European Network of Economic
Policy Research Institutes

ANCIEN

Assessing Needs of Care in European Nations

THE LONG-TERM CARE SYSTEM FOR THE ELDERLY IN PORTUGAL

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ENEPRI RESEARCH REPORT NO. 84

JUNE 2010

ENEPRI Research Reports present the findings and conclusions of research undertaken in the context of research projects carried out by a consortium of ENEPRI member institutes. This report was produced by the ANCIEN project, which focuses on the future of long-term care for the elderly in Europe. Funding for the project is received from the European Commission under the 7th Framework Programme (FP7 Health-2007-3.2.2, Grant no. 223483). See the back page for more information. The views expressed are attributable only to the authors in a personal capacity and not to any institution with which they are associated.

ISBN 978-94-6138-026-5
Available for free downloading from the CEPS website (www.ceps.eu) and
ANCIEN website (http://www.ancien-longtermcare.eu/node/27)

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Although Portugal is often described as a country where welfare provision and care services are rather precarious, thus requiring important contributions from family and informal networks, some significant changes have occurred during the last 30 years.

Portugal, like the other western European countries, is facing the phenomenon of an ageing population. One of the consequences is that care for the elderly has become a major issue on the policy agenda. The policies and services aimed at the elderly have expanded lately, but in the 1980s and 1990s their emphasis was on the development of services (attempts to increase and to diversify what was on offer and improvements in quality). We present some of the main developments since then.

1. The long-term care system in Portugal

1.1 Organization

Until very recently, long-term care did not feature public sector involvement and was mainly provided by *Misericórdias* (holy churches).

The *Misericórdias* are independent, non-profit institutions with a religious background. Only the *Misericórdia* in Lisbon has a different status; it is a public enterprise with a board nominated jointly by the Ministry of Health and the Ministry of Labour and Social Solidarity (Barros and De Almeida Simões, 2007).

In 2006, owing to the increasing number of elderly persons and the shortage of services, the National Network for Continuous Integrated Care was launched, based on the existing structure of services with a view to bringing them together. In each region, social services are provided by the Ministry of Labour and Social Solidarity, except for the Lisbon area where the Santa Casa da Misericórdia plays this role. Health and social care are provided mainly by private non-profit institutions (subsidized by the state) and by *Misericórdias*.

1.2 Available LTC services for elderly persons

Over the last three decades, the importance of supporting dependent elderly persons has been underlined and reinforced through the increase of and improvements to care services. We subsequently present the main changes in terms of the expansion of service provision, as well as the introduction of carers' benefits.

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Different forms of support and responses to the circumstances of the elderly were developed in Portugal in the 1980s and 1990s. They were characterized by variety owing to the heterogeneity of needs, as well as by a tendency towards deinstitutionalization, resulting from the negative perceptions often associated with institutional care.

The complementary role of formal and informal support was also stressed. Furthermore, to enhance the quality and suitability of the services, there were improvements in coordination among the various services engaged in care for the elderly, at the level of social and health care responses (Pimentel, 2006).

Nowadays, the services and facilities available to the elderly are diverse: daycare centres, home-based services (home help and integrated home care, including health care), nursing homes (long-term and palliative care) for highly dependent persons, as well as residential care (protected flats) and family accommodation (*Acolhimento familiar*). Yet the last two forms of care are still very poorly developed.

2. Funding aspects

To expand services, a new private/public mix centred on *public subsidies of non-profit institutions* was built up in the late 1980s. It was implemented through new legislation[1] on the legal status of non-profit institutions (known as private institutions of social solidarity, *Instituições Particulares de Solidariedade Social*, IPSS). In addition was the institutionalization of annual negotiations and agreements between third-sector representatives and the ministry in charge of social affairs, concerning the flat-rate subsidy paid by the state per elderly person cared for by the service providers.

The financial responsibilities of the public sector are shared between the Ministry of Health and the Ministry of Labour and Social Solidarity.

The costs applied by the National Network for Integrated Continuous Care are determined by the government (Decree Law No. 101/2006, 6 June 2006, Article 12) and co-financed by both the health and social security sectors (Portaria No. 994/2006, 19 September 2006) according to the type of service. Thus, the Ministry of Health finances the costs of health care provision, while care recipients make co-payments for the social care received. The care recipient will have to contribute a co-payment according to the individual's or his/her family's income (see Despacho Normativo No. 34/2007, which specifies the conditions for which social security will pay and the amount).

Financial benefits

The allowance for assistance by a third party,[2] renamed in 1999 as the **supplement for dependency** (*Complemento por Dependência: Prestação pecuniária mensal*, Decree Law No. 265/99, 14 July 1999), is available for pensioners needing permanent care by a third party.

