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ANCIEN

Assessing Needs of Care in European Nations

LONG-TERM CARE IN PORTUGAL: SOME ELEMENTS OF CONTEXT

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Although Portugal is often described as a country where welfare provision and care services are rather precarious, requiring as a consequence important investments from family and informal network, some important changes occurred during the last 30 years. We will present some of the main developments.

Portugal, like the other western European countries, has to face an ageing phenomenon. One of the consequences is that the care for the elderly people has become a major issue of the policy agenda.

Although policies and services towards ageing persons developed lately, in the '80s and '90s, their emphasis was put on the development of services (attempt to increase and to diversify the offer, quality improvement).

1 - The LTC system of Portugal

Organisation

Until very recently Long-term care was not part of the public sector involvement and was mainly provided by *Misericórdias* (Holly Church).

The *Misericórdias* are independent non-profit-making institutions with a religious background. Only the Lisbon *Misericórdia* 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, De Almeida Simões, 2007).

In 2006, due to the increasing number of elderly persons and the shortage of services, the National Network for Continuous Integrated Care was implemented, based on the existing structure and putting them together. In each region social services are provided by the Ministry of Labour and Social Solidarity, except for Lisbon area where the Santa Casa da *Misericórdia* (Holly Church) plays this role.

And health and social care are provided mainly by private non-profit-making institutions (subsidized by the State) and by *Misericórdias*.

Available LTC services for elderly persons

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

Different kind of supports and answers to the situation of the elderly persons developed in Portugal in the '80s and '90s. They were characterized by diversity due to the

heterogeneity of needs, as well as by a tendency to deinstitutionalization, resulting from the negative perceptions often associated with institutional care.

The complementary role of formal and informal support was also stressed. And furthermore, in order to improve the quality and suitability of the services the articulation between the various services engaged in the care for elderly, both at the level of social and health responses was improved (Pimentel, 2006).

Nowadays, the services and facilities available for the elderly are various: day-care centres, home-based services (home help and integrated home care (that includes health care), nursing-homes (long-term and palliative care) for highly dependant persons, but also residential care (protected flats) and family accommodation (Acolhimento familiar). However, the last two solutions are still very poorly developed.

2 - Funding aspects

In order to expand services a new private/public mix centred on the public subsidizing of non-profit institutions was built up in the late 1980s. It was implemented through a new legislation¹ on the legal status of non-profit provider institutions (designated as IPSS – *Private Institutions of Social Solidarity*) and the institutionalization of yearly 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 services.

The financial responsibility for the public sector is shared between the Ministry of Health and the Ministry of Labour and Social Solidarity.

The costs of the National Network for Integrated Continuous Care are defined by the Government (Decree-Law n°101/2006, 6th of June, Article 12) and co-financed by both Health and Social Security Sectors (Portaria N°994/2006, 19 September 2006) according to the type of services. Thus the Ministry of Health takes in charge the costs of health care provision, with the patients taking on co-payments for the received social care. The person in situation of dependency who uses the service will have to contribute with a co-payment according to his/her or his/her family's income (see Despacho Normativo n°34/2007 which specifies the conditions in which the social security pay and the amount).

Financial benefits

The Allowance for Assistance by a Third Party², renamed the **Supplement for dependency** (*Complemento por Dependência: Prestação pecuniária mensal*) in 1999 (Decree Law 265/99, 14 of July), is available for pensioners needing permanent care by a third party.:

It is a monthly financial benefit, non-mean tested that may be claimed by the beneficiaries of social security (pensioners) (*Regimes da segurança social*) in situations of dependency.

