97 %) Greeks are really or nominally associated, provides support to older people in local parishes who are in need; again the degree to which they will help family

carers is unknown, but regular or known members of the congregation and local community will be the concern of the parish priest and the church volunteers. Small minority religions (Jews, Armenians, Protestant, Catholic and Muslims) offer some support to the isolated elderly in their communities and where family carers are known to need help, undoubtedly they would receive some from church volunteers.

Local authorities have tried mainly through their KAPIs, to organize volunteers to support older people and their carers, but there is a lack of experience in developing voluntarism.

The Hellenic Red Cross offers systematic training to volunteers who work with the elderly and their families, though the focus remains primarily the older person rather than the family carer. Nonetheless they have experience in the systematic training, management and support of volunteers periodically called upon by outside NGOs.

There are no epidemiological or Health Interview Survey data on disability levels amongst Greek older people, although there are disability estimates for Greece from the WHO (WHO, 2003). These figures estimate that 5 % of the total population are in need of daily care (using the two severest Global Burden of Disease study disability categories, levels 6 and 7) rising to 7 % when the three severest G.B.D. study categories (levels 5, 6 and 7) are used. As can be see in the Appendix, about ½ of those needing daily care are older people, although the proportions are predicted to rise within the next 50 years.

There is limited evidence that older Greeks report poorer health than other older EU members– despite quite good longevity – suggesting that they may have a higher than EU average level of demand for care. (Triantafillou J et al, 1996)

There is no long-term care insurance in Greece, either in the public or private sectors. Socio-political discussion reflects debates on increasing employment rates and the viability, sustainability and rational reorganization of the pension funds, given the low percentage of 15-64 year olds (especially women) in the labour market and the rapid increase in the numbers of pensioners. A discretionary system of payment of tax rebates to family carers appears to be the main policy direction for the support of family carers at present. The large demand on the public health services comes mainly from the elderly and their family carers and reflects the lack of alternative forms of care. The use of acute general hospital admissions for dependent older people is a widely recognized form of “respite care” (Mestheneos, Triantafillou 1993, Triantafillou, Mestheneos1994). In addition though private clinics and residential homes may be used by family carers for respite care, there is considerable unwillingness both because of the negative image they have for older people

and family carers overall, and because the state has played a minimal role in their supervision, the training of their personnel and their accreditation.[2]

Training courses for paid carers have been rare to non-existent, although there have been sporadic attempts to implement these within the context of improving the labour market prospects for special groups e.g. migrant workers, as well as skills improvement / management courses for young, unemployed women.

No extensive research work or information is available on the dimensions of family care in Greece or the needs of carers. There is little indication that anyone is concerned with the support of family carers, with the exception of carers of those with Alzheimer disease. Other groups such as the isolated elderly or the disabled have political priority and appear in the government plans to overcome social exclusion. However some services, recognizing the need for support of older family carers, may well also be offering some form of carer support.

Since families do in general undertake their caring responsibilities, it is only in cases where this fails that the state will intervene. The use of migrant labour by an unknown but critical[3] proportion of the Greek population, for which there are no figures but only guesstimates, suggests that this is a political solution supported by the government.

There is no real discussion about the provision of integrated health and social care services for older people and even less about the inclusion of family carers in such plans.

[2] The only standards applied by the Ministry of Health and Welfare appear to be concerned with what can be termed the ‘hotel’ aspects of the facilities - space, cleanliness and kitchen/bathroom facilities.

[3] Private solutions are disproportionately used by the more educated and ‘modern’ section of Greek society, thus removing a potentially active source of pressure on government and local authorities to provide adequate public services and support for family carers.

1 Profile of family carers of older people

1.1 Number of carers

There is no Greek national data.

1.2 Age of carers

There is no Greek national data. In a small qualitative study of 24 carers in 1990 for the European Foundation (Triantafillou, Mestheneos 1993a) two thirds of carers were over 60 years of age.

1.3 Gender of carers

There is no Greek national data.

1.4 Income of carers

There is no Greek national data.

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

There is no Greek national data. In a small qualitative study of 24 carers in 1990 for the European Foundation (Triantafillou, Mestheneos 1993a) carers listed the tasks which they performed. For carers of a different generation one of the most difficult tasks was keeping company with the older person, while for all carers dementia caused the most distress. Physical problems arising from caring included bad backs from lifting heavily dependent people.

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

There is no Greek national data. The figures on educational levels overall, show that those with higher levels of education are more likely to be in the labour market e.g. those with a university degree constitute 9.4 % of the labour force and only 4.2 % are non active compared with those finishing primary school only who constitute 34.8 % of the population of working age, but 41.4 % of the non active; those with even lower levels of education e.g. 5.2 % having only some classes of primary school or 4.2 % with no schooling, are least likely to participate in the labour force, 9 % and 7.4 % respectively (NSSE Labour Force Survey 2002). However, low levels of education are also age related; thus older women with low levels of education are also those likely to

be economically inactive (73.4 % of older people had an educational level of ISCED 2 or lower, versus 50 % in the EU, and women were even less educated than men, with 8 out of 10 having only basic schooling). This situation is changing rapidly for the younger generation of women. In the recent EuroStat report (2003) overall 21 % of women aged 55-64 years were inactive because of family responsibilities; but in Greece many of these had also no work experience.

1.7 Generation of carer, in relation to OP. Relationship of carer to OP

There is no Greek national data. Based on the EuroBarometer study (1993) Walker (1998) reported the following breakdown in regular sources of help for older people.

Table 1: Regular sources of help for older people (1993)

Source of help	Greece	EU 12
Spouse	46.5	31.5
Co-residential child	38.6	19.3
Child not living with them	26.9	20.6
Other co-residential kin	3.2	5.9
Other non residential kin	7.3	7.9
Friends	2.4	5.6
Paid private help	6.4	16.7
Neighbours	6.5	5.9
Public services	2.2	12.5
Voluntary sector	0.7	2.6
Other	0.6	2.1

Source: Walker (1998)

1.8 Residence patterns

Data show an increase in the numbers of older people living alone. ECHR data for 1994 (Iakovou 2000) show that living alone is related to increased income levels. In Greece 63 % of older people over 70 years of age live alone or just with their partner. Non-married women are very likely to live alone. Women who never had children also are more likely to live alone (81 %) while 19 % live with others: they are also more likely to have a higher educational level and income than married women with children, 46 % of whom live alone, and 52 % live with their children. Increasing age was also related to the propensity to receive care.

FEANTSA (European Federation for the Homeless) in the National Report for Social Inclusion (2002.) reported that 29 % of all households care for someone

who is dependent; this includes children, the dependent disabled as well as dependent older people.

Previously established common patterns of residence in the 1950s-90s, in both urban and rural areas of Greece, of parents building flats and houses to ensure their children lived in close proximity to them, have gradually been replaced by the independent migration of children away from their parents to more affluent suburbs. No data is available on this or the current proximity of older parents to their children.

Seasonal differences in residence patterns also exist with the winter population of the two major cities (Athens and Thessaloniki) increasing as older people spend the winter with urban children, both to help with the care of grandchildren and the household in general while the parents are at work, and also to avoid the harshness of winter in rural village houses with no central heating or amenities, including lack of easy access to health care facilities. This situation is reversed in the summer when older Greeks usually go back to their village residences, frequently taking grandchildren to stay with them during the extensive school summer holidays. The onset of dependency upsets the balance of these reciprocal arrangements, since the working generation then has to provide care for both younger and older dependants.

In the major cities for non co-residents, distances and differences in location make caring more difficult.

1.9 Working and caring

There is no Greek national data. In the small qualitative study undertaken in 1990 in Lesbos and Athens with 24 family carers, only 3 were in full time work, while 4 had part time work: this reflected the relatively high average age of the carers, two thirds being over 60 years of age. (Triantafillou, Mestheneos 1993a)

1.10 General employment rates by age

There is no Greek national data on carers and employment.

General employment rates show that in the age group 45-64 years, 35.9 % of women are employed compared to 71.8 % of men (ESYE Labour Force Survey 2002). Overall the rate of labour market participation in paid employment in this age group went up from 34.8 % to 35.9 %. Overall women's LM participation rate is low though it has increased (42.3 % in 1992 to 50.2 % in 2002) and this has systematically affected overall labour market participation figures (58.7 % in 1992 to 64.47 % in 2002).

Table 2: Employment Rates for Men and Women over 30 years of age.

	2000			2002		
	Total	Men	Women	Total	Men	Women
Total	44.5	57.7	32.3	44.0	56.8	32.2
30-44	73.8	91.5	57.4	74.8	92.1	58.7
45-64	53.2	72.8	34.8	53.3	71.8	35.9

Source: NSSG Labour Force Survey, B Trimester. Figures from Chletsos 2002

It should be noted that in the working age group of women 15-64 years, 40 % of the labour force is aged 45-64 years. Part time employment is the lowest in the EU. Women continue to leave agricultural employment and employment as non-remunerated assistants in family businesses and enter salaried / waged employment.

However, still outstanding is the number of Greeks, including women, who are self-employed (44.3 % of those aged 45+ both sexes).

Table 3: Distribution of women's employment 2002-2002

Employment	2000	2002
Self employed with staff	3.8	3.4
Self employed without staff	17.8	18.9
Assistant in the family business	16.8	14.2
Employees	61.5	63.5

Source: NSSG – Labour Force Survey. Chletsos 2002

Thus, although part time employment may be desirable for family carers from the practical point of view of combining working and caring, it is perceived as earning inadequate wages. In fact much labour market flexibility with respect to combining family care responsibilities with work exists de facto for family carers in self employment and family businesses.

1.11 Positive and negative aspects of care-giving

In a small qualitative study undertaken in 1990 (Triantafillou, Mestheneos 1993a) amongst the 24 carers, 8 reported their health as bad and 11 said their health status had deteriorated while caring. Only 3 said they had no psychological problems as the result of caring. 7 had clinical depression while many others reported symptoms that were probably psychosomatic. 4 had back problems while there were multiple other physical complaints.

When asked about the positive aspects of caring, 50 % could say nothing positive about the caring role. Only 3 reported positive emotional rewards from caring e.g. sensitivisation and support from other family members, and emotional bonding for 2 carers who had "learned to love through caring" and appreciated the new experience of caring for a dependent person. For 3 carers

the financial aspects of caring were significantly positive as they benefited from the older person's income (pension, disability allowance etc).

