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# ANCIEN

**Assessing Needs of Care in European Nations**

## **THE SWEDISH LONG-TERM CARE SYSTEM\***

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## **1. The long-term care system of Sweden**

### *1.1 Overview of the system*

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

Any person with permanent residency in Sweden with impediments is eligible for care solely determined by 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 reservation imposed depending on the financial situation of the individual. This guarantees that all elderly in need of care are able to receive treatments in Sweden.

Since the welfare system was established and some of the former responsibilities of the individual (or the family) was taken over by the state, the Swedes have come to trust and rely on the state to take care of its elderly to the degree that the discussion of informal care started just some 15 years ago was just recently considered in the political decision making. However, the rapidly aging population has increasingly turned the policymakers' attention to care provided by relatives or friends as a partial solution to the anticipated demographic problems. Nonetheless, this does not mean that formal care has abated in importance - formal care is still the backbone of elderly care in the Sweden and is expected to remain so. However, home based care is still left behind to a great extent.

The available types of formal care in Sweden are; institutional care, home care, and home nursing care. Day activities, meals 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 the expenses but also permitted the elderly to sustain an independent life for much longer. However, increasing home care in replacement for institutional care has lately been heavily questioned. This, in combination with the increasing attention given to informal care, may give reasons to believe that Sweden could stand at the beginning of a new policy era concerning long-term care. (Mats Thorlund har lovat skicka teori-kapitel som han skrivit angående detta till oss)

### *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. Need of care is either assessed by a general practitioner, or following a request of assessment with the local authority. If request of care is made directly with the authority, an evaluator is assigned to interview the person and any possible family members to evaluate the extent of support the elderly requires, and if care can be provided in the caretakers 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 due to the construction of the building, institutional care is considered as a last resort.

There is today no general guidance for assessment of need in Sweden. Instead, the assessment is much 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 need of the elderly in Sweden are presented in Table 1 (The 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 receiver that clearly states each step of the required treatments and services. The plan must also disclose the name of the person that is officially in charge of the case and clearly specify which authority to be responsible for each component of service and care offered.

Methods for assessment are listed in Table 1.

Table 1

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

### 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), meals services, personal safety alarms, home adaptation, and transportation services for elderly and functionally impaired people who cannot ride regular public transport are entitled to transportation service<sup>1</sup>. Additionally, the local authorities also provide grants for certain measures needed for the disabled to use their homes efficiently, regardless of the applicant's financial situation.

In 2006, 98 619 people over the age of 64 received institutional care in Sweden. This is a reduction with 11.80 per cent compared to 2001. During the same observation period, 178 282 received home care service, which, on the other hand is an increase with 11.66 percent. According to the National Board of Health and Welfare (Wikgren-Orstam, 2006), 64 700 applicants were granted home adaptation in 2005, and approximately 57 300 people received

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<sup>1</sup> 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 the least, must provide.

meal delivery service during the same year. In 2004, 372 900 people had the right to transportation services, which accounts for 4.1 per cent of the population. Finally, according to a survey carried out among the local authorities, 157 169 people had personal safety alarms installed in the spring of 2006.

#### *1.4 Management and Organization*

The hierarchical bureaucratic structure that previously prevailed partially changed in Sweden after the Care of the Elderly Reform (Ädel-reformen) in 1992. Old-age care had until then been administered on a national level, but through the reform, the role of the government became restricted to that of a legislating, facilitating and controlling body, and all 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.<sup>2</sup> The municipalities and the county councils are today entitled to choose their own organization 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, whilst 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 remain the ultimate responsibility to supply and maintaining the level of care even when private organizations supplement some of their responsibilities.

The organizational division of social care and medical care between the two institutions was already implemented in 1950s. However, the reform in 1992 led to a diversification of the activities provided by the municipality and, on the other hand, a specialization of services for the county councils. The responsibilities of the municipality account for about 90 percent of all elderly care and no formal hierarchical order between the two authorities exists.

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<sup>2</sup> The regional authorities (Skåne and Västra Götaland) are more or less equivalent to the county councils but with some extended responsibility as they covers larger areas.

