European Network of Economic
Policy Research Institutes

ANCIEN

Assessing Needs of Care in European Nations

THE LONG-TERM CARE SYSTEM FOR THE ELDERLY IN SWEDEN

NANNA FUKUSHIMA, JOHANNA ADAMI AND MÅRTEN PALME

ENEPRI RESEARCH REPORT NO. 89

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 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 978-94-6138-031-9
Available for free downloading from the CEPS website (www.ceps.eu) and
ANCIEN website (http://www.ancien-longtermcare.eu/node/27

Contents

List of Tables

The Long-Term Care System for the Elderly in Sweden

ENEPRI Research Report No. 89/June 2010

Nanna Fukushima, Johanna Adami and Mårten Palme*

1. The long-term care system of Sweden

1.1 Overview of the system

Care of the elderly in Sweden is based on the philosophical aim of providing the elderly with support to live a high quality, independent life for as long as possible. The management and planning of care for the elderly is split among three authorities – the central government, the county councils and the local authorities. Each unit has a different but important role in the welfare system of Sweden. They are represented by directly elected political bodies and have the right to finance their activities by levying taxes and fees within the frameworks set by the Social Services Act.

Any person with permanent residency in Sweden and who has impediments is eligible for care, solely determined by an assessment of needs. To avoid financial exploitation of the individual, a maximum monthly fee for long-term care (LTC) is set by the central government with further conditions imposed, depending on the financial situation of the individual. This guarantees that all elderly persons in need of care are able to receive treatment in Sweden.

Since the welfare system was established and some of the former responsibilities of the individual (or the family) have been taken over by the state, Swedes have come to trust and rely on the state to take care of the elderly, to the extent that the discussion of informal care begun just some 15 years ago has only recently been considered in political decision-making. Yet the rapidly ageing population has increasingly turned policy-makers' attention towards care provided by relatives or friends as a partial solution to the anticipated demographic problems. Nonetheless, this does not mean that formal care has diminished in importance – formal care is still the backbone of care for the elderly in Sweden and is expected to remain so. Home-based care, however, is still largely left behind.

The available kinds of formal care in Sweden are institutional care, home care and home nursing care. Day activities, meal services, personal safety alarms, home adaptation and transportation services are additional services supplied by the municipalities and are also regulated by law.

Since the mid-1990s, technical advancements have made the less-costly home care and home nursing care a more attractive option for many of the municipalities. Transition from institutional care to home care has not only helped to reduce expenses but has also permitted the elderly to sustain an independent life for much longer. Still, the growth of home care as a replacement for institutional care has been intensely questioned lately. This, in combination

* Nanna Fukushima is a Master's student at the Department of Economics, Stockholm University. Johanna Adami is Associate Professor at the Clinical Epidemiology Unit, Department of Medicine at Karolinska Institutet, Stockholm. Mårten Palme is a professor at the Department of Economics, Stockholm University, whose research primarily focuses on the economics of social security, health economics and empirical public finance. The authors are grateful to Professor Mats Thorslund for comments on an earlier draft of this paper. For more information on Stockholm University, see the penultimate page of this study.

with the increasing attention given to informal care, may be reason to believe that Sweden could stand at the beginning of a new policy era concerning long-term care.

1.2 Assessment of needs

With the exception of care that requires supervision by a medical practitioner, everything concerning elderly care falls under the responsibility of the local authorities, including county councils and municipalities. The need for care is either assessed by a general practitioner or follows from a request for assessment by the local authority. If a request for care is made directly to the authority, an evaluator is assigned to interview the person and any possible family members to determine the extent of support the elderly person requires, and whether the care can be provided in the care recipient's own residence. Even many severe cases requiring extensive medical care can today be treated at home, as home help is offered around the clock, up to seven visits per day and sometimes even more. Nevertheless, if care is not recommended because of the construction of the building, institutional care is considered a last resort.

There is currently no general guidance on the assessment of needs in Sweden. Instead, the assessment is primarily down to the evaluator and is performed on a discretionary basis. Although there is no general guidance, the most commonly used tests when assessing the needs of the elderly in Sweden are presented in Table 1 (National Board of Health and Welfare).

As of 1 January 2010, the local authorities are required to draw up an individual plan for each care recipient, which clearly states each step of the required treatment and services. The plan must also disclose the name of the person who is officially in charge of the case and specify which authority is responsible for each component of the services and care offered.

Table 1. Assessment methods

Katz ADL (activities of daily living) index	ADL taxonomy	'ADL steps'
EQ-5D	Functional Independence Method (FIM)	Gottfries-Bråne–Steen Scale (GBS)
Residential Assessment Instrument (RAI)	SF-36 Short From Questionnaire	The Swedish National Study of Ageing and Care (SNAC)
Carers outcome agreement tool (COAT)	Camberwell assessment of need (CAN)	Mini Mental State Examination (MMSE)
Geriatric depression scale (GDS 20)	_	_

Source: National Board of Health and Welfare.

1.3 Available LTC services

The available LTC services in Sweden are home help in regular housing (home care), special housing (institutional care), day activities, home medical services (home nursing care), meal services, personal safety alarms and home adaptation. In addition there are transportation services for elderly and functionally impaired persons who cannot use regular public transport

and who are entitled to transportation services.[1] Additionally, the local authorities provide grants for certain measures to assist the disabled to use their homes efficiently, regardless of the applicant's financial situation.