An elderly abuse[4] study undertaken in 1989 indicated that Greece does not face a great problem of violence and mistreatment of its elderly citizens; the major forms of abuse are psychological, specifically, verbal abuse. (Pitsiou-Darrough, Spinelli, 1995, p.p. 45-64)

No specific reports on elderly abuse were found in the Greek literature.

1.12 Profile of migrant care and domestic workers (legal and illegal)

There is no research on the total numbers of migrant care workers for older people. Research by MRB-Hellas (2003) with 491 migrants aged > 18 years in Athens, speaking Greek and having applied for residence, showed that those from Eastern Europe were disproportionately female (60 %), while overall 13 % of respondents were domestic workers – though not all of these are involved in the care of the elderly. Women workers were less likely to be insured through the national social insurance funds. A very rough estimate suggests that the total numbers of legal and illegal migrants[5] is in the region of 1,000,000; if a half of the 13 % of those registered as domestic workers, i.e. 6.5 % (a conservative estimate), are involved in the care of older people, then 65,000 are probably working as carers for older people. Even in a much earlier study in 1986 (Pitsiou 1986) 18.1 % of Athenians reported receiving paid help for the care of older people. Based on a Eurbarometer study (1993) Walker (1998) reported 6.4 % of Greeks reporting having regular paid help to support older people. Since this date the numbers of domestic workers, mainly from non-EU countries, has increased.

The population of > 65 years from the 2001 National Census was 2,030,585 of which, using guesses and estimates from other countries, 10 % are in need of care support (203,058), though WHO gives a higher prevalence of dependency levels for > 60 year age group. Thus a very rough estimate might indicate that 27 % of older people in need of support receive it from foreign care workers. More accurate figures may be available when results from interviews with 1000 family carers in Greece through the EuroFamCare study are completed.

[4] Defined as an act of 'neglect', may be intentional or unintentional, may be of a physical nature, or psychological (involving emotional or verbal aggression), or it may involve financial or other material maltreatment.
www.who.int/entity/violence_injury_prevention/violence/global_campaing/en/chap5.pdf

[5] Definitions of legality/illegality are difficult since although earlier applicants received Green Cards (270,000) these also had to be renewed on a regular basis. The Greek public services are unable to speed up the regularization and legalization processes, leaving many migrants in insecure legal situations. This makes the situation of employing such care workers difficult for family carers. (Mestheneos, Triantafillou 1999)

There has been a substantial and interesting change in the numbers and country of origin of care workers; prior to 1990 such workers were from a few countries such as the Philippines, and mainly came in as invited employees of the wealthier and as nurses. Currently women from many countries, though especially Eastern Europe, (Bulgaria, Ukraine, Moldavia) actively seek employment in Greece as carers of older people. Such forms of care workers are found supporting family carers in rural as well as urban areas and in all social strata, except the very poor. (Mestheneos, Triantafillou 1999)

1.13 Other relevant data or information

No further data of relevance.

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

The grounds for the award of public social-economic support include old age and incapacity, though this does not directly include support for those offering informal care for older dependent people. There was some recent interest by the Ministry of Labour in family care policy but as yet little has been developed and there is no case law. In addition the government has changed and the policies and practices of this government are still unclear.

Only indirect care policy exists through insurance, welfare and tax support.

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

There is no published data from the Ministry of Health and Welfare on family care. Supplementary pensions for incapacity or dependency may be used by family carers to aid them in caring, but there is no data on this. IKA provides some benefits (epidomata) thorough its General Directorate; the analysis of epidomata in terms of the reasons for their allocation are not publicly available.

What are the expectations and ideology about family care? Is this changing?

For the current generation of those aged 40+ who may be involved in caring, the support offered within the family and by extension to all its older members, is part of a historic and critically important emotional and financial safety belt. While women traditionally provided physical and nursing care as spouses and daughters / daughters in law, men are also increasingly involved in caring and participate to varying degrees in the tasks associated with caring for older dependent parents and parents-in-law, as well as their wives. Men, as sons, may seek paid help from women if parents need physical care.

Earlier geographic mobility (rural to urban), the growth in the numbers of old people, and in the numbers of women in the paid labour market, are factors helping to change expectations about family care. (Triantafillou, Mestheneos 2001)

The rapid social and educational changes that have occurred have also made the gap between the generations substantive and children have other expectations as to what they will do in their lives, though this is not reflected in the EuroBarometer studies of 1992 and 1999 where Greeks of all ages still report that they would expect to care for frail relatives over 60 years of age (Walker 200). In 1990, in a small qualitative study, women expressed their wish to have had more choices about the extent to which they had to care for

elderly dependent relatives (Triantafillou, Mestheneos 1993). This may be interpreted as an expression of increasing individualization in Greek society as well as the higher levels of income, allowing more choices about the extent and types of care that will be offered to a dependent older person. Those able to afford paid carers are increasingly turning to migrants as a solution for care and domestic support. This is seen as generally preferable to institutional care since the older person is enabled to stay in their own, or their children's, home. In ideological terms the living-in paid migrant family care worker becomes an additional member of the extended family; the 'paid for' poor substitute daughter.

The Ministry of Health and Welfare refers in its reports (www.ypyp.gr) to such social changes in attitudes concerning care. Media programmes still pick on institutional / residential care as being the 'bad' form of care for the elderly, thus supporting the continued use of migrant workers and making those families using such homes feel slightly guilty.

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

Invalidity is defined in terms of the percentage of total disability of the individual. Applications for pensions and benefits are judged by the various Medical Committees for the different Insurance Funds and decisions made after the appearance in person of the applicant. Obviously this is a difficult process for highly dependent older people and, in theory, arrangements can be made for home visits when indicated. However, the bureaucratic procedures involved may deter all but the most persistent families from pursuing such applications (Triantafillou and Mestheneos, 1993a). Each social insurance fund has a different legal basis for the granting of pensions and benefits, which are based not only age but also on the individual contribution record.

There are no legal entitlements to benefits for carers.

There are Invalidity supplements for those needing constant care (see below).

Who is legally responsible for providing, financing and managing care for older people in need of help in daily living?

The family under civil law is responsible for the care of its dependent members of all ages.

Where the family cannot provide such care, then Social Security policy operates. This legal responsibility of the family is specified in the Constitution of 1975, amended in 1986 and 2001, which includes the highest norms in the hierarchy of rules of law.

Although the constitution itself does not mention the concept of "social security", two provisions in the revised text are particularly relevant for the recognition of the fundamental right to social security: in Section 21 the following is stated (those parts of relevance are mentioned and in bold):

- **The family**, as the basis for the preservation and progress of the nation, as well as marriage, mother and childhood are under the protection of the State.
- Large families, war invalids and invalids of peacetime, victims of war, war widows and orphans, as well as the incurable physically and mentally sick, are entitled to special State care.
- The State will care for the health of citizens and will adopt special measures for the protection of young people, **the elderly and invalids**, as well as for assistance to the needy.
- For those without any or with insufficient accommodation, housing support is subject to special State care.
- Persons with special needs are entitled to take advantage of measures, which "guarantee their personal autonomy, employment inclusion and participation in the social, economical and political framework of the country".

Despite responsibility being delegated to both the family and to the State there is very great difficulty in enforcing these provisions since it requires action by the public legal service (legislator). Both in legal doctrine and in case law the legislator is given a wide discretion with regard to the concrete implementation of social rights. It should also be pointed out that in Greek law there is no legal remedy by which the legislator can be forced to act. (Amitsis, see www.ggka.gr)

Psychosocial services are available in the community mental health centres, but there is no data on their use by family carers.

In cases where family care is inadequate, the political authorities have the responsibility to intervene for the care and protection of the older person.

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

There are virtually no experts on family policy – many lawyers handle family cases and thus there are no specialists in family law.

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

There is no national legal definition of old age but rather the various Insurance Funds make rules which define the age or length of service which confers

rights. There are over 200 funds with a large variety of systems and rules. Over 50 % of the population are insured by IKA (Urban Workers' Insurance Fund), which defines retirement in terms of contribution payments completed, so workers in what are called dangerous or dirty / heavy occupations may obtain entitlements to a pension earlier than the current standard 65 years for men and 60 years for women. Individuals with inadequate numbers of years of contributions or no insurance coverage are granted the lowest level of pension entitlement.

Another major section of those on pension receive an entitlement to pension without necessarily having made any insurance contributions – OGA, the Agricultural Workers' Pension, awards pensions both to non insured farmers and others not insured at the age of 67. Until recently, this was a non-contributory system, which was financed by contributions from other pension funds and the state. However, additional voluntary contributions can now be made to bring the amount up to the level of other basic pensions.

Women with under age children in some insurance funds e.g. Civil Servants and Bank Employees, used to be eligible to receive a pension after 15 years of work – thus pensions have been conferred without reference to age and current attempts to reform these unsustainable systems are being met with fierce resistance by those negatively affected.

People aged 60+ or 65+ may have access to subsidized rail fares, and through the KAPIs may obtain Culture Cards for free or reduced tickets to museums, theatres, cinema etc.

2.2 Currently existing national policies

Family carers?

No national policies exist that directly concern family carers.

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

There are invalidity allowances i.e. special supplements that are provided to persons with increased needs due to invalidity:

- Paraplegics and tetraplegics who have established a contribution record of at least 1,000 days are entitled to a special monthly allowance equal to 20 times the minimum daily wage of an unskilled worker. (20 X 22.35 euros in 2002)
- Persons with an invalidity degree of 100 %, who are in need of constant care by a third person, are entitled to a monthly allowance equal to 50 % of the basic pension rate.

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

There is labour legislation e.g. a right to take paid and unpaid days off from work for family obligations. This is significant in the public sector (6 days unpaid for family care responsibilities). Given that most employers run small businesses and that many people are self-employed, there is often some flexibility through personal relations.

2.3 Are there local or regional policies or different legal frame-works for carers and dependent older people?

No.