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

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

### *1.5 Integration of LTC*

The Care of Elderly-reform was an attempt to shift the administration from the county councils to municipalities in order to increase the flexibility to easier respond to the local demand. Almost twenty 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 of medical treatment end and where social care begins. The lack of clear definition and explicit rules have, according to Johansson and Borell (1999)(Mats Thorslund föreslår färskare referens), many times led to inefficient utilization of resources, co-operation issues, lack of continuity and attempt by county councils and municipalities to transfer responsibility and cost to each other. This in turn has caused many individual to receive insufficient amount of care and get stuck in the bureaucratic red tape.

Another issue that have complicated the organizational cooperation is the fact that many old people suffer from multiple illnesses. Incentivised to keep the cost down and the lack of clear commissions have caused the county council to transfer the responsibility of care to the municipality as soon as treatment for the illness for which the individual was initially cared

for is completed. This might have caused many LTC patients to receive insufficient care because the municipality has considered the remaining illnesses to be outside their scope of responsibility.

Henriksen et al. (2003) discuss and summarize issues raised by managers from local authorities and county councils in a workshop held in Sweden in 2002. The topic at the workshop was to discuss the collaboration shortcomings between the two authorities. The concerns raised at the workshop rhymes well with the problems discussed previously and are listed as follows:

- Lack of communication between care levels
- Lack of chain of care or structural care network
- Lack of Professional steer-management
- Lack of coordination between the local municipalities and the county councils
- Difficulties in making the district nurses visit the elderly in their own home or at the nursing homes
- 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 emphasize 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 of care expenditure more defined. Despite the law enforcements, the government’s own calculations indicate that only two out of three care receiver have a written individual care plan (The Riksdag, 2009).

Starting 1 Jan 2010, local authorities and county councils are required to draw up an individual plan in accordance to a given format for each care receiver. The plan should clearly state what treatment the individual requires, which authority to provide for what sort of care, specification of care if provision of care is required by any other than the local authority or the county council, and the name of the authority that has the principal responsibility of the health of the individual.

## 2. Funding

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

The average local tax rate in Sweden in 2003 was 31.17 per cent, of which 20.7 per cent went to the municipalities and 10.47 to the county councils (Johansson, 2008). Itemizing the expenditure, institutional care is by far the highest LTC expenditure for the municipalities at 64 percent. Care in ordinary housing accounted for 34 per cent and preventive activities for 2 per cent. More than 80 per cent 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 per cent 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 1612 per month, is fixed and charged irrespectively of the individual's income. Nevertheless, the fee may be reduced if the monthly income does not exceed the minimum costs of living, the reserved amount, also set annually by the government. In 2007, the reserved amount was SEK 4346 per month for a single elderly and SEK 3640 per person and month for a couple.

Within the frameworks of these rules, each municipality decides its own system of charges and the fee paid by the individual. As of 2006, approximately 19 per cent of home care recipients receive 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 per cent of the Swedish population, or about 1.6 million people, are 65 years old or older. Population projections forecast that in the next 30 years, the largest population growth will be among the population aged 65 and over (Table 2). At approximately 5 percent, Sweden has already the highest proportion of elderly over 80 in Europe. In 2060, this number is expected to double to 10 percent of the population. Although the population in Sweden is increasing, the aging population will have a negative impact on the old-age dependency ratio putting pressure on the working age population to support an increasing number of elderly. The old-age dependency ratio, measured as the ratio between the population over 65 and the working age population, is estimated to become as high as 47 percent in 2060, which is a growth of over 20 percent from the 26 percent old-age dependency ratio in 2007 (the National Board of Health and Safety, 2008).