In 2006, 98,619 persons over the age of 64 received institutional care in Sweden. This is a reduction of 11.80% compared with 2001. During the same observation period, 178,282 received home care services, which on the other hand is an increase of 11.66%. According to the National Board of Health and Welfare (Wikgren-Orstam, 2006), 64,700 applicants were granted assistance with home adaptations in 2005, and approximately 57,300 persons received meal delivery services during the same year. In 2004, 372,900 individuals had the right to transportation services, which accounts for 4.1% of the population. Finally, according to a survey carried out among the local authorities, 157,169 persons had personal safety alarms installed in the spring of 2006.

1.4 Management and organisation

The hierarchical bureaucratic structure that previously prevailed in Sweden changed somewhat after the Care of the Elderly Reform (*Ädel-reformen*) in 1992. Old-age care had until then been administered from the national level, but through the reform, the role of the government became restricted to that of a legislating, facilitating and controlling body. All of the detailed planning, funding and allocation of resources henceforth became the responsibility of the municipalities together with the county councils.

There are 280 municipalities, 18 county councils and 2 regional authorities in Sweden.[2] Today the municipalities and the county councils are entitled to choose their own organisation and are free to participate in various forms of collaboration. The responsibility of the county councils are to provide health services, such as hospitals, health centres and other institutions, while the responsibility of the municipalities covers all other aspects of care, including social care, institutional care and home nursing. Although special housing and home care can be run by a municipality or by a private health and social care provider (such as companies, trusts or cooperatives), the local authorities retain the ultimate responsibility for supplying and maintaining the level of care, even when private organisations supplement some of their activities.

The organisational division of social care and medical care between the two authorities had already been implemented in the 1950s. Yet the reform in 1992 led to a diversification of the activities provided by the municipality, and at the same time, a specialisation of services for the county councils. The responsibilities of the municipality account for about 90% of all elderly care and no formal hierarchical order between the two authorities exists.

Both authorities have the right to levy taxes, which, according to Johansson and Borell (1999), makes the specialisation of services an economic as well as an organisational matter. County council elections and municipal elections are held every fourth year in conjunction with the general elections.

At the central level, the Ministry of Health and Social Affairs (Socialdepartementet) is responsible for developments in areas such as health care, social insurance and social issues.

---

[1] Although detailed regulation was replaced by looser framework laws in the Local Government Act from 1991, the local council and county councils are still not entirely without restrictions and must follow the Social Services Act in terms of the type of care and service they (at least) must provide.

[2] The regional authorities (Skåne and Västra Götaland) are more or less equivalent to the county councils but with some extended responsibilities as they cover larger areas.

The ministry draws up terms of reference for government commissions, drafts proposals for parliament on new legislation and prepares other government regulations.

The National Board of Health and Safety (Socialstyrelsen) is the government's central advisory and supervisory agency in the fields of health services, health protection and social services. The key task of this agency is to follow up and evaluate the services provided to see whether they correspond with the goals laid down by the central government.

1.5 Integration of LTC

The Care of the Elderly Reform was an attempt to shift the administration from the county councils to municipalities, with a view to increasing flexibility in responding to local demand. Almost 20 years since the reform, the division of responsibility in LTC may be considered well established in Sweden. Nevertheless, it is not always clear where the responsibilities for medical treatment end and where social care begins. The lack of a clear definition and explicit rules, according to Johansson and Borell (1999), has on many occasions led to an inefficient utilisation of resources, cooperation issues, lack of continuity and attempts by county councils and municipalities to transfer responsibilities and costs to one another. This in turn has caused many individuals to receive insufficient care and get stuck in the bureaucratic red tape.

Another issue that has complicated organisational cooperation is that many of the elderly suffer from multiple illnesses. Incentives to keep costs down and the lack of clear divisions of work have caused the county councils to transfer the responsibility of care to the municipalities as soon as treatment for the illness for which the individual was initially cared for is completed. This might have resulted in many LTC patients receiving insufficient care, because a municipality could have deemed the remaining illnesses to be outside its scope of responsibility.

Henriksen et al. (2003) discuss and summarise issues raised by managers from local authorities and county councils in a workshop held in Sweden in 2002. The topic of the workshop was the shortcomings in collaboration between the two authorities. The concerns raised at the workshop reflect the problems previously discussed and are listed below:

- lack of communication between the levels of care provided;
- the absence of a chain of care or structured care network;
- lack of professional management;
- lack of coordination between the local municipalities and the county councils;
- difficulties in making the district nurses visit the elderly in their own homes or at the nursing homes; and
- issues in the coordination of financial matters between the two governmental bodies.

Improving the level of collaboration between the two authorities has been debated since the 1970s. For instance, in an attempt to make the division of work more conspicuous, a law was enforced in 1990 to emphasise the 'planning of care' (*vårdplanering*) by the authorities when the initial assessment of need is conducted. In 1993 a new law made the interpretation of the responsibility for care expenditures more explicit. Despite the laws enforced, the government's own calculations indicate that only two out of three care recipients have a written, individual care plan (Ministry of Health and Social Affairs, 2009).