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

Some local authorities give discretionary grants and benefits (epidomata). There is a legal basis for this, but the details and exact extent are unknown. Such grants are given through the Social Service Dept of the municipality or the elderly service and KAPIs. Several of the newly developed Help at Home services which mainly focus on poor and isolated dependent older people, are starting to extend their programmes to offer family carers support, thus freeing women who wish to stay in or reenter the labour market. This policy is unofficial and depends on staff and the individual Local Authorities access to funding enabling them to extend their activities. There is still no centralized data available on the services currently operating in local authorities. (Personal communication)

3 Services for family carers

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standard-ised assessment of the caring situation)	X[6]							
Counselling and Advice (e.g. in filling in forms for help	X							
Self-help support groups		X[7]					X	
“Granny-sitting”		X					X	X
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X				X[8]		
Weekend breaks	X							
Respite care services		X[9]			X	X		
Monetary transfers								
Management of crises		X[10]						
Integrated planning of care for elderly and families (in hospital or at home)	X							
Special services for family carers of dif-ferent ethnic groups	X							
Other								

3.1 Examples

Greek Alzheimer support group - GARDA

See Appendix for a description of GARDA. Similar groups are described as being run by the Hellenic Gerontological and Geriatric Society and two Hospitals in the National Report for Greece within the ProCare EU funded programme (Leichsenring,Alaszewski, 2004).

[6] The COPE Index, a screening instrument for carers, has been translated and validated for Greece, but there is no information on whether it is being used. (McKee, Prouskas et al. 2003)
[7] very few
[8] Red Cross
[9] Summer camps
[10] new service

A Support Group for Family Carers of Dependent Older Members of the KAPI Neos Kosmos, Athens also existed as a voluntary initiative, though it is currently not functioning due to lack of funding.

"HELP AT HOME" Pilot Programme

See Appendix.

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

For family carers attempting to access health and social services both for the older person they care for and for their own use, a major problem is the lack of available information and data at a national level and the Greek Company for Local Authorities' Development (EETAA) is currently collecting such information for public use. This lack of information reflects a corresponding lack of formal, well-organised services in both the public and private sectors, although in the private sector the ability to pay gives a greater choice in decisions about how to manage different aspects of care. In using available services in the public, private and NGO sectors, older people and their family carers act as consumers, frequently utilising a mixture of these in attempting to address their needs for health and social care, depending on their resources.

4.1 Health and Social Services

Health services

Within the framework of national and local health care provision, there are no health services specifically for older people, although the Open Care Community Centres for Older People (KAPI) offer some primary health care services, mainly focussing on preventive and health promotion programmes and often in collaboration with other local primary care services such as IKA clinics for the provision of continuing care e.g. management of chronic conditions, drug prescriptions, blood pressure and diabetes monitoring etc.

In 1983, a National Health System was introduced (Law L1379 / 1983), operating initially at the hospital or secondary health care level, but expanding over the next few years into the primary care sector with the building and operation of 196 Health Centres in rural areas, administered through the Peripheral Health System. In urban areas, primary care is still fragmented and unevenly and unequally distributed, depending on the user's insurance fund. General hospital emergency services are heavily "mis"-used by older people especially (Triantafillou and Mestheneou, 1994a), reflecting the non-comprehensive nature of primary care and the gaps and difficulties in using the primary care services of many insurance funds, as well as the additional costs frequently incurred. There have been recurrent attempts to unify the primary health care system, but both the high cost involved and the vested interests of those with better insurance funds, as well as the complex combination of health insurance and pension contributions in most of the funds, has resulted in minimal reforms until now. Thus, the main public health services used by family carers and those they care for are the IKA primary

health care centres, the rural Health Care Centres and the acute hospitals. Some general observations affecting family caregivers are:

- Emergency hospital admission frequently involves long delays in the Emergency Department, followed by a shorter or longer period in a temporary corridor bed in the admitting clinic when there is a shortage of beds.
- Poor patient record systems result in family carers having to take responsibility for keeping all medical records, remembering prior interventions, medications etc.
- Long waiting lists for some public health services e.g. hip replacement, catarract operation, with the consequence that carers are often forced to pay for services in the private sector.
- In rural areas waiting lists tend to be shorter; however the absense of some essential specialities is still notable, meaning family carers have to make enormous efforts to get to a centre offering a needed specialty.

It should be noted that these problems in health service use are not confined to older people, but are common to users of all ages. However, the increased needs for services by older people means that their family carers experience the problems with greater frequency than other sectors of the population.

4.1.1.1 Primary health care

General or family practice, which is the basic medical specialty for primary care, has only recently been introduced in Greece and is still not a popular option for both doctors and patients, although numbers are increasing.

There are community and home care teams attached to the IKA primary health care centres, the KAPIs[11] and the rural Health Centres, although most are not comprehensive in their cover. Family carers can access these and for IKA clinics there is now a central appointments system. Where the person cared for is known to be housebound, home visits may occur, though some payment is expected. Most family carers use a mixture of public and private services to obtain the necessary care for their dependent older relatives.

There is an overall shortage in numbers of nurses at the secondary or hospital care level and thus home nursing care is very limited. District or community nursing is an underdeveloped branch of the profession, although there is a recent government proposal to provide more extensive nursing services in the primary health care sector.

Physiotherapists may make home visits though mainly privately.

There are no home dental services and this can cause great problems for house-bound older people and their carers.

[11] Open Care Community centres for the Elderly

Chiropody is not a recognized profession, although pedicures can be privately arranged.

Home lab tests are relatively easy to arrange for a fee in the extensive private laboratory service sector, and there is some limited public sector provision– the family carer usually acts as the coordinator in arranging these.

4.1.1.2 Acute hospital and Tertiary care

As already noted, there are long waiting periods in many emergency or out patient departments in hospitals that affect both family carers and the cared for person.

For routine admissions, Hospital Admissions lists may not be strictly adhered to, with the result that family carers try to use any personal contacts to “pull strings” and facilitate the admission of their cared for person. Carers also find difficulties in the public sector in planning for their own admissions for health problems and in making alternative care arrangements for the cared for older person. (Mestheneos and Triantafillou,1993)

Geriatrics is not a recognised specialty and there are no professorial university departments, geriatric beds or special geriatric facilities. Many hospital clinics are disproportionately used by older people, for example internal medicine, cardiology, neurology and orthopaedics, as well as the Emergency Department. (Triantafillou and Mestheneos, 1994a)

There are 3 rehabilitation centres in the Athens area in the public sector, serving all ages but heavily used by older people. There are also private rehabilitation centres but usage depends on the ability to pay rather than age e.g. one such private centre is well known for treatment of basket ball players and for older people with motor problems. Most family carers have to undertake rehabilitation by themselves at home with suitable medical and physiotherapy advice and one hospital orthopaedic department makes specific efforts to recruit family carers to collaborate with rehabilitation of post-operative hip-replacement patients, after self-audit showed clearly superior results in home vs. institutionalized rehabilitation. (Triantafillou and Mestheneos, 1994a)

4.1.1.3 Are there long-term hospital care facilities?

There are 3 state owned units for care of patients of all ages with chronic conditions, comprising a total of 2,600 beds (Ministry of Health and Welfare July 2002, reported in Sissouras et al. 2003).

Many private clinics are used both for remedial and palliative care of older people. Some of these private clinics take in patients insured under various Insurance Funds; thus IKA will pay a large part of the private costs for terminal patients or up to a period of 6 months. However, there is minimal or no cover for this type of care by the Agricultural Workers Fund, which is the only

insurance cover held by a large proportion of older people and no public long term care facilities or insurance.

State General Hospital departments offer acute treatment facilities and stays are necessarily limited. The common practice by family carers of using acute hospitals for "respite care" occurs especially during holiday periods and is well-recognized by hospital staff, who may concur with or resist such attempts at "unnecessary" admissions (Mestheneos and Triantafillou, 1993). Also, some overburdened carers are driven to abandoning the older person in the Emergency Department or by not coming to pick them up when acute treatment is finished and the EKAB (Emergency Ambulance Service) have a rule that they cannot take home dependent older people unaccompanied.

4.1.1.4 Are there hospice / palliative / terminal care facilities?

At least two Athens hospitals, serving mainly cancer patients, operate home nursing and palliative care services for cancer victims of all ages, many of whom are older people.

There is no hospice movement and acute general hospitals as well as private clinics are often used for terminal care.

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

Although inpatient admission of their older person may initially relieve the family carer's immediate burden of total care, carers are still expected to participate actively in most aspects of hospital care. Laundry, nursing assistance, personal care, help with feeding etc are all assumed to be tasks performed by the patient's family members, who have to devise a complicated rota system to cover the older persons various care needs.[12] In cases where this is not possible, paid carers may be used and lists are provided by the hospital administration of "apokleistikes" i.e. privately employed, semi-trained nursing assistants who can be hired, especially for the night shift, on an 8 hourly basis to provide individual care for any sick patients. Limited re-imbursement of these costs is given by some insurance funds e.g. IKA, but this involves a lengthy bureaucratic process and most carers simply pay out of their own pockets for this service, if required. This is expensive and issues of equity arise, with the wealthier being able to afford such payments or choosing to go into private hospitals. Alternatively, a previously employed migrant carer may accompany and stay with the older person during a hospital admission. Additional tasks which are expected of and usually undertaken by family carers are facilitating contacts and communicating with health care personnel, accompanying the patient to appointments, taking specimens and collecting

[12] Family care is provided for patients of all ages, since the absence of adequate nursing provision remains problematic.

results, being responsible for test results and discharge summaries and delivering them to the primary health care doctor.

Although the acute hospitals are well staffed with doctors and recruitment to the nursing profession has increased somewhat, overall numbers of nurses are still inadequate and less that in most EU countries. (WHO 2003) Problems also exist in the mutual expectations of nurses and family carers regarding obligations and duties in the care of patients, especially when these are older people with their increased needs for intensive personal and nursing care.

Social services

The 1998 Law 2646: Development of the National System for Social Care: and a National Action Plan for Social Integration 2001-3, contains a section on "Regional Organization of National Systems of Social Care" (Ministry of Health and Welfare). It is foreseen that the coordination of the health and social services will take place under the health administration as a centralized mechanism implemented through the 17 Regional Health Systems. Welfare services will be means tested for all persons in relation to their particular personal, family, financial and social needs (Sissouras et al. 2002). However, the new government (March 2004) has new plans for health and social services reform.

Residential care (long-term, respite)

Residential care has never played a major part in long term care for older Greeks, due to a mixture of traditional cultural values regarding the roles and obligations of the family, together with a corresponding lack of high quality care facilities.

Family carers sometimes use private residential homes for temporary respite care. However, the quality of care may not be sufficiently high to meet carers' standards and carers reported finding their older person dirty and uncared for, and with a marked deterioration in their physical and mental condition, following an unavoidable temporary admission to residential care (Triantafillou, Mestheneos 1993). Also, the cost of care affects staffing levels, which may be inadequate, thus further contributing to poor quality of care.