It is a monthly financial benefit that is not means tested, which may be claimed by the beneficiaries of social security (pensioners) (*Regimes da segurança social*) in situations of dependency.

[1] See Decree Law Nos. 129 (25 February 1983) and 519-G2/79.

[2] This allowance was implemented by Decree Law No. 29/89, 23 January 1989. It was first introduced in 1975 (Portaria nº144/75 de 3 de Março) as a supplement for highly dependent invalids.

Individuals are considered **dependent** if they cannot manage in an autonomous way to carry out the daily activities related to domestic life, in terms of both ambulatory abilities as well as health care and who therefore need the intervention of someone to help them. Moreover, **two different degrees** of dependency are distinguished: the first degree concerns pensioners dependent on others to carry out daily activities, more specifically those related to food, locomotion and personal care. The second degree concerns pensioners who, in addition to the first degree of dependency, are bedridden or suffer from severe dementia.

The amount of this supplement for dependency corresponds to a percentage of the value of the social pension and varies according to the degree of dependency (Decree Law No. 309A/2000, 30 November 2000). Respectively, 50% of the value of the social non-contributory pension may be provided to a person with the first degree of dependency (€90.96 in 2008) and 80% (increased to 90% in 2000) to a person with the second degree of dependency (€163.72 in 2008).

This supplement introduced additional financial support for dependent elderly persons who have someone caring for them. Still, it is only a small sum, which does not represent a 'salary' for the carer.

Tax benefits

Tax deductions also exist for families paying for care services or caring for a live-in relative in the ascending line. A deduction of 25% (up to a maximum of 85% of the minimum wage income in 2007, which was €343) is allowed for families paying the fees of nursing home care or for any other kinds of care services for a member in the ascending or collateral line, but only if the elderly person's income is below the minimum wage (€403 in 2007, according to Decree Law No. 2/2007, 3 January 2007).

For persons with a live-in elderly relative (whose income is below the minimum pension of the contributory regime), there is an allowance (Tax Reform Law No. 198/2001) that was increased to 55% of the national minimum salary (Law on the State Budget No. 32-B/2002, 30 December 2002).

3. Demand and supply of LTC

3.1 Demographic trends: An ageing population

During the last 40 years the number of persons aged 65 and older has doubled, so that by 2006 elderly persons represented 17% of the total population. This proportion is expected to rise to 32% by 2050.

In 1990, Portugal counted 1,356,709 persons aged 65 and older and this increased to 1,828,617 in 2006. Among the elderly, women are more representative, with 1,064,865 women compared with 763,752 men in 2006 (see Table 1). In addition, there is an ageing phenomenon among the elderly themselves, with those aged 75 and older rising from 533,379 in 1990 to 820,425 in 2006. Compared with the total population, between 1960 and 2000 the number of persons aged 75 and older grew from 2.7% to 6.7%. Between 1960 and 2004, those aged 80 and older increased from 1.2% to 3.8%, and according to demographic forecasts they will represent 10.2% of the total population by 2050.[3]

[3] See Eurostat, European Commission – Ageing Working Group EPC/AWG, in Ministry of Labour and Social Solidarity, *National Plan for Social Inclusion 2006–2008*, Lisbon (2006).

Table 1. The ageing population in Portugal, 1990–2006

	1990	1995	2000	2005	2006
Aged 65 and older	1,356,709	1,508,091	1,677,287	1,810,100	1,828,617
Men	563,367	626,300	701,217	756,973	763,752
Women	793,342	881,791	976,070	1,053,127	1,064,865
Aged 75 and older	533,379	588,194	694,667	793,761	820,425
Men	198,371	219,616	264,732	302,312	313,034
Women	335,008	368,578	429,935	491,449	507,391

Source: Statistics Portugal (INE), *Statistical Yearbook of Portugal – 2006*, INE, Lisbon, 2007 (information available up to 30 September 2007).

3.2 Supply of formal care

3.2.1 The three main services offered

In this section we consider the three main services available in more detail (home-based services, daycare centres and nursing homes) (see also Table 2).

Home-based care services

Among other services, home-based care offers meals-on-wheels, cleaning, laundry and assistance with personal care (through one- to two-hour visits by a staff carer), but permanent care at home is not provided.