Since 1 January 2010, local authorities and county councils have been required to draw up an individual plan in accordance with a given format for each care recipient. The plan should plainly state what treatment the individual requires and which authority is to provide what sort of care, the specifications of the care if its provision is required by any other than the local

authority or county council, and the name of the authority that has the principal responsibility for the health of the individual.

2. Funding

The total cost of institutional care, measured per capita of the Swedish population age 65 and older was approximately SEK 30,000 (about €3,000) in 2007. The corresponding cost of home care per individual over age 65 was SEK 19,000. Dividing the total costs by the number of care recipients, the same care amounted to SEK 513,000 per institutional care recipient on average, and SEK 220,000 per person for home care recipients. The total expenditure on LTC for individuals over age 65 was SEK 168 billion in 2006, which equates to approximately 3.5% of GDP. Less than 5% of the total cost of LTC is financed privately, while the rest is covered by public funds, mainly raised through taxes. The cost of LTC for the municipalities and the county councils was about SEK 80 billion each in 2005 (Ministry of Health and Social Affairs, 2007).

The average local tax rate in Sweden in 2003 was 31.17%, of which 20.7% went to the municipalities and 10.47% to the county councils (Johansson, 2008). Itemising the expenditure, institutional care was by far the highest for LTC expenditure by the municipalities – at 64%. Care in ordinary housing accounted for 34% and preventive activities for 2%. More than 80% of the health care and social care services provided by the municipalities are financed by taxes levied on the residents. A smaller part of this elderly care is financed by government grants to the municipalities and the remaining 4% by charges (Ministry of Health and Social Affairs, 2007).

Charges for care of the elderly are regulated by the Social Services Act and designed to protect the individual from excessively high fees. Each year the government decides a maximum fee the service provider may charge an individual. The fee, which in 2007 corresponded to SEK 1,612 per month, is fixed and charged irrespective of the individual's income. Nevertheless, the fee may be reduced if the monthly income does not exceed the minimum cost of living (the reserved amount), also set annually by the government. In 2007, the reserved amount was SEK 4,346 per month for a single elderly person and SEK 3,640 per person and month for a couple.

Within the frameworks of these rules, each municipality decides its own system of charges and the fees paid by the individuals. As of 2006, approximately 19% of home care recipients received the entire service free of charge, as their income did not exceed the reserved amount (Ministry of Health and Social Affairs, 2007).

3. Supply of LTC

3.1 Old-age dependency ratio

Over 17% of the Swedish population, or about 1.6 million persons, are age 65 or older. Population projections forecast that in the next 30 years, the largest population growth will be among the population aged 65 and older (Table 2). At approximately 5%, Sweden already has the highest proportion of the elderly aged over 80 in Europe. In 2060, this number is expected to double to 10% of the population. Although the population in Sweden is increasing, population ageing will have a negative impact on the old-age dependency ratio, putting pressure on the population of working age to support an increasing number of elderly persons. The old-age dependency ratio, measured as the ratio between the population over age 65 and the population of working age, is estimated to grow as high as 47% in 2060, which is a growth rate of over 20% from the 26% old-age dependency ratio in 2007 (Swedish Association of Local Authorities and Regions, 2008).

Table 2. Population by gender and at age 65+

Year	Total pop.	Women	Men	65+/pop.	65+
1950	7,046,920	3,535,877	3,511,043	0.102	721,316
1960	7,497,967	3,757,848	3,740,119	0.118	887,964
1970	8,081,142	4,045,374	4,035,768	0.138	1,111,902
1980	8,317,937	4,198,115	4,119,822	0.163	1,359,391
1990	8,590,630	4,346,613	4,244,017	0.177	1,521,699
2000	8,882,792	4,490,039	4,392,753	0.171	1,523,313
2008	9,256,347	4,652,637	4,603,710	0.177	1,634,401

Source: Statistics Sweden.

The average life expectancy at birth has steadily increased and reached 79 and 83 in 2008 for men and women, respectively (Table 3). This number is expected to rise another six years for men and three years for women by 2050, narrowing the gap between the life expectancies for men and women. As a consequence of the changes in the mortality rate for men, more women are expected to retain their partner in old age. At the current retirement age of 65, men are expected to live another 17 years and women another 21 years.

Table 3. Average life expectancy at birth (years)

Year	Men	Women
1951-60	70.89	74.1
1961-70	71.73	76.13
1971-80	72.26	78.1
1981-85	73.55	79.53
1986-90	74.37	80.22
1991-95	75.6	80.98
1996-2000	76.89	81.83
2001-05	77.99	82.41
2008	79.1	83.15

Source: Statistics Sweden.

3.2 The role of informal and formal care in the LTC system (including the role of cash benefits)

The social welfare system was quickly adopted by Swedish policy-makers at the beginning of the 20th century and is today deeply rooted in the minds of people. In 1956, when the law making children responsible for their parent's welfare was abolished, it instead became the responsibility of society to take care of the elderly. Initially, only simpler home care services were provided by the state. Since then, high taxation has enabled the state to finance generous and diverse safety nets for all its citizens, irrespective of means.