Private medical clinics are also used as long-term care facilities for older people with more severe health problems and higher levels of dependency. They are regulated regarding basic levels of medical and nursing staff, although for very intensive care needs, it is often still necessary to employ private nursing assistants as in state hospitals. Admission to such clinics mainly depends on the ability to pay.

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

Residential care is used by less than 1 % of those over 65 years of age and the oldest and most dependent sector of the elderly population, as well as those without family carers who tend to be in this type of long term care. In a small, non-representative study of family care of older people in the Athens area, 17 % of the men and 29 % of the women being cared for spent their terminal phase in a nursing home or clinic. (Amira, 1990)

There is limited information about residential care facilities and no reliable statistics available (Ministry of Health and Welfare 1999). Indeed the figures available are suspect since many residential homes operate without any license from the Ministry of Health, or may be licensed only as a private hotel, whilst operating effectively as a care facility for older people. Many state residential institutions are primarily geared to those with a low income or the chronically ill (2,600 places only). There are an estimated 57 private not for profit institutions for 2,800 individuals over 60; the Orthodox Church has 74 care institutions and hosts 2,700 persons (Sissouras et al 2002 p.22). There has been no change since the report which pointed out that in Attica alone in 1997 there were 300 private homes functioning without any legal coverage (Emke-Poulopoulou, 1999: p. 449) Estimates for private residential care homes suggest that they had 3,200 older people in residence.

In a recent media interview (October 2004) the Minister admitted that the largest, oldest and amongst the best residential units, operated without a license from the State. The supervision of homes is spasmodic and partial and family carers have to judge for themselves and from the opinions of others as to whether the standards are adequate.

There is no formal sheltered housing. Many families make their own arrangements for “supervised care” by living in the same block of flats or very near to their older relatives. This contributes to reciprocity in care by facilitating both child-care for working parents and flexible support for increasing age-related dependency when this occurs.

Criteria for admission (degree of dependency, income)

Amongst the standard criteria for admission to a Residential Care facility is the ability to be self-caring regarding personal care needs. However, there are indications that, as in other EU countries, there is an increasing trend for Residential Care to be used by more highly dependent older people, in the absence of other alternative care facilities or of suitable and adequate home-care services (Leichsenring, Alaszewski 2004). Being a member of a religious group may facilitate admission to some residential homes run by specific religious organisations, which often subsidise costs for those unable to pay the full price.

Thus, income is effectively the main criteria for admission to most private homes, with the degree of dependency affecting the price, as most homes charge extra for those requiring special or increasing levels of care.

In public foundations (NIPD) there is considerable discretion as to the criteria for admission and insurance funds may contribute to the costs for those older people unable to live at home.

Public / private / NGO status

As already indicated, there are no reliable official figures on numbers and types of residential care facilities and although most are private, there are also some large homes run by public foundations e.g the two main Elderly Care Units in Athens and Pireas, as well as many smaller local units run by the Orthodox Church and other churches of various denominations. The latter are usually subsidized and take a proportion of residents who are unable to pay the full cost of care. Private facilities range from luxury class – and expensive – to very poor, overcrowded, understaffed and not registered.

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

Small residential homes which exist in local areas, such as those run by the Orthodox Church in the different parishes, are often used by working family carers when there is no possibility of accommodating the older person in their own home – the proximity gives the opportunity for frequently popping in and out to provide personal care, food and company for the older person when the carer is not at work. Most residential homes encourage the active participation of family carers as it both eases the care tasks for the staff and improves the well-being of the older person.

The number of institutions in this category is unknown.

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

The provision of community care services depends on each local authority; if they create an agency, then the services are publicly available. A legal regulation exists (Law 3106 / 2003) that covers welfare law. Most existing community care centres (190) are primarily geared to older people living alone or with their spouse or another older person. Although stated by the Ministry that there are plans for 1000 such units throughout the country, the insecure funding they currently have makes this a problematic statement. (Ministry of Health and Welfare 2003)

Home-help

Home Help services began developing on a pilot basis 20 years ago by the Hellenic Red Cross (Triantafillou, Mestheneos 1993) and other voluntary bodies and church organizations on a small scale.

At the public level the "Help-at-Home" programme for older people began in 1998 in collaboration with some selected KAPIs or in some cases directly through the social services of the Local Authorities and contains two linked social and home care services – the "Unit of Social Care - Monada Koinonikis Merimnas' and the "Help-at-Home - Boeithia sto Spiti". This programme was extended and funded further by the Ministry of Health with EU funding and it is estimated that a third of Municipalities have such home help services (Sissouras et al 2002) with figures quoted on 714 home helps employed, supplemented by the support of a large number (1200 individual volunteers and groups and organizations of volunteers). 253 Municipalities are reported to have such services (KEDKE 2002) with 285 operating units (Sissouras 2002); however actual figures for functioning units are unknown and are the current subject of review by EETAA on behalf of the Municipalities. In a report it was stated that 47 % of users lived alone (KEDKE 2002). In many such services funding has been irregular, with many staff remaining unpaid for months.

The service involves home care services such as shopping, laundry and cleaning, finding doctors and medical support. A social worker, nurse and home help / family assistant are normally attached to each service. Many of these services are now being passed into the full control of the Municipalities by making them part of the structures of Municipal Enterprises.

Whilst the "Help-at-Home" programme in general gives priority to dependent older people living alone without financial resources, some units have extended their services to include the support of family carers (mainly women) by supervising the older person for part of the day and thus enabling the carer to enter the labour market.

Personal care

The Red Cross has run a Nursing-at-Home service in Athens for the past 20 years which has as one of its key tasks the training of family care workers in nursing skills and personal care. It also runs training courses in other areas and a voluntary service using both nurses and trained volunteers.

Meals service

Free meals are provided in some areas at the discretion of the Local Authority and many parishes of the Orthodox Church offer meals to any needy parishioners of all ages, but actual numbers are unknown. The review by EETAA of current social and welfare provision by Local Authorities may help provide some data on their extent, funding etc.

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

There are some social welfare programs designed mainly to support elderly people who live alone with various levels of dependency. A 24-hour tele-alarm system can transmit a call for help in case of emergency to family, neighbours, the police or ambulance service. This program has been developed in Athens and Thessalonika with a staff of 14 people. Similar programs are not available in the rural areas of Greece.

The Orthodox Church runs 3,714 Parish Charity funds and has 1360 associations and over 30,000 volunteers of whom 23,000 give several hours of voluntary work per year – this includes supporting family carers who are seen to need help.

Community Care Centres

There are a reported 607 KAPIs throughout the country (Sissouras 2002), covering 50 % of Local Authorities. The main aim of these centres is, "to maintain older people in their own homes as active, independent and participating members of their communities", through the provision of integrated health and social care services, consisting of some primary health care, including health promotion and disease prevention programmes, together with social care services and recreational facilities. The KAPI staff usually consists of a social worker, health visitor or registered nurse, home-care worker, doctor, physiotherapist, ergotherapist and other associated specialists and volunteers as required. Whilst the KAPI services are oriented mainly towards keeping older people independent, many of the centres now also collaborate with the "Help-at-Home" programme to support the more dependent older people in the area and their carers.

There are also a few Community centres run by voluntary bodies or by the Local Authority directly e.g. Athens Municipality runs "Centres for Love and Friendship" which are similar to the KAPI centres but without the health care services.

Day care ("protective" care)

Under the National Social Care System (established in 1998) the Ministry of Health and Welfare stated that it was developing Day Care Protection Centres for the Aged (National Plan for Social Inclusion) which are designed to help working family members who need to find support for the older person they care for. They are closely connected with the KAPIs or other community care facilities for older people. They can also in exceptional circumstances offer 24 hour care and hospitality (Sissouras 2002). The Ministry of Health and Welfare approved an initial 27 and now has approved the operation of 67 such Centres (Ministry of Health 2002), with a further 40 to be developed. While a few are in operation there is no evaluation report on their functioning as yet.

Some such centres, primarily designed for those at risk of other forms of social exclusion, are being run by NGOs.

A Network of Social Support Services under the Operational Programme "Health-Welfare" of the 3rd Community Structural Fund (Ministry of Health and Welfare) has started in 25 municipalities with a further 75 having approval. These are seen as supporting families caring for the disabled of all ages – but it does not appear that older people 65+ who constitute over 50 % of the disabled will be using such centres.

Other social care services e.g. counseling agencies, technical aids, home adaptations, training of care-personnel and / or family carers for providing care at home

The National Centre for Immediate Social Assistance is another new service (Sissouras et al 2002), for which details concerning their operation are not yet available.

The community Centres for Mental Health, which have been operating throughout Greece since the mid 1980s, constitute the main axis of provision of continuous out-patient care and counseling for mental health problems. They are not specifically geared to providing counseling to family carers and information on the extent to which they are used by older people and their family carers is not easily accessible.

Volunteer organizations for the support of patients and their families with Alzheimer disease have activities and operate centres mainly in the Athens and Thessaloniki areas (see Appendix). These are currently the only organizations which offer support to family carers in Greece.

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

Who manages and supervises home care services?

The Local Authority through its Social Services Departments is responsible for the management and supervision of the "Help-at-Home" programme.

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?

There is no legal basis for quality control and no regular controls on any kind of home or institutional / residential facility. The very limited legal controls that exist are based mainly on rules of health and safety (hygiene), planning and environmental legislation e.g. food preparation, number of lavatories etc.

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

In the professional nursing sector, attempts to remedy the chronic shortage of trained nurses have focused on both improving recruitment to the higher grades by conferring university degrees for the 3 and 4 year courses, and upgrading the professional skills of those working as "practical" nurses, by training all such personnel for a minimum of 2 years.

The Centres for Professional / vocational Training (K.E.K) have conducted several training courses aimed at improving the skills of migrant workers in the care sector, and also for unemployed women with higher educational attainments to manage care services, but there is no regular training programme, certification and diploma recognition. Under the 3rd Structural Funds some training courses for paid family carers of the dependent elderly are planned.

Is training compulsory?

Training is not compulsory.

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

Work in the private care sector for older people is both demanding and generally poorly paid and there are problems in recruiting and retaining suitable staff. Many of the cheaper residential homes rely to a great extent on migrant care workers. In addition, despite high rates of unemployment, many Greek women prefer to remain unemployed rather than undertake personal care for strangers as paid, professional care workers.

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

There is some integration of health and social care within the KAPIs, especially when they also provide a Help-at-Home service. Usually the social worker and / or health visitor evaluate care needs and coordinate the care provided. The government is abolishing separate social care units and such types of social care will now be administered through the health sector.