Very rare until 1974, the first significant development in home-based care services occurred between 1975 and 1985, with 139 institutions beginning to deliver home-based care. This development continued and accelerated: from 1986 to 1995, 748 institutions opened (on average 74.8 new institutions per year) and then in only three years (1996 to 1998), more than 367 institutions began to deliver home-based care services. This represents a mean of 122.3 per year (Table 2). This continuous increase resulted in the establishment of more than 344 new institutions providing home care services in 2004–06, which represents a mean of 114.6 per year.

Although initiated earlier, home-based care services really developed in the 1990s as a social response offering individualized and personalized care at the person's home when s/he cannot manage alone, temporarily or permanently, to ensure basic needs are met or daily activities are carried out (Despacho normative No. 62/99, 12 November 1999).

The number of users also evolved considerably, from 20,568 users in 1992 to 24,934 in 1994 and 30,645 in 1998. In 2006, 70,450 persons benefited from such services.

Some local health centres provide public domiciliary services, but there are very few that do so compared with providers in the private non-profit sector, which are financially supported by the state (payment depends on family income).

The availability of home-based care services has increased thanks to the integrated support plan for the elderly (*Programa de apoio integrado a idosos*, PAII), involving the Ministry of Health and the Ministry for Labour and Social Solidarity.

Private, for-profit services are also available and often more successful at meeting the needs of the elderly and their care. They offer occasional care, home-helpers for part or all of the day or 24-hour care for highly dependent elderly persons. But these services are expensive.

Table 2. Three main services for dependent elderly persons, Portugal, 1998, 2004 and 2006

	Number of institutions			Total number of places			Number of users			Coverage rate (no. of places/population)		
	1998 [a)]	**2004 [b)]**	**2006 [c)]**	**1998 [a)]**	**2004 [b)]**	**2006 [c)]**	**1998 [a)]**	**2004 [b)]**	**2006 [c)]**	**1998 [a)]**	**2004 [b)]**	**2006 [c)]**
Nursing homes	1,181	1,517	1,572	49,059	58,565	63,087	47,129	56,535	61,313	3.4 (>=65) 7.6 (>=75)	3.7 (>=65)** 8.9 (>=75)**	3.4 (>=65) 7.7 (>=75)
Daycare centres	1,341	1,766	1,899	46,273	57,591	60,813	36,328	42,158	41,507	3.2 (>=65) 8.3 (>=75)	3.5 (>=65) 8.5 (>=75)	3.3 (>=65) 7.4 (>=75)
Home-based services	1,288	1,947	2,291	38,022	61,429	78,268	30,645*	58,992	70,450	2.6 (>=65) 6.8 (>=75)	3.8 (>=65) 9.1 (>=75)	4.3 (>=65) 9.5 (>=75)

* Data for 1997; *source*: Estatísticas da Segurança Social, Dados Físicos 1997, Vol. II, Acção Social, Instituto de Gestão Financeira da Segurança Social, Lisbon.

** Calculation of the coverage rate in 2004; for the number of residential care/nursing homes it also includes *residências para idosos*, which are protected flats.

a) *Source*: Carta Social, Rede de Serviços e Equipamentos, Departamento de Estudos, Prospectiva e Planeamento, Ministério do Trabalho e da Solidariedade, Lisbon, 2000.

b) *Source*: Taxas de Cobertura 2004, ISS, Departamento de Planeamento e Sistemas de Informação, MTSS, Lisbon, 2004.

c) *Source*: Carta Social, Gabinete de estratégia e Planeamento, MTSS consulta disponível em, Lisbon, 2006 (www.cartasocial.pt/index2.php).

d) Calculated on the basis of the data available by Statistics Portugal (INE), *Statistical Yearbook of Portugal – 2006*, INE, Lisbon, 2007.

Daycare centres

These offer a variety of daily care services, roughly from 9:00 am to 5:00 pm on weekdays, targeting elderly persons with low or medium levels of dependency. Daycare centres began to develop in an experimental way in the mid-1970s, with the aim of helping an individual to remain in his/her own socio-familial context for as long as possible and offering an alternative to institutional care (Carta Social, 2000). The latter form of care was not always the most appropriate response and moreover implied a substantial financial investment. Between 1986 and 1995, the number of daycare centres increased steadily (+55% from the previous period of 1975–85).

The number of centres rose during the 1990s as did the number of users: in 1987 there were 11,370 users, in 1992 there were 27,967 and in 1998 there were 36,328, reaching 41,507 elderly persons in 2006 (see Table 2).

On the whole, these establishments are mainly run by the private non-profit sector, which has agreements with the social security centres. This was true in 1998 as well as in 2004 (representing respectively 99.3% and 94.5% of all daycare centres).

Nursing homes

Nursing homes offer support through collective accommodation, meals, health care and leisure activities.