The close tie between the state and the people has strengthened the Swedes' association of care of the vulnerable and weak in society as a state matter. For example, the public sector is also the single biggest employer in Sweden and currently employs about 20% of the entire labour force

between the ages of 20 and 64. Thus, it is not surprising that the Swedish government has for a long time almost exclusively concerned itself with formal LTC care.

Although informal care has always existed alongside the services provided by the government, it is not until quite recently that, when faced with the notion of an ageing population and the economic effects, the government has seriously begun to consider the option of voluntary informal care in relation to LTC (Jegermalm, 2004). This in turn is the reason studies on informal care are so very few in Sweden. Still, another reason often mentioned to explain the scarcity of studies on informal care is the difficulty of obtaining information about the care providers. This is because the focal point of the few studies in existence has almost entirely been the condition of the care recipients, leaving out most matters concerning care providers (Sundström & Malmberg, 2006). When institutional care played a greater role in LTC in Sweden, i.e. before the reform and before technical progress enabled more advanced care at home, the relatives of care recipients were often only considered visitors of the patient (Whitaker, 2009). Yet with the increasing number of elderly persons now been cared for at home, the role of relatives has in the eyes of the legislature changed to that of an important additional resource to the services already provided by the municipalities. Nevertheless, although informal care is now receiving more recognition than ever, only a handful of studies have so far investigated the supply of informal care from a quantitative and qualitative perspective, and there are even fewer that have investigated the effects that caregiving has on the caregiver's situation.

The first initiative to support informal care providers came in 1997, when the government proposed a new bill (1997-98: 113) to invest SEK 300 million in projects with the aim of supporting relatives who cared for elderly individuals between 1999 and 2001. The objective behind the bill was to provide mental and physical relief for heavily burdened relatives, and at the same time stress the importance of the support received from voluntary organisations, such as the Red Cross, as an important supplemental resource to public services.

The kinds of support an informal caregiver may receive today are much broader than before. The creation of the National Centre for the Support of Informal Care Providers (authors' translation of Nationellt Kompetenscentrum Anhöriga (NKA)) in 2008 is an example. NKA is co-run by several research institutes in Sweden with a mandate from the National Board of Health and Welfare. Its aim is to coordinate research and development within the field of informal care and to supply information and documentation to caregivers while increasing the awareness of informal care among the public, and also among the many different authorities in Sweden. In addition to the above, as of 1 July 2009, the municipalities have been required by law to support informal caregivers. The Social Services Act states that municipalities are obliged to respect and cooperate with informal caregivers, and offer individually tailored support when needed. The objectives of the Act are to help reduce the workload, prevent illnesses and give informal caregivers the knowledge and information they need to continue providing support. An additional purpose of the Act is to officially recognise informal care providers and acknowledge the importance of their work.

The support provided to informal caregivers is not yet clearly defined in Sweden. The National Board of Health and Safety has expressed the purpose of this support to relatives as an effort to i) make the situation of the caregivers visible, ii) prevent burnout and fatigue, and iii) improve the quality of life for those caring for a person requiring assistance with the activities of daily living (ADLs). According to a report published by the County Administrative Board of the region Västra Götaland (Länsstyrelsen i Västra Götaland, 2009), the main reason different municipalities offer different types of support to relatives is the lack of a clear definition. For instance, education for informal caregivers was only offered in 38% of the municipalities in 2008 (Länsstyrelsen i Västra Götaland, 2009).

Table 4 lists the kinds of support informal caregivers may receive in Sweden today. Since informal care may reduce the care providers' ability to work, financial compensation is sometimes granted. The number of recipients of such support was 5,200 in 2006, which is an increase from 4,600 in 2000.

Table 4. Support available for informal care providers

Kind of support	**Description**	**Assessment**	**Special remarks**
Employment	Full compensation may be given for the work of caring for an elderly person when the care provided at home is insufficient.	Required	–
Cash benefit	Symbolic compensation is provided for the effort of caring for an elderly person. The benefit varies between SEK 1,000-3,000 per month. The benefit is paid to the care recipient, who is responsible for forwarding the amount to the caregiver.	–	Not available nationwide.
Support centres	These are gathering points for informal caregivers to offer support to each other and receive information and guidance from professional caregivers.	Not required	–
Support groups	Support groups offer mutual support for informal caregivers.	Not required	–
Relief support	This form of support offers temporary relief to the caregiver, usually by staff from home care services or a voluntary organisation.	Depends on the municipality	Half of the municipalities offer this service for free, others for a small charge.
Temporary residence	The care recipient is offered temporary residence in a nursing home.	Required	Frequency and length of stay vary depending on municipality; the same applies to charges for care.
One-to-one support	Caregivers are offered consultation about the planning of care. The COAT method is most frequently used.	–	–
Volunteers	Volunteers can assist with both care of the elderly and support for the caregiver.	Not required	–
IT support	This form of support entails finding information and receiving help over the Internet, e.g. Actionservice.se provides professional advice directly over the Internet to elderly persons and informal caregivers.	Not required	Services are only provided through municipalities with a service contract with Action service.
Feel-good activities	Spa treatments, massages and health consultations may be offered to caregivers.	–	The availability of services differs depending on the municipality.