Table 2

Population by Gender & Age 65+

Year	Total Pop	Female	Men	65+/Pop	65+
1950	7046920	3535877	3511043	0.102	721316
1960	7497967	3757848	3740119	0.118	887964
1970	8081142	4045374	4035768	0.138	1111902
1980	8317937	4198115	4119822	0.163	1359391
1990	8590630	4346613	4244017	0.177	1521699
2000	8882792	4490039	4392753	0.171	1523313
2008	9256347	4652637	4603710	0.177	1634401

Source: Statistics Sweden

The average life expectancy age at birth has steadily increased and reached 79 and 83 for men and female in 2008 (Table 3). This number is expected to increase with another 6 years for men and 3 years from women by 2050 narrowing the gap between life expectancy for men and women. As a consequence of the falling mortality among men, more women are expected to retain their partner in old age. At the current retirement age at 65, men are expected to live for another 17 years and women for another 21 years.

Table 3  
Average Life Expectancy at Birth

Year	Men	Female
1951-1960	70.89	74.1
1961-1970	71.73	76.13
1971-1980	72.26	78.1
1981-1985	73.55	79.53
1986-1990	74.37	80.22
1991-1995	75.6	80.98
1996-2000	76.89	81.83
2001-2005	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 the Swedish policy makers in the beginning of the 20<sup>th</sup> century and is today deeply rooted in the mind of the people. In 1956, when the law making children responsible for their parent's welfare was abolished, it became the responsibility of the society's to take care of the elderly instead. Initially, only simpler home care services were provided by the state. High taxation has enabled the state to finance generous and diverse safety nets to all its citizens, irrespectively of means ever since.

The close tie between the state and the people has strengthened the Swedes association of care of the vulnerable and weak in the society to a state matter. For example, the public sector is also the single biggest employer in Sweden and currently employs about 20 percent of the entire labour force between the age of 20 and 64. Thus, it is not surprising that the Swedish government has for a long period of time almost exclusively concerned itself with formal LTC care.

Although informal care have always existed alongside the services provided by the government, it is not until quite recently, faced with the notion of an aging population and of economic reasons, that the government has seriously began to consider the option of voluntary informal care in LTC (Jegermalm, 2004). This in turn is the reason why studies on

informal care are so very few in Sweden. Still, another reason often mentioned to explain the scarcity of studies about informal care is the difficulty in obtaining information about the care providers. This is because the focal point of the few studies in existence has almost entirely studied the condition of the care receivers, leaving out most discussions concerning care providers (Sundström & Malmberg 2006). When institutional care played a greater role in the LTC of Sweden i.e. before the reform and before any technical progresses enabled more advanced care at home, relatives of the care receiver were often only considered as visitors of the patient (Whitaker 2009). However, with the increasing number of elderly now being 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 today 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 even less are the studies concerning the effect care has on the care giver's own 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 into projects with aim to support relatives who care for an elderly in the years between 1999 and 2001. The objective behind the bill was to create mental and physical relief support for the heavily burdened relatives, and at the same time stress the importance of support received from voluntary organizations such as Red Cross as an important additional resource to the public services.

The types of supports an informal care giver may receive today are much broader and exhaustive than before. The creation of the National Centre for support of Informal Care Providers (free translation of "Nationellt Kompetenscentrum Anhöriga" (NKA)) in 2008 is an example of such. NKA is co-run by several research institutes in Sweden with 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 documentations to caregivers whilst 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 are by law required 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 provide informal caregivers with the knowledge and the

information they need in order to continue the support. An additional purpose of the introduction of the act is to make informal care provider officially recognized and to acknowledge the importance of their work.

The supports provided to informal caregivers are not clearly defined in Sweden as of today. The National Board of Health and Safety have expressed the purpose of support to relatives as i) a mean to make the situation of the support providers visible; ii) to prevent burnout and fatigue; iii) to improve the quality of life for those caring for an ADL person. According to a report published by County Administrative Board of the region Västra Götaland (Länsstyrelsen i Västra Götaland, 2009), the main reason why different municipalities offer different type of support to relatives is due to the lack of clear definition. For instance, education for informal care providers was only offered in 38 percent of the municipalities in 2008 (Länsstyrelsen i Västra Götaland, 2009)

Table 3 lists the type of support informal care givers may receive in Sweden today. Since informal care may reduce the care providers' ability to work, financial compensation is sometime granted. The number of recipients of such support was 5200 in year 2006, which is an increase from 4600 in year 2000.