Some Local Authorities e.g. Acharnes in Crete, have made positive attempts to integrate social and health care services for older people (see www.carmen-network.org) at the local level.

However, in the vast majority of cases, family carers undertake the work of case management and integrating care for the older person, by being responsible for record keeping, making and keeping appointments, coordinating medical care, finding paid carers and supervising the care

provided – all this in addition to providing much or all of the everyday care themselves.

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

It is common for many older people with health problems to rely on their close relatives (spouse, children and any family in the health professions) and expect them to be actively involved when dealing with the health system. This expectation is reflected by many health and social care professionals, who will usually conduct interviews, examinations and discussions in the presence and with the participation of the accompanying relative, if the older person indicates that this is agreeable. Additionally, the families of older patients may be perceived by the staff as making a lot of demands on the hospital system by approaching them with an air of, "We do all the caring and deserve some support!" (Triantafillou and Mestheneos, 1994a). Whilst few could disagree with this statement, the fact that such support was sought from the acute hospital sector is indicative of the scarcity of alternative forms of care for dependent older people in Greece.

5 The Cost – Benefits of Caring

Per capita income in 2001 was 11,405 euros.

"The Social Situation in the EU 2003" gives figures for all EU and Accession countries concerning old age dependency ratios, employment rates for older workers (female), expenditure on social expenditure as % of GDP, old age and survivors benefits as % of total social benefits, inequality of income ratio, risk of poverty before and after social transfers, life expectancy and healthy life expectancy.

See also National Reports for ProCare.

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

26.4 % of GDP is given for social protection (EU 2003). In Greece old age and survivors' benefits represent 49.4 % of total social benefits (av. EU 46.4 %).

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

No Greek national data.

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

It is a common practice (although illegal in state hospitals) for ex gratia payments ("fakellakia") to be given to doctors, nurses and even cleaners in the hospitals in exchange for favourable or personal attention. In addition, according to the user's insurance fund, payment for primary care services may be only partly refunded although some are theoretically free at the point of use. However, for a doctor's home visit to an elderly bed-bound patient, most family carers would expect to give an extra payment or a substantial tip, since some insurance funds reimburse the doctor only a minimal amount for office visits and patients' rights to free home visits are frequently not clear.

In addition for family carers having to stay extended periods with the older person in hospitals is exhausting and often necessitates the temporary employment of a private "nurse" (apoklistiki) for shorter or longer periods with the associated high costs.

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

9.1 % of GDP is spent on health (ESYE 2001). 5.2 % of GDP was from Public Health Expenditure, and 3.9 % from Private Health Expenditure. Private expenditure has risen faster than public health spending.

In 1998-9, 6.9 % of household budgets was spent on health.

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

There is no official data or central source of information on costs of residential care. The minimum – in illegal, crowded facilities is approximately 600 euros – rising to 1000 –1400 for average facilities in single rooms, with the best residential homes costing approximately 2000 euros (see KEDKE Report below). The cost also depends on the degree of dependency. IKA pensions are approximately 500 euros per month and average wages approximately 1500.

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)?

Community care services are free at point of use. Currently they are funded through central government to local authorities or in part through EU special programmes e.g. some of the KAPI's home care services. They are now being funded through the Municipal Enterprises created in the Local Authorities.

Residential care is funded by the older person or family e.g. through pensions, savings and out of pocket payments; only in exceptional cases do the Insurance Funds pay the full costs.From KEDKE Evaluation report of Help-at-Home programme_"As an example of comparative financial evaluation, one Help at Home programme with 3 employees, operating from a local KAPI center and providing full support at home for 60 dependent older people, cost 35,216 Euros per year. In contrast, the average cost of institutional / residential care for 1 older person is 17608 Euros per year i.e. the equivalent of supporting 30 dependent older people at home."

5.7 Funding of family carers

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

	Attendance allowance	Carers´ allowance	Care leave
Restrictions			
Who is paid?			
Taxable			
Who pays?			
Pension credits			
Levels of payment / month			
Number of recipients in 2002			

None of these are available in Greece.

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

No.

Are there tax benefits and allowances for family carers?

The support of a dependent older relative can be claimed for income tax relief.

Does inheritance or transfer of property play a role in the caregiving situation? If yes, how?

Generally parents try to transfer money or property at the time of their children's marriage. They may also transfer property as a way of avoiding what used to be very heavy death duties; in the latter case the parents drew up a contract that gave them the legal right to use the property until their death. Those older people without children may also transfer their property to e.g. nieces / nephews etc. with the clear understanding, which can also be sealed by a legal agreement, that it remains theirs to use during their life time and that some care and protection will be available from these family members when and if needed. Since Greeks have a very high rate of home and second home ownership, this inheritance plays a significant role in assuring parents and older people of some care. However they have no legal recourse if this care is not forthcoming.

Carers' or Users' contribution to elderly care costs

***N.B.** Many of these care arrangements used are not available as organized services but can be arranged privately by the family carers.

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

[13] Type of payment depends on Health Insurance Fund. It is the usual custom to give an extra payment to the visiting doctor, or indeed anyone of the health professionals, for home visits.

[14] There are experimental schemes in some outlying islands, which are free. Other systems are totally private e.g. in Athens.

b. Social Care Services	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Permanent admission into residential care / old people's home			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.)						
Laundry service						
Special transport services						
Hairdresser at home			X			
Meals at home	X		X			
Chiropodist / Podologist						
Telerescue / Tele-alarm (connection with the central first-aid station)	X					
Care aids		X	X			
Home modifications						
Company for the elderly						
Social worker	X					
Day care (public or private) in community center or old people's home						
Night care (public or private) at home or old people's home		X	X			
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	X			
Social home care for hygiene and personal care	X		X			
Telephone service offered by associations for the elderly (friend-phone, etc.)	X					
Counselling and advice services for the elderly	X					
Social recreational centre	X					
Other, specify						

c. Special services for family carers	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Training courses on caring						
Telephone service offered by associations for family members	X					
Internet Services						
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)			X			
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?

Care for dependent older people is still assumed by National Governments to be primarily the responsibility of the family. This (convenient for the State) policy line is perpetuated from one Government to the next with no real attempt to examine the impact of demographic and social changes upon family carers. Public reference is frequently made to "the Greek tradition" in this area, in which families do not abandon their older members when dependency supervenes and much is made of the benefits of this for the older people themselves. Indeed, personal observations by the authors confirm that, for the majority of dependent older people being looked after at home by their families, the standards of care (personal cleanliness, good and careful diet, keeping company, drug regimes etc) are excellent.

On the other hand, the increasingly problematic nature of providing care for older dependent family members for extensive periods of time is recognized and discussed informally by all sectors of society and harrowing personal experiences in this area are exchanged, along with helpful tips and practical aids in care-provision. Health care professionals are also often sympathetic to the plight of over-burdened family carers and may comply with short-term hospital "respite admissions" for dependent older people who "always have a little something wrong with them to justify admission!" (Mestheneos and Triantafillou, 1993). For families and older people with adequate incomes, the use of foreign care workers takes away much of the pressure they would otherwise exert to obtain suitable care services from the public sector.

In the public sector, some brief mention is made of family carers in a positive way, but very little attention is given to the issue of their needs for support. The Ministry of Health and Welfare, under the PASOK government (until March 2004), appeared to be still adopting the perspective of taking any responsibility for care only when the family 'fails'.

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

There is some political rhetoric about supporting the family, but it is clear that family carers are viewed primarily as a resource and not considered to have their own needs for support. Even where Home Care Service provision is being designed and the family is mentioned, it is not clear if these services will

really be open to family carers and / or dependent older people, or will continue, as at present, to focus mainly on those without family carers and on very low pensions. As an indication of the numbers in the latter category, the implementation of the Social Solidarity Supplement for Pensions (EKAS), introduced for low rate pensioners, covers 350,000 beneficiaries.

A recent small study by students of the NSPH looking at how current services support family carers of older people, showed indications that some services are becoming more aware of carers needs and making informal modifications to their official service provision to accommodate certain aspects of caregiving e.g. the needs of working carers for daytime supervision of the dependent older person, including family carers in the activities of Community Care Centres.

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

Some such groups have been started but mainly by professionals working with older people with a specific disease e.g. Alzheimer patients, and their carers. As yet they are few, have limited state support and have little political clout.

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

There is no data on this, although the general impression is that family carers mainly undertake their obligations at considerable cost to their own health and well-being.

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

Since very little has been researched in this area, the current research interviews within the context of the EuroFamCare project will contribute much previously unavailable information on the situation of family carers.

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

The mobile telephone has helped communication between family carers and older people, since both can now get in touch with each other quickly and easily.

Internet connections are still amongst the lowest in Europe though increasing rapidly and there are plans to try and extend usage to more citizens, including the more socially excluded.

6.7 Comments and recommendations from the authors

- The lack of data on the situation of family carers in Greece has been a major obstacle to policy and planning for their support which the current research project will substantially reduce.
- Women will continue to assume the burden of home care for dependent older people within the family while women's wages remain low and unemployment rates for women high. However, as these conditions change and more women enter the labour market, especially women over 45 years of age, then family care will become an issue for governments. The increasing levels of education amongst women will almost certainly lead to more individualistic life choices, higher incomes and less willingness to directly provide all forms of physical, social and economic support to the dependent elderly.

7 Appendix to the National Background Report for Greece

7.1 Socio-demographic data

Profile of the elderly population - past trends and future projections

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

Life expectancy at birth in 2001: 76 years for males, 81 years for females (EUROSTAT 2003). Life expectancy at age 65 years: in 1998 it was 16.2 for males and 18.5 for females (NSSG 2000).