Table 4. cont'd

Cash benefit (temporary)	A temporary cash benefit is offered to caregivers of up to 60 days to compensate for lost income when caring for a terminally ill close relative.	Required	Paid by the national social insurance (Försäkringskassan).
Technical aid	Technical aids may be installed or homes adapted.	Required	Costs vary depending on municipality.
Education	Seminars and education are offered to informal caregivers.	Not required	–

Source: Nationella Komepetenscentrum Anhöriga (2009).

3.3 Demand and supply of informal care

Although there are still relatively few reports written about informal care in Sweden, the existing studies have estimated that a person who needs assistance with ADLs and lives outside an institution receives two to three times more informal care than care provided by the public home-care services on average (Johansson, 1991; Sundström et al., 2002). While the studies undertaken have not covered the extent of care, the same studies have also found minimal change in the prevalence of informal care over time.

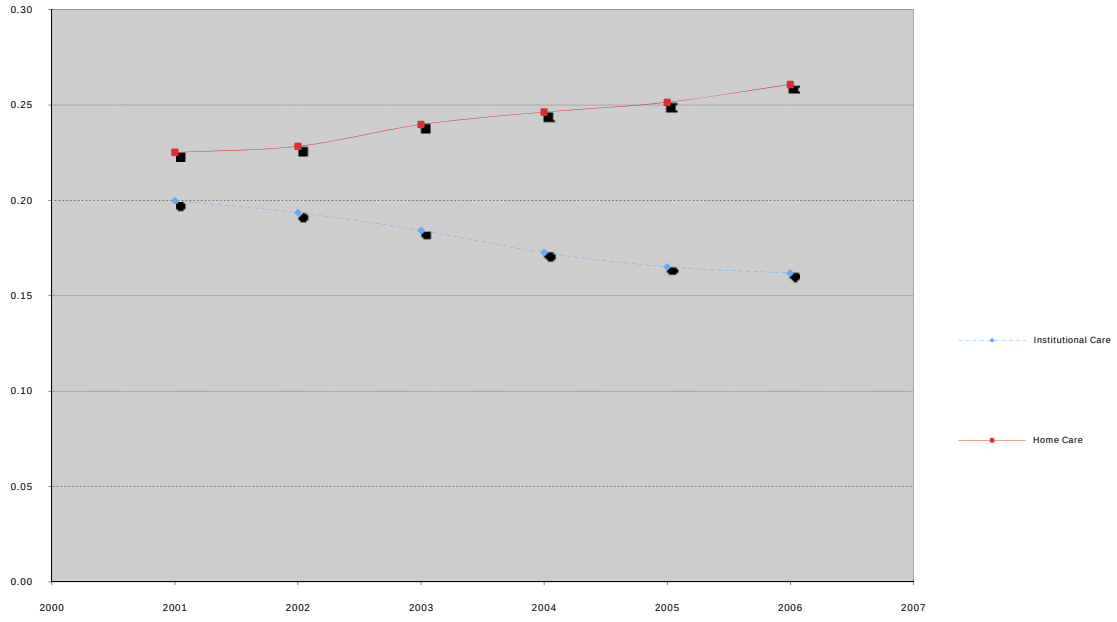
As previously mentioned, it is very difficult to give a straight answer to the question of what informal care looks like in Sweden. Questionnaires and studies concerning institutional care are not only few in number, but vary in the questions asked and the method employed, making comparability problematic (Szebehely, 2006). Sundström & Malmberg (2006) have in a report to the National Board of Health and Welfare listed many previous findings: although the studies, stretching from 1994 to 2005, are diverse in format and are far from conclusive, they seem to point towards a slight increase in informal care over the observation period, especially among the age group 75 and older. Their findings support previous studies in which it was observed that informal care is more common among women than men. The age group of 45 to 64 is (in relative terms) the most common among those providing informal care to someone needing assistance with ADLs, with three out of four care recipients being over age 65. Szebehely's (2006) study estimates that one in four persons over age 55 regularly supports a disabled individual needing ADL help outside his or her own household. Sundström & Malmberg (2005) estimate that approximately 20% of the total adult population provides care for someone else (anything from keeping company to provision of heavy care such as bathing, cooking and shopping) but only 7% of the population care for a disabled person with ADL needs on a daily basis. Sundström & Malmberg (2005) have reported results from a survey conducted by the Swedish National Institute of Public Health (Folkhälsoinstitutet) in 2005. According to this information, the average weekly number of care hours received by the age group 16 to 84 was 15 for men and 13 for women. Nordberg et al. (2005) studied informal care, especially among those suffering from dementia. They found that on the recipient side, 38% of the disabled persons needing ADL help received approximately 2.6 hours of care per day by an informal care provider. According to Larsson's (2006) report in the Survey on Living Conditions (ULF) published by Statistics Sweden, the proportion of the elderly who received help with some kind of chore or personal care increased in the age groups over 65. If one does not consider gender differences, the share of the elderly who received help increased from 2% in 1998 to 5% in 2003. In addition, when the living arrangement was taken into account, it was found that informal care had increased by as much as 10% among single households but hardly any at all among the cohabiting elderly.