In the early 1980s, only 2% of the population aged 65 and older had places in nursing homes. Then a significant rise in the number of nursing home units occurred, initiated by the solidarity network: 32 nursing homes per year between 1986 and 1995 and then 45 nursing homes per year between 1996 and 1998, bringing the coverage rate up to 3.4% in 1998 (Table 2). The number of nursing homes continued to increase between 1998 and 2006, from 1,181 to 1,572, with the number of places expanding from 49,059 to 63,087. During the same period, the users also increased from 47,129 to 61,313.

Nevertheless, while the number of places increased, owing to the increasing number of elderly persons there is still a shortage of places. Nowadays the long waiting lists persist, particularly for the low-cost, non-profit institutions where families pay according to their means.

Among the three services, care in nursing homes entails the highest proportion of facilities provided by private for-profit institutions (which accounts for 30% of them), a feature that remained constant between 1998 and 2004.

Considering the *coverage rates of facilities for the elderly* (in terms of nursing homes and daycare centres), while the number of institutions, the capacity and the users grew during this period (from 1998 to 2006), these increases did not induce a significant rise in the respective coverage rates (see Table 2). In fact, the latter remained constant between 1998 and 2006. Between 1998 and 2004, there was a slight increase in this coverage rate, but that was no longer the case between 2004 and 2006. On the contrary, during the latter period there was a slight decrease, specifically for those aged 75 and older.[4] It seems that in spite of important investments in terms of both institutional care and daycare centres, these efforts were not sufficient to meet the needs of a growing population aged 65 and older.

[4] The only coverage rate that shows an increase is that for home-based services (from 2.6% to 4.3% between 1998 and 2006).

3.2.2 Who provides the services?

The services and facilities for the elderly are mainly provided by *non-profit institutions* (partly financed by the state), which assume the role of a solidarity network. To a lesser degree, these services are also provided by public and private for-profit institutions.

Private institutions of social solidarity (IPSS) have emerged from the initiatives of private individuals or associations. They are non-profit, oriented towards social solidarity and recognized by the state, to which they may apply for subsidies.

4. Policies and services for dependent elderly persons

4.1 Historical developments

The family, the state and the market are the three main sources of protection and three policies are involved: those on family, old age and employment. During the past 30 years, the Portuguese state has defined a set of social policy measures aimed at supporting the elderly in situations of dependency, and even if to a lesser extent, providing assistance to their carers. This has resulted in the gradual building up of different kinds of services and benefits.

Efforts to progressively strengthen cooperation between the state, non-governmental organizations, local government and representatives of civil society were undertaken during the late 1980s and the 1990s, in order to develop service provision for families.

During the 1990s, dependency – considered a new social risk to be prevented – became a focus of social policy and even one of the main political priorities, with a political and social orientation concentrated on maintaining the elderly at home.

Various **national programmes** were set up by the government:

- the **Programme of Integrated Support to the Elderly** (Programa de Apoio Integrado a Idosos, PAII; *Despacho conjunto, de 1 de Julho de 1994*), whose main purposes included maintaining elderly dependent persons in their environment and providing support for families who have to look after dependent, elderly family members;
- the **Programme for the Elderly in Nursing Homes** (Programa Idosos em Lar, PILAR; *Despacho de Secretário de Estado da Inserção social, 20 de Fevereiro 1997*), was launched with the objectives of reinforcing and stimulating the services offered in terms of institutional care (nursing homes), especially in areas less well equipped, and of improving the quality of those already existing; and
- the **Programme of Continuous Care** (Programa de Cuidados Continuados), which appeared in the *XIII Governo*, 1995–99, with the goal of providing a wide range of caregiving facilities for elderly persons and for cases of high levels of dependency. It implies the establishment of hospitals for convalescence and temporary permanent care of elderly persons as well as efforts to improve the coordination of the different services supporting dependent elderly persons.

4.2 Recent reforms

The last ten years have been characterized by the implementation and consolidation of the services previously developed (which remains true for the present situation), with particular attention paid to increasing the number of services but also their quality.

The **National Network for Integrated Continuous Care** (Rede nacional de Cuidados Continuados Integrados, RNCCI; Decree Law No. 101/2006 of 6 June 2006)[5] has been implemented jointly by the Ministry of Health and the Ministry of Labour and Social Solidarity. Its mission is to provide various, coordinated services according to the level of dependency that meet *both medical and social care needs*. It has mainly led to the setting up of a network for long-term and palliative care, which can take care of elderly persons in highly dependent situations.