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

Table 4: Population by gender and age group in Greece (2001)

Total	**10,964,020**
Males	5,427,682
Females	5,536,338

Those 65+ = 16.7 % of the total population

5-year age group	Males		Females		Total	
	number	%	number	%	number	% in total population
65-69	292,730	46.82 %	332,472	53.18 %	625,202	5.7 %
70-74	247,769	45.35 %	298,474	54.65 %	546,243	4.98 %
75-79	145,035	44.01 %	184,494	55.9 %	329,529	3 %
80-84	78,804	41.8 %	109,666	58.2 %	188,470	1.7 %
85+	55,397	38.98 %	86,699	61.02 %	142,096	1.29 %

Source: NSSG 2002

Table 5: Projected increases in the > 65 year old population groups; Demographic data and projections; Eurostat 2000-2050 (thousands of persons)

	2000	2010	2020	2030	2040	2050
Population	10,543	10,768	10,806	10,710	10,562	10,231
Persons per age group						
> 65	1,820	2,073	2,297	2,582	2,943	3,100
IKA limits	2,143	2,391	2,654	2,980	3,336	3,410
75	708	1,001	1,125	1,263	1,470	1,679
20-65	6,423	6,553	6,415	6,195	5,730	5,276
< 20	2,300	2,143	2,094	1,933	1,889	1,855
% of overall population:						
65	17.3 %	19.2 %	21.3 %	24.1 %	27.9 %	30.3 %
IKA limits	20.3 %	22.2 %	24.6 %	27.8 %	31.6 %	33.3 %
> 75	6.7 %	9.3 %	10.4 %	11.8 %	13.9 %	16.4 %

Source: Ministry of Economy and Finance / Ministry of Labour and Social Insurance, The Greek Report for the European Strategy on Pensions, Athens, September 2002

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

Table 6: Marital status 2001 (%)

Age group in years	Unmarried		Married		Widowed		Divorced / Seperated	
	Males	Females	Males	Females	Males	Females	Males	Females
65-69	3.86	5.18	88.49	62.39	5.30	28.62	2.35	3.81
70-74	3.49	5.66	86.21	51.08	8.25	39.91	2.05	3.35
75-79	3.54	5.80	81.87	37.4	13.19	53.43	1.40	3.37
80-84	3.24	5.57	74.49	25.17	21.07	65.88	1.20	3.38
85+	3.37	4.69	60.27	14.88	34.77	76.57	1.23	3.86

Source: NSSG 2002

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

Table 7: Men and women aged 65+ living with their children as % of those who ever had children. (cell percentages)

	Women without partner	Women with partner	Men without partner	Men without partner
Greece	48	24	39	33
'South' average	53	34	50	42

Source: Iakovou 2000 ECRH data 1994

Table 8: Sex and marital status of co-resident children*

	Single daughters	Married daughters	Single sons	Married sons	Sons and daughters	Sample size
Greece	15	22	18	43	3	369
Total 10 countries	20	30	23	24	5	1697

* sample: women not currently married over age 70 who live with their children
Source: Iakovou 2000 ECRH data 1994

Urban / rural distribution by age

Table 9: Urban / rural distribution by age

Age group	Urban 6,036.660 (58.8 %)		Semi-urban 1,312,774(10.8 %)		Rural 2,910,466 (28.36 %)	
	Males	Females	Males	Females	Males	Females
65-69	106,030	132,785	26,730	28,556	77,388	82,366
70-74	75,490	105,000	18,606	22,227	56,531	66,169
75-79	62,071	85,347	15,796	19,687	51,536	61,715
80-84	37,376	54,653	9,732	13,198	34,328	42,770
85-89	15,718	25,103	4,261	6,294	14,998	19,498
90-94	4,466	8,258	1,051	1,924	3,861	6,665
95-99	710	1,358	174	344	639	1,226
100+	259	483	49	148	203	575

Source: 1991 Nat. Pop. Census

Disability rates amongst those > 65 years. Estimates of dependency and needs for care

As stated in the Introduction, there are no epidemiological or Health Interview Survey data from Greek studies on disability, so the following disability / dependency levels are **estimates** only.

The WHO, based on the **two severest** Global Burden of Disease study disability categories **(levels 6, 7 = severe disability),** give the following figures for Greece for the numbers of people requiring daily care, total population, proportion of total population requiring care, and dependency ratio by year.

Table 10: Numbers of people requiring daily care, total population, proportion of total population requiring care, and dependency ratio by region, country and year, based on two severest Global Burden of Disease study disability categories (levels 6, 7).

Year	Prevalence (thousands) by age in years						Total population (thousands)	Prevalence increase %	Proportion total population %	Dependency ratio (%)*
	0-4	5-14	15-44	45-59	60+	Total				
2000	1.5	3.3	165.9	85.9	248.8	505.5	10,610.0	0	4.8	7.7
2010	1.3	3.0	152.9	96.5	275.4	529.2	10,579.2	5	5.0	8.3
2020	1.2	2.6	131.3	105.2	304.7	545.1	10,324.7	8	5.3	9.1
2030	1.2	2.5	110.0	101.8	341.1	556.5	9,955.4	10	5.6	10.4
2040	1.2	2.4	99.4	82.1	372.4	557.5	9,512.6	10	5.9	12.1
2050	1.2	2.4	92.6	70.2	365.9	532.3	8,983.3	5	5.9	12.8

* (total number of dependent people) / (population aged 15-59)
Source: Greece WHO "Home based Long-term Care – Greece." (last update 13th August 2003)

When disability estimates are based on the **three severest** Global Burden of DiseaseStudy disability categories **(levels 5, 6, 7 = moderate to severe disability),** the numbers increase accordingly, as do the dependency ratios.

Table 11: Sensitivity analysis; Numbers of people requiring daily care, total population, proportion of total population requiring care, and dependency ratio by region, country and year, based on three severest Global Burden of Disease study disability categories (levels 5, 6, 7).

Year	Prevalence (thousands) by age in years						Total population (thousands)	Prevalence increase %	Proportion total population %	Dependency ratio (%)*
	0-4	5-14	15-44	45-59	60+	Total				
2000	3.9	8.2	231.0	122.6	365.4	731.1	10,610.0	0	6.9	11.2
2010	3.4	7.4	213.0	137.7	404.4	765.8	10,579.2	5	7.2	11.9
2020	3.1	6.5	183.1	150.1	447.3	790.1	10,324.7	8	7.7	13.1
2030	3.0	6.1	153.3	145.4	500.8	808.6	9,955.4	11	8.1	15.1
2040	3.0	6.0	138.7	117.3	546.8	811.7	9,512.6	11	8.5	17.6
2050	3.0	5.9	129.1	100.2	537.4	775.6	8,983.3	6	8.6	18.7

* (total number of dependent people) / (population aged 15-59)
Source: Greece WHO "Home based Long-term Care – Greece." (last update 13th August 2003)

As can be seen, in 2000, approximately half those in both disability categories (severe and moderate to severe) were 60+. However, the projected prevalence of disability declines for all age groups over the next 50 years,

except for the 60+ age group, where disability in both categories is predicted to increase to more than 2 / 3 of the total prevalence.

It should be noted however that disability and dependency levels amongst older people are difficult to estimate reliably. Thus, figures from an earlier study of family carers of older people in Europe, COPE, estimate higher numbers than those given above, as seen in the following two tables.

Table 12: Estimates of population needing full-time or part-time care in the COPE countries (1999)

Country	% of total population needing care:								
	full time				part-time				
	age group			Sub-total	age group			Sub-total	Total
	65-69	70-79	80+		65-69	70-79	80+		
EU-15	0.2	0.7	1.1	2.1	0.5	1.5	2.2	4.2	**6.3**
France	0.2	0.7	1.1	2.1	0.5	1.4	2.2	4.1	**6.2**
Greece	**0.3**	**0.7**	**1.1**	**2.1**	**0.6**	**1.5**	**2.1**	**4.1**	**6.2**
Italy	0.3	0.8	1.2	2.3	0.5	1.6	2.4	4.5	**6.8**
Poland	0.2	0.5	0.6	1.4	0.4	1.1	1.2	2.7	**4.1**
Sweden	0.2	0.8	1.4	2.5	0.4	1.6	2.9	5.0	**7.4**
United Kingdom	0.2	0.7	1.2	2.2	0.4	1.5	2.4	4.3	**6.5**

Source: Lamura G, Polityńska B, 2001

Data have been estimated according to following assumptions:

- the elderly population needing full time care is equivalent to the percentage of severely disabled elderly, which on turn is estimated to be 5 % for the 65-69 year-old age group, 10 % for the 70-79 age group, and 30 % for the 80 and over age group (Walker and Maltby, 1997: 92);
- the elderly population needing part-time care is twice as numerous as the one in need of full time care (usually a higher ratio of two and half is reported, (Eurolink Age 2000);
- there are no differences between countries (while recent findings show a decline in the percentage of severely disabled elderly in most developed countries, as a consequence of better health and living conditions: (WHO 1999).

Table 13: Estimates of population needing full-time or part-time care in Greece.

	Numbers % of total population needing care:								
	full time				part-time				
	age group			Sub-total	age group			Sub-total	Total
	65-69	70-79	80+		65-69	70-79	80+		
%	0.3	0.7	1.1	2.1	0.6	1.5	2.1	4.1	6.2
N	307,80	71,819	112,859	215,458	61,559	153,899	215,458	420,656	636,114
									> 80 = 328,317

Total population 10,259,900 (1991 Nat. Pop. Census)

Summary

- Pop > 65 yrs = 16 % = 1,641,584
- 6.2 % of 10,259,900 = 636,114
- 39 % > 65yrs needs full or part-time care (probably an overestimate)

Thus, in a total population of **10,259,900** (National Statistical Service of Greece, 1991 Population Census), with almost 16 % > 65 years of age, it can be estimated that **215,458** older people are **severely dependent** and in need of full-time care (needing help with personal ADL for several or more hours every day) and a further **420,656** are **partially dependent** (needing help with instrumental ADL on a daily basis).

This results in a projection of **636,114 older people in need of care and support.**

Finally, the Help at Home service made the following *estimations of need for care* amongst older Greeks (Amira et al 2002).

"It is estimated that 5 % of the elderly population have need of help similar to that provided by the programme. With an elderly population of 1,600,000, the total number in need reaches 80,000 people. International statistics estimate that 2 / 3 of those in need are cared for by their families. Thus, the needs of 27,000 people remain un-met. The current programme serves just 1 / 3 of these."

Income distribution for top and bottom deciles

At 60 % of median income, 17 % of Greeks overall are poor. On the 50 % median line (OECD and most Member States use this figure) the percentage is 10 %. The poor tend to live in their own homes and poverty associated with old age is probably declining. One action helping this is the supplementary payment and income transfer made to low income pensioners (EKAS) covering 350,000 people. Farmers' and agricultural workers' pensions, received by 770,000 people, have been very low but were non contributory

until recently, when the introduction of voluntary contributions has positively affected pension levels amongst this section of the population. Households in rural areas are more likely to be poor since disproportionately more older people live there, and also the proportion of the population on low pensions is positively related to the age of pensioners.