Are considered as **dependent** persons who can't manage in an autonomous way to carry out the daily activities linked to domestic life, moving abilities as well as health care and who therefore need the intervention of somebody to help them. Moreover, **two**

¹ See Decree-Laws n°129, 25 February 1983, n°519-G2/79

² Introduced by the Decree-Law 29/89, 23 of January. Before, it was first introduced in 1975 (Portaria n°144/75 de 3 de Março) as a Supplement for high invalids

different degrees of dependency are distinguished: the 1st degree concerns pensioners dependent on others to carry out daily activities: food, locomotion, caring. The 2nd degree concerns pensioners who besides the 1st degree of dependency are bed-ridden 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 309A/2000, 30 November). Respectively 50% of the value of the social non-contributory pension for a person with a 1st degree of dependency (90,96 Euros in 2008) and 80% (changed to 90% in 2000) for a person with a 2nd degree of dependency (163,72 Euros in 2008).

This supplement introduced an additional economic support for dependant elderly persons who have someone caring for them. However, it is only a small sum that does not represent a “salary” for the carer.

- Tax benefits also exist for families paying for care services or caring for a live-in relative in ascending line. A deduction of 25% (up to a maximum of 85% of the minimum wage income in 2007: 343 Euros) is allowed for families paying the fees of nursing home care or any other kind of care services for a member in ascending or collateral line, but only if elderly person’s income is below the minimum wage income (403€ in 2007 according to Decree-Law 2/2007, 3 of January).

For persons with a live-in elderly relative (with an income below the minimum pension of the contributory regime), there is an allowance (Tax reform law 198/2001) which was increased up to 55% of the national minimum salary (Law on the state budget: n°32-B/2002, 30 December

3 - Demande and supply of LTC

Demographic trends: an ageing population

During the last 40 years the number of persons aged 65 and over has doubled, so that by 2006 elderly persons represented 17% of the total population. This proportion is expected to go up 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 people, women are more represented, with 1'064'865 women for 763'752 men in 2006 (See Table 1). Besides, there is an ageing phenomenon of the elderly, with the 75 year old and older passing from 533'379 in 1990 to 820'425 in 2006. Compared to the total population, between 1960 and 2000, the number of persons aged 75 and over increased from 2.7% to 6.7%. Between 1960 and 2004, the 80 year old and over increased from 1.2% to 3.8%, and according to demographic forecasts they will represent 10.2% of the total population by 2050³.

Table 1 *The ageing population in Portugal, 1990-2006*

	1990	1995	2000	2005	2006
65 years old and more	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
75 years old and more	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: INE, Portugal 2007, Statistical Yearbook of Portugal 2006 (information available till 30th September 2007)

Supply of formal care

1) The three main offers in terms of services

We will consider more in detail the three main services available (home-based services, day-care centres and nursing homes) (see table 2):

a) Home-based care services

³ EURSTAT European Commission – Ageing Working Group EPC/AWG, in PNAI 2006-2008

Home care delivery services offer among others meals on wheels, cleaning, laundry and personal care (through 1-2 hours visits by personnel), but permanent care at home is not provided.

Very rare until 1974, a first significant development occurred between 1975 and 1985, with 139 institutions beginning to deliver home-care services. This development continued and accelerated: from 1986 to 1995, 748 institutions opened up (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-care services. This represents a mean of 122.3 per year (Table 2). This continuous increase resulted in 2004-2006 in the building up of more than 344 new institutions providing home care services, which represents a mean of 114.6 per year.

Although initiated in the 80s, home-based care services really developed in the 90s as a social response offering individualised and personalised care at the person's own home when she/he can not manage alone, temporarily or permanently, to ensure basic needs and/or daily activities (Despacho normative 62/99, 12 de Novembro).

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

Some local health centres provide public domiciliary services but they are very few in comparison with the offer of the private non-profit-making sector, financially supported by the State (payment depends on family income).

The offer in terms of home-based care services has increased thanks to the Integrated Support Plan for elderly (Programa de apoio integrado a idosos (PAII), common to the Ministry of Health and Ministry of Labour and Social Solidarity).

Private profit-making services are also available and often more accurate in meeting the needs of the elderly and their care. They offer occasional care, home helpers for part/all of the day or 24 hours care for highly dependent elderly persons. But they are expensive services.