3.4 Demand and supply of formal care

In the 1950s, when the Poor Relief Act (making children responsible for their elderly parents) was abolished, the pension had just been raised to a level that was enough to survive on. At the outset of the social welfare reform, approximately 5% of Sweden's GDP was spent on the elderly, which included pensions, housing subsidies, social services and health care. This share quickly escalated and reached about 14% of GDP in the 1990s. But the recession in the 1990s along with the introduction of the *Ädel* reform in 1992 came to burden the already financially strained local authorities and put an end to the rising expenditure on elderly care in Sweden. Many municipalities had to face a shrinking income owing to the financial turbulence and were forced to increase the fees for users of elderly care and impose stricter needs assessments in order to save costs. The more costly institutional care was gradually replaced by the cheaper home care and home nursing care. The reallocation of resources also happened to coincide with the new policy of providing the elderly with the possibility of living an independent life as long as possible, making this transition easier for the municipalities to justify. Institutional care was thus reserved for those most in need, who required more professional and medical attention than is possible to provide in their own residence (Figure 1).

As noted above, the available formal care services are home help in regular housing (home care), special housing (institutional care), day activities, home medical services (home nursing care), meal services, personal safety alarms, home adaptation and transportation services.

Figure 1. Demand for institutional care and home care (80+ years)



3.4.1 Institutional care

Table 5 lists the number of institutional care recipients in Sweden. The proportion of institutionalised persons aged 80 and older was about 20% in 1950, but saw its peak in 1975 when the corresponding number reached 30% (Sundström et al., 2002). The number has since steadily decreased, reaching 16% in 2007.

Table 5. Institutional care recipients

Year	1950	1975	2000	2001	2002	2003	2004	2005	2006	2007
Population aged 80+	106,804	224,610	452,562	464,211	469,526	475,938	482,337	487,163	490,254	490,962
% aged 80+ institutionalised	0.20	0.30	0.21	0.20	0.19	0.18	0.17	0.17	0.16	0.16
No. aged 80+ institutionalised	21,361	67,383	95,038	92,807	90,898	87,697	83,291	80,468	79,390	76,143

Sources: Authors' calculations based on data obtained from Statistics Sweden, Sundström et al. (2002) and the National Board of Health and Welfare.

In 2008, the number of elderly persons in institutional care was 95,600, out of which approximately 80% were aged 80 or older and 70% of the care recipients were women. The number of places in institutional care has decreased by almost 10% from 106,000 in 1998 to 95,600 in 2008.

The average waiting time for institutional care (measured from the day the application was made until the person is taken in) was on average 57 days in 2008 but ranged from 10 to 170 days depending on the municipality (Swedish Association of Local Authorities and Regions, 2008).

Besides the explanation that institutional care has been replaced by the cheaper home care, other reasons mentioned for the decreasing number of places in institutional care are that the elderly today in general are healthier and demand less care than before. Furthermore, Larsson (2006) claims that the elderly (particularly men) have become more independent than before and are thus able to continue living at home for a much longer period, reducing the need for care even more.

Nevertheless, increasing critical opinion about cuts in institutional care has lately caused the political discussions to change course and further reductions seem unlikely at present. But since many municipalities are struggling with financial troubles, partially caused by the current recession, it is not reasonable to expect that the municipalities will prioritise such moves immediately since the cheaper home care services ought to be a more attractive option for them. Hence, it may still take some time until we can see any change on an aggregate level, as the matter of capacity is decentralised and the responsibility lies with the local authorities.

3.4.2 Home care

Home care in Sweden was first implemented after the Poor Relief Act was revoked in the 1950s. In 1957, the Social Services Act was introduced, making the municipalities responsible for providing any elderly or disabled person in need of care support in the individual's own residence. At the time, the objectives of the services provided were merely to temporarily replace a family member when required and the duties involved were only simpler household chores. Home care only seriously took off after a government grant was introduced in 1964 and it gradually extended to include time for socialising and personal care of a heavier kind. Almost 50 years later, the responsibility of home care still remains with the municipalities and is regulated by the Social Services Act. Yet the focus of home care is almost entirely personal care and does not include social activities.

Table 6 displays home care for the population group aged 80 and older (the group with the highest levels of home care) between 2001 and 2006. In 2008, 156,200, or about 9% of the population aged over 65, received home care in Sweden. About 70% of the home care recipients were women.

Table 6. Home care (HC)

Year	2001	2002	2003	2004	2005	2006
Population aged 80+	464,211	469,526	475,938	482,337	487,163	490,254
% aged 80+ with HC	0.23	0.23	0.24	0.25	0.25	0.26
No. aged 80+ with HC	104,538	107,234	114,146	118,817	122,484	12,7862

Note: Home care does not include home nursing care; however, the data includes individuals who receive home care and home nursing care simultaneously.

Sources: Authors' calculations based on data obtained from Statistics Sweden, Sundström et al. (2002) and the National Board of Health and Welfare.

Home nursing care only became significant in the 1990s after the *Ädel* reform in 1992, which transferred to the municipalities the responsibility of medical care not requiring a physician. Table 7 presents home nursing care among the age group 80 and over between 2001 and 2006.

Table 7. Home nursing care (HNC)

Year	2001	2002	2003	2004	2005	2006
Population aged 80+	464,211	469,526	475,938	482,337	487,163	490,254
% aged 80+ with HNC	0.023	0.019	0.019	0.018	0.019	0.017
No. aged 80+ with HNC	10,664	9,140	9,187	8,756	9,152	8,504

Sources: Authors' calculations based on data obtained from Statistics Sweden and the National Board of Health and Welfare.