Older women are more likely than older men to be living alone and have a 23 % greater risk of poverty when living alone than men.

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

No information available.

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

74 % of households own their own homes and this includes 73 % of poor households, a high proportion of whom are older people in rural areas.

5.8 % live rent free in family owned houses.

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

There is no data available by age groups. NSSG in a 1999 sample showed that

- 91.7 % of house had indoor toilets (97.7 % in urban areas, 93.7 % in semi-urban areas and 82.3 % in rural areas. Older people tend to have fewer facilities;
- In total 93.7 % have a bathroom or shower (98.57 in urban, 93.5 % in semi urban and 86.7 % in rural areas;
- 97.2 % of households had colour TV – a number which has increased since 1999;
- 16 % had a holiday home;
- 21.9 % had inadequate space;
- 27 % had inadequate heating (27 % in urban, 15.9 % semi-urban and 43.1 % in rural areas).
- Damp was a problem for 16.5 % of households (12.1 % in urban, 22.8 % rural areas).
- Telephone – 95.4 % overall (98 % urban, 95.9 % semi-urban and 91.2 % in rural areas). From other reports mobile phone ownership is very high.

7.2 Examples of good or innovative practices in support services

The Greek Alzheimer and Related Disorders Association (GARDA)

A description of an innovation in the field of care in Greece

Dr. Stelios Frangidis, Thessaloniki.

Introduction

In this brief report the Greek Alzheimer and related Disorders Association (**GARDA**) is introduced as an innovative attempt to help those with Alzheimer and their carers; it has become a 'state of the art' model for the integration of care services.

Profile

GARDA was established in Thessaloniki in 1995, as a non-profit, non-governmental organization, whose purpose is to optimize the quality of cure and care for AD people and their carers. The whole idea arose on a riverboat on the Mississippi river when Mr. Rafael Billingston (secretary of the International Alzheimer Association) proposed that Ass. Prof. Magda Tsolaki (today's President of GARDA) should create a Greek branch of the organization.

The main reasons giving rise to GARDA were:

- The current steady increase in the life expectancy of Europe's population has led to a dramatic increase in the number of people affected by age-related diseases such as Alzheimer's disease (almost 9 % of the elderly population in Greece).
- The fact that the majority of AD's sufferers live at home and are cared for by their relatives and friends. Furthermore carers often work alone, and lack know-how and inspiration which could be given by others. The inadequacy and inefficiency of the national health and care system drove

the society to find other ways of care provision. This, together with a large number of volunteers among professionals and informal carers, led to GARDA's formation.

In 1996 GARDA became a member of the Alzheimer Disease International (ADI), and Magda Tsolaki became a Member of the Executive Committee of ADI.

ADI provided great help in developing skills for setting up the Association, identifying aims, fundraising, recruiting volunteers, running support groups, raising awareness and providing information.

In 1997 GARDA became a member of Alzheimer Europe.

In 1998 GARDA expanded by creating branches in four other cities (Athens, Xanthi, Volos, Hania). Another branch is under development in Larissa.

Since its founding GARDA functions as an organized and professional counseling Center.

The core of the foundation is a large team of volunteers from various fields such as physicians (mostly neurologists), psychologists, physiotherapists, social workers, nurses and of course family carers.

Activities

GARDA promotes its fundamental aims through many and varied activities- it:

- Provides clear, comprehensive and accurate information on all forms of dementia, on caring, legal and financial matters, social and health services and benefit.
- Provides a network of carers groups, carers contacts and a **telephone helpline.**
- Produces booklets (e.g. translation of the Alzheimer's Europe manual and the Children's Brochure), publishes its own magazine reviewing all the activities of GARDA and presenting all the progress in AD in scientific and social level.
- Runs courses, meetings and conferences. Every Tuesday and Thursday professionals and informal carers give lectures, covering all aspects of AD. GARDA has organized two national Alzheimer conferences so far and the 13th European Alzheimer Conference in 2003 in Thessaloniki.
- Delivers quality day care. Three day centers function so far, offering discussion groups, seminars for caregivers and professionals, memory training for patients presenting with early-stage disease, music therapy for patients at all stages, speech therapy and physiotherapy.
- One of GARDA's latest objectives is to raise money in order to build a Clinic where patients in late stages of AD will get the care they need.

- Promotes research, education and training. A large number of AD patients and their carers take part in research activities (validation of neuropsychiatric scales, genetic research, and new pharmacotherapeutic trials, epidemiological aspects in Greece, prevalence, incidence, outcome, institutionalization). In all the above activities GARDA collaborates closely with Thessaloniki's Memory Clinic. In the field of education, every year since 1995, about 120 students from the department of Psychology attend a course on the Neuropsychological assessment of elderly people. Students of the Medical school also have the opportunity of attending seminars and conferences about dementia.
- Campaigns for the needs and interests of people with dementia and their carers. Campaigns range from trying to influencing national government legislation to raising awareness of dementia in local communities.
- GARDA, as a member of Alzheimer Europe and ADI, contributes to worldwide efforts to tackle the international problem of dementia.

Funding

As GARDA is a non-profit organization all fundraising arises from donations (mostly from pharmaceutical companies), by organizing charity activities and by its member fee.

The Orthodox Church has also been a great supporter in many fields (finance, accommodation etc)

The government, at national and local level, provided a little help, mostly accommodation, but recently the Minister of Civilization approved a budget to support the building of GARDA's Clinic.

Relations with other care services

Since its establishment GARDA has been in close collaboration with all the K.A.P.I.'s of Thessaloniki. (K.A.P.I. is a primary health care center, funded by the state, providing medical and nursing care and day-center functions). GARDA gives lectures about AD every week in a different center.

There is also a strong interaction between GARDA and other voluntary and charity organizations mostly from the local community.

Furthermore it should be noted that all GARDA's research activities, treatment, screening tests and training programs take place in a state Memory Clinic, part of the NHS and the Medical School of Thessaloniki, while a large number of volunteers come from these health sectors.

Outcomes

One of the major outcomes is that GARDA managed to show the multidimensional dimensions of the AD problem and tried to provide coordinated solutions. It is now understood that AD is not only a matter of doctors providing treatment and therapy. GARDA's approach is to develop

multifunctional teams consisting of professionals from various care sectors such as doctors, gerontologists, psychologists, occupational therapists, speech therapists, social workers, nurses, lawyers, policy makers and others in order to provide the optimum way of care for the patient.

During the last seven years GARDA has managed to become a significant and reliable provider of services for AD persons and their carers. The number of calls to the telephone helpline everyday and the remarkable presence of people in all GARDA 's activities (lectures, meetings, conferences) indicates this.

Additionally GARDA takes part in a number of European research projects (with scientific and social interest) as a reliable and valuable participant.

The next goal is to convince the government to learn from our model, to understand how people from different care sectors can work together with efficiency and efficacy, so as to promote integration in public care services according to the principle of 'quality of care'.

Changes in attitude

The inadequate, inefficient care services, the low budget in social care, the lack of integration, the poor quality of provision especially for long-term care, are the main features of social policy for the elderly in Greece the last… fifty years! What really changed in thinking that made possible the development of GARDA?

The policy of the Greek State concerning older people's rehabilitation and care is part of the general social policy of the government and is therefore directly affected by the startling developments that European integration has brought about in almost every field of our life.

The EU countries adopted new concepts such as quality of care, client-oriented services, independence of the elderly and improved living standards. The Greek community tried to respond to this challenge by developing new quality providers of services, like GARDA.

Professionals (doctors, nurses, social workers) had difficulties in dealing with the growing numbers of AD persons and their carers. There was insufficient education, training and awareness about AD. Besides the lack of short-term care homes, nursing homes, rehabilitation centers drove to an increase of 'bed-blocking'. The indifference of the government drove some volunteers to the creation of GARDA.

THE "HELP-AT-HOME" SERVICE

"HELP AT HOME" PILOT PROGRAMME: IMPLEMENTATION REPORT

A) PROGRAMME MONITORING COMMITTEE

B) GREEK SOCIETY FOR SOCIAL PARTICIPATION

Editors: Amira Anna, Stounara Amalia, Manara Chrysa

Published by: Central Union of Municipalities and Communities (KEDKE), Athens, 2002.

Background to Help-at-Home services in Greece

Sporadic services and programmes operated since the early 1980s, initially mainly organized and run by NGOs such as the Volunteers' Association and the Hellenic Red Cross, always with the support of the Ministry of Health and Welfare. Most of these were later incorporated into the KAPI network and the Local Authorities (Municipalities and Communities) and expanded in number to the 100 that constitute the pilot programme reported upon here. Additionally, the Ministry of Employment set up a large number of Social Care Units, offering similar services.

The "Help-at-Home pilot programme, as defined in the Ministerial Directive P4b / 5814 (FEK917, 17.10.1997, Volume B).

Aims of the programme

The general aim of the programme is to cover the basic needs for social care of older people at home, in order to achieve and maintain with dignity an autonomous lifestyle, priority being given to those who:

- are not completely self-caring / independent;
- need special care;
- live alone;
- have insufficient resources to improve their quality of life whilst remaining in their own and their family's natural and social environment.

The **objectives** of the programme are:

- The investigation, recording and study of the needs of older people for social care at home.
- The provision of organized and systematic care to older people and their families by specialized professionals, trained workers and volunteers to meet their immediate needs for a dignified way of life.
- The location and utilization of Municipal resources, local citizens and local organisations for meeting the needs of their elderly citizens.
- The systematic use of volunteer initiatives, the development of Social Solidarity, and the continuous sensitization of the general public of the needs, the special features and the potential capabilities of older people with emphasis on solidarity between the generations.
- The introduction of the older service users to the KAPI and the simultaneous motivation and utilization of the KAPI members for visits to their homes.

- The organization and systematic provision of Social work, Nursing Care, Physiotherapy and Home-help to meet the needs of older people.
- The long-term study and evaluation of the needs of older people, in order to submit the relevant information to the authorities for use in the planning of measures to meet these needs.
- The long-term processing and evaluation of data collected during the implementation of the programme, together with the results, for the re-evaluation of the plans and methods being used.