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 (n° 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	1181	1517	1572	49059	58565	63087	47129	56535	61313	3.4 (>=65) 7.6 (>=75)	3.7 (>=65)** 8.9 (>=75)**	3.4 (>=65) 7.7 (>=75)
Day care centre	1341	1766	1899	46273	57591	60813	36328	42158	41507	3.2 (>=65) 8.3 (>=75)	3.5 (>=65) 8.5 (>=75)	3.3 (>=65) 7.4 (>=75)
Home-based care services	1288	1947	2291	38022	61429	78268	30645*	58992	70450	2.6 (>=65) 6.8 (>=75)	3.8 (>=65) 9.1 (>=75)	4.3 (>=65) 9.5 (>=75)

- a) Source: Carta Social, Rede de Serviços e Equipamentos, Departamento de Estudos, Prospectiva e Planeamento, Ministério do Trabalho e da Solidariedade, 2000
- b) Source: Taxas de Cobertura 2004, ISS, Departamento de Planeamento e Sistemas de Informação, MTSS 2004.
- c) Source: Carta Social 2006, Gabinete de estratégia e Planeamento, MTSS consulta disponível em www.cartasocial.pt/index2.php (6th of February)
- d) Calculated on the basis of the data available in the Statistical Yearbook of Portugal 2006.

* Data for 1997. Source: Estatísticas da Segurança Social, Dados Físicos 1997, II Volume, Acção Social, Instituto de Gestão Financeira da Segurança Social.

** Calculation of the coverage rate in 2004: regarding the number of residential care/nursing homes also includes "residências para idosos" which are protected flats.

b) Day-care centres

They offer a variety of daily care services, roughly from 9 to 5 on week days targeting elderly people with low or medium dependency. Day-care centres began to develop in an experimental way in the mid '70s, with the aim of keeping a person in his/her own socio-familial context for as long as possible and to offer an alternative to institutional care (Carta Social, 2000). The latter weren't always the most adequate response and moreover implied an important financial investment. Between 1986 and 1995 day-care centres increased steadily (+ 55% from the previous period of 1975-1985).

The number of centres increased during the 90s as well as the number of users (See Table 2): 11'370 users in 1987, 27'967 in 1992 and (36'110) 36'328 in 1998, to reach 41'507 elderly in 2006.

On the whole, these establishments are mainly provided by the private non-profit-making 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 the day-care centres).

c) Nursing homes

They offer support through collective accommodation, meals, health care, and leisure time activities.

In the early '80s only 2% of the 65 and over had a place in nursing homes. Then a significant increase in the number of nursing homes units created by the solidarity network occurred: 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. The number of nursing homes institutions continued to increase between 1998 and 2006, from 1'181 to 1'572, with the number of places passing from 49'059 to 63'087. During the same period the users also increased from 47'129 to 61'313.

However, although the number of places increased, due to the increasing number of elderly there still are places missing. Nowadays they are still long waiting lists, in particular for the low-cost non-profit institutions where families pay according to their means.

Among the three services, nursing home care has the highest proportion of structures provided by private profit-making institutions (it applies to 30% of them) and this has remained constant between 1998 and 2004.

Considering the coverage rates of equipments for the elderly, in terms of nursing homes and day-care centres, although the number of institutions, the capacity as well as the users increased during this period (from 1998 to 2006), it didn't induce a strong increase of the respective coverage rates (See Table 2). In fact, the latter has remained constant between 1998 and 2006. Between 1998 and 2004 it is possible to see a slight increase in this coverage rate, but this is no longer the case between 2004 and 2006. During this period, on the contrary, a slight decrease appeared, specifically for the 75 and older⁴. It seems that in spite of an important investment both in terms of institutional care and day-care centres, those efforts are not sufficient to reach out to the needs of a growing population of 65 and older.

2) Who provides the services?

The services and facilities for the elderly are mainly provided by non-profit-making institutions (partly financed by the State) that assume the role of a solidarity network. In a less important way, they are also provided by public and private profit-making institutions.