3.4.3 Semi-institutional care

Short-term care (*Korttidsvård*) is offered in a semi-institutional setting that works as a complement to home nursing care, home care services and institutional care. Its purpose is to provide a place for rehabilitation and care after hospitalisation, and a facility providing relief support for informal care providers. Today, however, it is also often used as a 'waiting-room' for those waiting for permanent placement in an institutional care setting.

After years of investments in home care and following a dramatic decrease in the number of places available in institutional care, Sweden is again taking steps towards investing in and reinstating institutional care. A new version of institutional care, 'secure housing' (*Trygghetsboende*), has recently gained much attention. The aim of secure housing is to provide an alternative form of residence for those who do not feel secure enough to be cared for at home but at the same time are too healthy to require care in an institutional care environment. The secure housing is an alternative to independent accommodation in that residents have access to additional services, such as staff that are on call around the clock, a common lounge and the possibility for the residents to dine together. The government currently contributes approximately SEK 500 million per year to support investments made in institutional care alone. From 2009 to 2012, however, the same amount will also cover any investments made in secure housing.

4. LTC policy

The massive expansion of institutional care settings that started in the 1950s and stemmed from reasons such as cost efficiency and technical progress were replaced by political emphases on

the home care system in the late 1990s. The efforts made to increase home care were partly at the expense of institutional care and Sweden witnessed a decrease in capacity in institutional care of close to 10% in the ten years between 1998 and 2008.

Although home care gives the elderly the possibility to live an independent life for as long as possible, it has also made it difficult for those in need of more attention to receive the sort of care only provided in an institutional setting. Because of problems like increasing waiting times for placement in institutional care and growing attention on the mismanagement of care for the elderly in institutions owing to economic retrenchments, policy-makers have in the last couple of years been favourably inclined towards the restoration of institutional care (albeit somewhat modified and modernised to account for present circumstances). Demographic changes and cost awareness have also made policy-makers progressively turn their attention to informal care, as it is not only a cheaper care solution than any service provided by the government, but it is also considered to require fewer human resources.

4.1 Policy goals

The official objectives of LTC care in Sweden are to provide the elderly with support to carry on living a high quality and independent life for as long as possible, to participate and engage in civic and personal life, to be treated with respect and to have access to good elderly care (Ministry of Health and Social Affairs, 2009). The government guidelines are meant to ensure that care recipients along with their relatives are able to trust that the care offered in Sweden is both dignified and high in quality.

Currently, about SEK 2 billion of government spending in 2010 is budgeted for elderly care, from which close to SEK 1 billion constitutes financial contributions disbursed to the municipalities. In an attempt to improve the quality of the care provided in Sweden, the government has proposed a gradual shift from the simple proportional contribution of today to an incentivised system that will reward well-performing municipalities for their achievements. Additionally, to enable any in-depth analysis of the administration, a more comprehensive and evidence-based follow-up on any policy changes and policy implementation is proposed. Improved statistical record-keeping is stressed as a crucial tool for this project to work.

Other officially stated policy objectives are to provide training to supervisors and managers in elderly care, which in trials has proven to improve quality and efficiency, along with some educational requirements for all staff involved in elderly care.

4.2 Current policy debates

As the social welfare system in Sweden is highly dependent on tax contributions to maintain the public services, it is sensitive to any changes that may alter the balance between the population in the labour force and those who stand outside it. Thus, one of the main issues discussed concerning elderly care in Sweden today is the sustainability of long-term care in Sweden in view of the changing demographic structure.

The issues Sweden is facing in the shorter term are listed below (recently discussed and presented by the Ministry of Health and Welfare to an open audience at the parliament – see Ministry of Health and Social Affairs, 2009).

- Home nursing-care services
  - The supply of nurses and MDs are too low in relation to the ever-advancing medical treatments provided at home.
  - The structure of home nursing care is inconsistent and depends on whether care is provided by a county council or by a municipality.

  - The absence of a uniform description of the responsibilities covered by home nursing care results in unequal care in different regions.
  - There is a lack of procedures in some areas, e.g. it is difficult to access medical records outside office hours.
- Psychological wellbeing of the elderly in Sweden
  - This subject has not been given enough attention although research indicates that one in three elderly persons is depressed and the elderly are the most suicidal group in the country.
  - There is a lack of procedures and coordination necessary to treat an elderly person between establishments, such as psychiatry, geriatric care, primary health care and LTC.
  - There is a need to increase awareness and knowledge among staff about mental illness.
- Polypharmacy in LTC
  - The problem of polypharmacy has increased substantially in recent years. Those most affected are usually the most fragile elderly persons in institutional care, who on average receive ten different medications per day. In general, the population aged over 80 receives six different drugs on average per day.
  - It is estimated that 30% of the hospitalisation among the elderly is due to side effects caused by drugs.
  - A plan of action is needed – an explicit stipulation for the elderly to have individually assigned physicians who are directly responsible for their medical treatment.
- Shortage of institutional care
  - The substantial decrease in the number of places available in institutional care during the last ten years has led to increasing waiting times and inadequate care.
- Individually tailored elderly care
  - According to responses to a questionnaire, most care recipients are very satisfied with the quality of care provided to the elderly today. The main dissatisfaction concerns the lack of social activities in LTC.
  - No strategy is currently available on how to accommodate elderly persons who have foreign backgrounds or who are homosexual, bisexual or transgender.
- Staff training
  - Around 70–75% of the total labour force currently has specific occupational training in LTC. This is an increase of 10% compared with ten years ago.
  - The proportion of staff with post-secondary school education has not changed in the last ten years and represents about 13–15% of the labour force.
  - More support and attention ought to be offered to middle management.
- Extension of support to informal care providers
  - Governmental grants have helped local authorities to increase support for relatives and next of kin. It is now statutory for the municipalities to offer help to relatives who care for an elderly person.