The goal is to promote individual autonomy and to strengthen family competences and involvement, prioritizing the opportunity for the elderly to remain at home. This network is made up of public and private institutions providing care to dependent persons (not just the elderly), and includes community services, hospitals, health-care centres and ambulatory units. It also places particular emphasis on the establishment of hospitals for long-term and palliative care. The network will be progressively expanded until 2016. Between 2006 and 2007, several nursing homes for highly dependent persons were set up, with 2,718 places created in 2006–07. The number of places is expected to increase to 5,000 by the end of 2008 (according to the *National Plan for Social Inclusion 2006–2008*, PNAI).[6]

Long-term care will also be provided through nursing homes, a policy that is associated more with a medical perspective than one focusing on the social integration of the dependent elderly in their own homes. Still, the latter continues to be emphasized in the care of those with low or medium dependency levels.

A number of public programmes have sought to promote and stimulate the development of services provision. The government published a **National Plan for Social Inclusion** (for the period 2003–05 and subsequently for 2006–08), with the aim of expanding home-based care services for dependent elderly persons (expanding the services on offer as well extending the opening hours to longer periods during the day and to seven days a week). The goals included developing social care facilities, equipment and services (institutional care/nursing homes, home-based care and daycare centres) with 19,000 new places (by 2009).

The need to enhance the quality of care has also been underlined as a central issue in recent years. The need for improvement results from the poor quality of care, especially in residential care/nursing homes, which has been a persistent issue in public debate and policy over the last decade. This has led to different governmental programmes not only to increase the number of places but also to facilitate systematic inspections and improve the quality of care at nursing homes.

[5] This initiative was already announced in the 1990s under the Programme of Continuous Care.

[6] See the Ministry of Labour and Social Solidarity (2006).

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About the Dauphine University (Paris), Laboratoire d'Economie et de Gestion des Organisations de Santé (LEGOS)

Since its creation in 1973, the Laboratoire d'Economie et de Gestion des Organisations de Santé (LEGOS) has been active in research, teaching and consulting in the field of economic analysis of health and social policy, notably health economics and public policy, the structural and institutional evolution of the public and private health-care system and options for decentralization and regulation. The research includes health and the social economy, chronic disease analysis and more particularly the economics of ageing.

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FP7 HEALTH-2007-3.2-2

Launched in January 2009, ANCIEN is a research project financed under the 7th EU Research Framework Programme. It runs for a 44-month period and involves 20 partners from EU member states. The project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular:

1) How will need, demand, supply and use of LTC develop?

2) How do different systems of LTC perform?

The project proceeds in consecutive steps of collecting and analysing information and projecting future scenarios on long term care needs, use, quality assurance and system performance. State-of-the-art demographic, epidemiologic and econometric modelling is used to interpret and project needs, supply and use of long-term care over future time periods for different LTC systems.

The project started with collecting information and data to portray long-term care in Europe (WP 1). After establishing a framework for individual country reports, including data templates, information was collected and typologies of LTC systems were created. The collected data will form the basis of estimates of actual and future long term care needs in selected countries (WP 2). WP 3 builds on the estimates of needs to characterise the response: the provision and determinants of formal and informal care across European long-term care systems. Special emphasis is put on identifying the impact of regulation on the choice of care and the supply of caregivers. WP 6 integrates the results of WPs 1, 2 and 3 using econometric micro and macro-modelling, translating the projected needs derived from WP2 into projected use by using the behavioral models developed in WP3, taking into account the availability and regulation of formal and informal care and the potential use of technological developments.

On the backbone of projected needs, provisions and use in European LTC systems, WP 4 addresses developing technology as a factor in the process of change occurring in long-term care. This project will work out general principles for coping with the role of evolving technology, considering the cultural, economic, regulatory and organisational conditions. WP 5 addresses quality assurance. Together with WP 1, WP 5 reviews the policies on LTC quality assurance and the quality indicators in the EU member states, and assesses strengths, weaknesses, opportunities and threats of the various quality assurance policies. Finally WP 7 analyses systems performance, identifying best practices and studying trade-offs between quality, accessibility and affordability.

The final result of all work packages is a comprehensive overview of the long term care systems of EU nations, a description and projection of needs, provision and use for selected countries combined with a description of systems, and of quality assurance and an analysis of systems performance. CEPS is responsible for administrative coordination and dissemination of the general results (WP 8 and 9). The Belgian Federal Planning Bureau (FPB) and the Netherlands Bureau for Economic Policy Analysis (CPB) are responsible for scientific coordination.

For more information, please visit the ANCIEN website (http://www.ancien-longtermcare.eu).