The institutions called Private Institutions of Social Solidarity (*Instituições Particulares de Solidariedade Social, IPSS*) emerge from the initiative of private individuals or associations, are non-profit-making and underline a social solidarity aim and they are recognised by the State they may apply for subsidizing.

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

4 - Policy and services for dependent elderly person

Historical developments

The family, the State and the market are the three main sources of protection and three policies are concerned: family policies, old age policies and employment policies. During the past three decades the Portuguese State defined a set of social policy measures aiming to support elderly people in situations of dependency and, even if to a lesser extent, to provide support for the carers of elderly persons. This has resulted in the gradual building up of different kinds of services and benefits.

The strengthening of cooperation between the State, non-governmental organisations, local government and representatives of civil society expanded during the late 80s and the 1990s in order to develop service provision for families.

During the '90s dependency - considered as a new social risk to prevent - became in itself an aim of social policy and even one of the main political priorities with a political and social orientation focusing on maintaining the elderly at home.

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

- **“Programme of Integrated Support to the Elderly”** (Programa de Apoio Integrado a Idosos (**PAII**); Despacho conjunto, de 1 de Julho de 1994). One of the main purposes was to maintain elderly dependant persons in their environment, and also to provide support for families who have to care and give attendance to dependent elderly family members.

- **“Programme for elderly in nursing home”** (Programa Idosos em Lar (**PILAR**); Despacho de Secretário de Estado da Inserção social, 20 de Fevereiro 1997). The objective is to reinforce and stimulate the offer in terms of institutional care (nursing homes), especially in areas less equipped and also to improve the quality of the ones already existing.

- **“The Programme of Continuous Care”** (Programa de Cuidados Continuados) appeared in the XIII Governo, 1995-1999, with the aim of providing a wide range of caregiving facilities for elderly persons and in cases of high dependency. It implies the setting up of hospitals for convalescence and temporary permanent care of elderly persons as well as efforts to improve the articulation of the different services supporting dependent elderly persons.

Recent reforms

The last ten years (the present situation) are characterised by the implementation and consolidation of the services developed previously, with a particular attention paid to increasing the number of services but also to their quality.

- “**National Network for Integrated Continuous Care**” (Rede nacional de Cuidados Continuados Integrados (**RNCCI**); Decree-law 101/2006 of 6 June)⁵ was implemented jointly by the Ministry of Health and the Ministry of Labour and Social Solidarity.

The objective is to provide various and co-ordinated services according to the level of dependency and meeting both medical and social care needs. Mainly it has led to the setting up of a network of long-term and palliative care, which can take care of elderly persons in highly dependant situations.

The issue is to promote the person’s autonomy and to strengthen families’ 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 dependant persons (not only elderly persons): community services, hospitals, health-care centres, ambulatory units. It also places particular emphasis on the setting up of hospitals for long term and palliative care. The network will be built up progressively until 2016. Between 2006 and 2007 several nursing homes for highly dependent persons were set up, with 2718 places created in 2006-2007. The number of places is expected to increase to 5000 by the end of 2008 (PNAI 2006-2008).

Long term care will also be provided through nursing homes, a policy which is more associated with a medical perspective than a perspective of care focusing on the social integration of the dependant elderly in their own home. However, the latter perspective for those with low or medium dependency continues to be emphasized.

Various public programmes promote and stimulate the development of services provision:

- The Government created a **National Plan for Social Inclusion (PNAI)** (2003-2005; 2006-2008) which aims are to expand home-based care services for dependent elderly persons (not only to increase the offer of services but also to extend the opening hours to longer periods during the day and 7 days a week). The aims are to develop social equipments and services (institutional care/nursing homes, home-based care and day-care centres) with 19’000 new places (until 2009).

⁵ Already mentioned and announced in the 90s under the name Program of continuous care.

The need to improve the quality of care has also been underlined as a central issue these last years. It results from the poor quality of care, especially in residential care/nursing home, which has been a constant trend 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 create systematic inspection and to improve the quality of nursing home.

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Assessing Needs of Care in European Nations



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L 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>).