References

Henriksen, E., G. Selander and U. Rosenqvist (2003), "Can we bridge the gap between goals and practice through a common vision? A study of politicians and managers' understanding of the provisions of elderly care services", *Health Policy*, Vol. 65, No. 2, pp. 129-137.

Jegermalm, M. (2004), "Informal care and support for carers in Sweden: Patterns of service receipt among informal caregivers and care recipients", *European Journal of Social Work*, Vol. 7, No. 1, March, pp. 7-24.

Johansson, L. (1991), *Caring for the Next of Kin: On informal care of elderly in Sweden*, Uppsala University, Uppsala.

Johansson, R. and K. Borell (1999), "Central Steering and Local Networks: Old-age Care in Sweden", *Public Administration*, Vol. 77, No. 3, pp. 585-98.

Johansson, T. (2008), "Municipal Contracting Out: Governance Choices, Misalignment and Performance in Swedish Local Government", *Financial Accountability & Management*, Vol. 24, No. 3, August.

Larsen, T., B.J. Eriksson and B. Johansson (2009), *Hur har de statliga stimulansbidragen använts i Västra Götalands län?*, FoU i Väst, Länsstyrelsen Västra Götaland, Göteborg, March.

Larsson, K. (2006), "Hemtjänst och anhörigvård", *Living conditions of the elderly: Work, economy, health and social networks 1980–2003*, Report No. 112, Statistics Sweden, Stockholm, pp. 421-434.

Ministry of Health and Social Affairs (2007), Facts about elderly in Sweden, Government Offices of Sweden No. 17, September.

———— (2009), Elderly Care (http://www.regeringen.se/sb/d/1954/a/102991).

Nationella Kompetenscentrum Anhöriga (2009), Available forms of support to relatives (http://www.anhoriga.se/sv/Om-anhorigstod/Olika-typer-av-anhorigstod/).

Nordberg, G., A. Wimo, E. von Strauss, I. Kåreholt and L. Johansson (2005), "The amount of informal and formal care among non-demented and demented elderly persons – Results from a Swedish population-based study", *International Journal of Geriatric Psychiatry*, Vol. 20, No. 9, pp. 862-71.

Sundström, G. and B. Malmberg (2006), "Balancing family and state care: Neither, either or both? The case of Sweden", *Ageing and Society*, Vol. 26, No. 5, pp. 767-782.

———— (2006), *Omsorg människor emellan – En översikt av omsorgsgivande i den svenska befolkningen*, National Board of Health and Welfare, Stockholm, May.

Sundström, G., L. Johansson and L.B. Hassing (2002), "The Shifting Balance of Long-Term Care in Sweden", *The Gerontologist*, Vol. 42, No. 3, pp. 350-355.

Swedish Association of Local Authorities and Regions (2008), Öppna jämförelser 2008 – Vård och omsorg om äldre, Västerås.

Swedish Institute (1999), "Fact Sheets on Sweden – The Health Care System in Sweden", FS76 xVpb, Swedish Institute, Stockholm, May.

———— (2007), "Elderly Care in Sweden", FS8p, Swedish Institute, Stockholm, December.

Szebehely, M. (2006), "Informella hjälpgivare", *Living conditions of the elderly: Work, economy, health and social networks 1980–2003*, Report No. 112, Statistics Sweden, Stockholm, pp. 435-462.

Whitaker, A. (2009), "Family involvement in the institutional eldercare context: Towards a new understanding", *Journal of Aging Studies*, Vol. 23, No. 3, pp. 158-167.

Wikgren Orstam, A. (2006), *Care of the Elderly in Sweden Today*, Health and Social Care Division, Swedish Association of Local Authorities and Regions, Stockholm.

About the Stockholm University, Department of Economics

The Department of Economics at Stockholm University has about 1,000 undergraduate students each term and 25 faculty members. Courses are also taught by researchers at the Institute for International Economic Studies (IIES) and the Swedish Institute for Social Research (SOFI).

The Doctoral Programme in Economics, which has about 60 students, is run jointly by the Department, IIES and SOFI.

The Department has bilateral ERASMUS agreements with close to 20 universities in Europe, and also takes part in Stockholm University's NORDPLUS and central exchange agreements.

The research at the department is focused on the fields of welfare economics, international trade and labour economics.

The Department also hosts the editorial office of *The Scandinavian Journal of Economics*, one of the oldest economics journals in the world.

ANCIEN

Assessing Needs of Care in European Nations

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).