Planned activities and services

- The investigation, documentation, analysis and study of the data on the needs of older people in the Municipalities in which the programme is to be implemented, leading to the creation of a "Social Map".
- The training of volunteers and the organization of Social Solidarity activities.
- Social work with individuals, groups and families, with the aim of:
    - Informing the clients of their welfare rights.
    - Creating links and contacts with services (Health and Welfare, Insurance Organisations and others), which cover the needs of older people.
    - Continuous medical supervision, nursing care and physiotherapy at home or wherever these are provided.
    - Services of family support and care (personal and home hygiene, covering the needs of everyday life etc.).
    - Promoting the participation of older people in cultural, religious, recreational and social activities.
    - The systemisation of the network of LA services for the social care of older people at home and the creation of links with similar services in the broader community.

Surveillance and Management of the Programme

A 7 member monitoring committee was set up and activities and responsibilities defined over a 3-year period.

The findings reported cover the first 3 years' operation of a pilot programme of Help at Home services for older people in 97 Municipalities and Communities in Greece.

Based on these findings, recommendations have been made for the continuation and expansion of the programme for a further 5 years by its integration into the Municipal and Community social services or the local KAPI centers (Open Care Community Centres for Older People). Alternatively, the

programme could be funded by the 3rd KPS (3rd Framework fund), under human resources. The pilot programme was funded by the European Social Fund and if this funding source is continued, then the national contribution covering all social care provided by the LAs would be included in the Social Exclusion programme.

Thus, the approximately 400 Municipalities currently operating Home Care Units (100 Help-at-Home and 300 Social Care Units) are recommended for extension to cover 1100 Municipalities.

As an example of financial evaluation, one Help at Home programme with 3 employees, operating from a local KAPI center and providing full support at home for 60 dependent older people, cost 12,000,000 GDR (35,216 Euros) per year. In contrast, the average cost for of institutional / residential care for 1 older person is 6,000,000 GDR (17,608 Euros) per year i.e. the equivalent of supporting 30 dependent older people at home.

Implementation of the Programme:

- Professional Team
- Social worker
- Nurse
- Home-help
- Their work regulations and contracts are with KEDKE

Reported problems

1) and 2) Need more staff, especially Home-helps, in widely scattered areas and areas with a high proportion of dependent older people.

3) Need other professionals e.g. physios, occupational / ergo therapists, chiropodists, psychiatrists, psychologists, a need which can be covered by co-operation with other services locally e.g. KAPI, local hospital, private sector, but must have a clear source of funding.

Lack of transport, especially in remote rural areas. Needs currently met by use of taxis, LA vehicles, private cars and volunteer drivers, the latter, however, needing a degree of punctuality that is not always possible.

The need for a common method of data recording and processing.

Problems with staff contracts.

Volunteers

Approx. 1,200 volunteers were recruited to the programme and many organisations and bodies offered help and support

Evaluation

1) The Help-at Home programmes described in the Ministerial decision P4b / 5814 (FEK 917,17.10.1997, Volume B), operated in accordance with the directive:

- They were installed in the Municipalities.
- They created links with the community.
- The employed social workers, nurses and home-helps.
- The offered counseling, nursing, home-help and whatever other services were necessary, even if these were not foreseen in the directive.
- They served older people who were isolated, dependent / non-self-caring and with limited financial resources.
- They utilized local resources.
- They recruited and trained volunteers.

2) The new service was accepted very positively by the residents in the areas served by the programme, and supported by donations in cash and in kind as well as volunteer services. 1,200 individual volunteers and a large number of groups and organizations supported the programme.

3) The programme served > 9000 people in total. Given that the needs of only a few Municipalities in the country were covered, this can be considered a very high number. It is estimated that 5 % of the elderly population have need of help similar to that provided by the programme. With an elderly population of 1 600,000, the total number in need reaches 80,000 people. International statistics estimate that 2 / 3 of those in need are cared for by their families. Thus, the needs of 27,000 people remain un-met. The current programme serves just 1 / 3 of these.

4) The cost of the services was very low. If each programme cost between 10-12,000,000 GDR (29,347-35,216 Euros) / year, then the cost of 100 programmes was 1-1.2000,000,000 GDR (3,521,643 Euros) i.e. 130,000 / 200,000 GDR / person / year or around 11,000 / 16,700 GDR (32 / 49 Euros) / person / month. Of course there were other expenses since the Municipalities and individuals made many contributions such as transport, repairs, food, clothes, drugs, incontinence pads, payment of water and electricity bills, administration and housing costs, as well as rent and many other gifts.

5) It is not possible to estimate accurately the considerable savings from the non-use of hospital services by the programmes users, many of whom would have occupied a hospital bed for long periods, or would simply have suffered at home. However, there is no doubt that the use of hospital beds was satisfactorily reduced, taking into account that the programme:

- provided a sense of security to the isolated and poor service users;

- provided the necessary nursing and support services to those who had no further need to remain in hospital;
- provided the opportunity for various tests and checks at home such as blood pressure and blood sugar monitoring, microbiological tests etc., which would otherwise have necessitated hospital outpatient attendance if not admission;
- prevented deterioration of chronic conditions by frequent and even daily supervision of drugs and monitoring of drug regimes;
- contributed to the prevention of crises in conditions such as stroke, amputations, psychiatric states etc.
- Prevention and correct management of pain, depression, malnutrition and poor diet, etc.

6) Problems were reported in relation to the following:

Difficulties in covering adequately the multiple needs of older people in outlying areas, both due to lack of staff and lack of transport. Temporary solutions were found in many cases, but more permanent solutions are needed for the optimum operation of the programmes in these areas:

Poverty – older people on low pensions, especially the Agricultural Workers' OGA pension (currently around 50,000 GDR / 150 Euros per month), were only able to manage financially if they owned their own property and could grow their own produce or keep a few animals. The isolated and the dependent on low pensions who had to pay rent were unable to survive independently without the support of others (the Municipal authorities or volunteers) in paying the rent, water and electricity bills and providing meals.

Difficulties in securing the few supplementary benefits available e.g.

Rent benefit can only be given on production of a signed contract, which is rarely made in the cases most in need.

Disability benefits are only granted in accordance with very restrictive criteria such as paraplegia, but not hemiplegia resulting from stroke or other causes of major disability in older people*. Furthermore, assessment for disability benefit is bureaucratically arduous and usually necessitates the transport of the disabled person to the Assessment Committee, since home assessments are only rarely granted.*

When isolated or dependent older people need hospitalization for a shorter or longer period, they frequently need the services of a private nurse, at great cost to themselves and / or their families and only partly reimbursable from some insurance schemes.

Many older people receiving the Help-at-Home service are unable to afford a telephone, which is a problem both for themselves and for the Service staff.

The Help-at-Home service does not currently cover all the country's municipalities and many gaps are filled by the Social Welfare Units (run by the Ministry of Employment), which may collaborate and cooperate very satisfactorily with the Help-at-Home service, but in some areas there is rivalry between the two. Also, in some areas the Mayors delegate common premises for the above 2 services and the KAPI. Where this leads to harmonious collaboration under a common administration and optimum use of all available resources, the results are very positive with full coverage of needs for care. Despite this collaboration, there are areas which are only partly covered or not at all e.g. some islands and mountain areas, as well as some whole Municipalities.

The recruitment, retention and utilization of volunteers occupies a lot of time for the staff, who request help in devising more efficient and effective strategies for the management of volunteer services.

Both staff and volunteers have expressed the need for a training programme as well as for exchange of experience with other countries.

In the opinion of the staff, other specialties are needed in the programme e.g. physiotherapists, doctors, psychiatrists, for the provision of a more effective service.

There is no intermediate framework of nursing care between hospital and Primary care.

The staff expressed great anxiety regarding both the continuation of the programme and the regularization of their positions.

Recommendations

1. Continuation and expansion of the programme.

2. Co-operation and collaboration with other programmes and services for older people (and possibly for People with Special Needs) at the LA and Municipality level.

3. Employment of new staff and services to unfilled positions in the Help-at Home and Social Welfare programmes at the LA and Municipality level.

4. Expansion of the programme to cover the needs of Municipalities not currently served by the programme.

5. Creation of mobile units to cover the needs of island, mountainous and other remote rural areas.

6. Training of the staff and volunteers as well as the relatives / family carers in topics related to their work (special conditions, symptomatology, prevention of bed-sores etc.).

7. Visits and exchange of information with similar programmes in other countries such as Denmark and Norway.

8. Collaboration and exchange of experiences between staff employed in different areas of implementation of the programme.

9. The provision of supervision, direction and support in their work is considered essential and specifically requested by the staff.

10. Continued co-operation with local bodies (welfare, hospitals, Health Centres, church, organizations etc.) for common planning of programmes. The avoidance of overlap and conflict between services.

11. The development of additional methods of support to cover the needs of older people (Day Centres for social and nursing care, respite care, mobile acre units, long-term social and nursing care centres and centres for the care of active dementia sufferers.

12. The supplementation of the current programme with more Home-helps and other specialists such as psychiatrists, doctors, physiotherapists on a full or part-time basis.

13. The provision of transport for both staff and clients by whatever method is most effective and economical.

14. The extension of the programme to include the support of families with a dependent member to enable them to continue to provide care at home and to avoid "burn-out" leading to the demand for institutional or hospital care, which is a common occurrence.

15. Programmes that are limited only to the care of the financially weak are often avoided by users as offending their dignity. Since the aim of the programme is the avoidance of institutional care with its associated high costs and the unburdening of the hospitals from cases that could be cared for at home, the possibility should be examined of extending the programme to all citizens in need. This would ensure a feeling of security and stimulate the offer of volunteer services and donations to the programme. The possibility of financial contributions by those able to pay for care should not be excluded.

16. The possibility of linking the Help-at Home programme with the Health and Social Security Insurance Organisations to which the clients belong and covering the costs from this source, needs to be examined.

17. The challenge of a study of the private life and health insurance companies for the possibility of group coverage for help and nursing at home for citizens who are a financial burden to the municipality.

18. A study of the people it was not possible to include in the programme to identify any areas of unmet need.

19. A common method of electronic data recording and processing in a data bank, in order to have immediate access to statistical data and results regarding the functioning and outcomes of the programme overall.

20. The definition and description of the role of national advisory bodies for social care and welfare committees for the monitoring and supervision of programmes of ministries such as Health and Welfare and Employment.

21. Resolution of the problems arising from the present work contracts of the staff, their salaries and their social security coverage.

22. The need for continual vigilance regarding the quality of service provision and avoidance of relaxation of standards.

Detailed examples of referral and follow-up procedures, evaluation instruments for all services and specialties, recording of visits, regular group meetings and methods of sharing information are included in the report.

Translation – J. Triantafillou, Athens, October 2003.

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