<b>Table 3</b>			
<b>Support Available for Informal Care Providers</b>			
<b>Type of Support</b>	<b>Description</b>	<b>Assessment</b>	<b>Special Remarks</b>
<b>Employment</b>	Full compensation for work of caring an elderly when the care provided by home care is insufficient.	Required	
<b>Cash benefit</b>	Symbolic compensation for effort of caring for an elderly. The benefit varies between SEK 1000 - 3000 per month. The benefit is paid to the care receiver who is responsible of forwarding the amount to the care giver.		Not available nationwide.
<b>Support centers</b>	Gathering points for informal care givers to offer support to each other and receive information and guidance from professional care givers.	Not required	
<b>Support groups</b>	Groups for informal care givers to find and offer support to each other.	Not required	
<b>Relief support</b>	Support to offer temporary relief to the care giver. Usually by a staff from home care services, or from a voluntary organization.	Depends on the municipality.	Half of the municipalities offer this service for free, others for a small charge.
<b>Temporary residence</b>	Temporary residence of the care recipient is offered in a nursing home.	Required	Frequency and length of stay varies depending on municipality. Same for charge of care.
<b>One-to-one support</b>	Care giver is offered consultation about planning of care. COAT-method is most frequently used.		
<b>Volunteers</b>	Volunteers who can assist with both care of the elderly, and support the care giver.	Not required	
<b>IT support</b>	Provide support in finding information and receiving help over the internet. E.g. Actionservice.se provides professional advice directly over internet to elderly and to informal care givers.	Not required	Service only provides through municipalities with service contract with actionservice.
<b>Feel-good activities</b>	SPA, massage, health consultation etc. offered to care givers.		Different supply of service depending on municipality.
<b>Cash benefit (temporary)</b>	A temporary cash benefit is offered to carers up to 60 days to compensate for lost income when caring for an terminally ill close relative.	Required	Paid by the national social insurance (Förskärskassan)
<b>Technical aid</b>	Installation of technical aids and/or home adaptation.	Required	Varying cost depending on municipality.
<b>Education</b>	Seminars and education are offered to the informal care giver.	Not required	

Source: Nationella Kompetenscentrum Anhänga, 2009

### *3.3 Demand and Supply of Informal Care*

Although the number of reports written about informal care is still relatively few in Sweden, the existing studies have estimated that an ADL person living outside institutions in average receives two to three times more informal care than care provided by the public home care services (Johansson, 1991; Sundström et al., 2002). Although studies about the extent of care are currently not established, the same studies have also found a minimal change in the prevalence of informal care over time.

As previously mentioned, it is very difficult to give a straight answer to how informal care looks like in Sweden. Questionnaires and studies concerning institutional care are not only few in numbers but vary in the question asked and the methods employed, making the issue of comparability problematic (Szebehely, 2006). Sundström and Malmberg (2005) have in a report to the National Board of Health and Welfare listed the many previous findings: although the studies, stretching from 1994 to 2005, vary in format and are far from conclusive, they seem to point towards a slight increase in informal care over the observation period, especially in the age group 75 and over. Their findings support previous studies in which it was observed that informal care is more common among women than men. The age groups between 45 and 64 are, in relative terms, the most common age group to provide informal care to an ADL person, and that 3 out of 4 care receivers are over 65 years old. Szebehely's (2006) study estimates that 1 in 4 over 55 regularly support an ADL disabled person outside his or her own household. Sundström and Malmberg (2005) estimate that approximately 20 percent of the total adult population provides care to another person (anything from keeping company to heavy care such as bathing, cooking, and shopping) but only 7 percent of the population care for an ADL disabled person on a daily basis. According to a survey conducted by the Swedish National Institute of Public Health (Folkhälsoinstitutet) in 2005, the average numbers of hours of care per week is approximately 15 for men and 13 for women for the age group 16 to 84. Nordberg et al (2005) have studied informal care, especially amongst those suffering from dementia, and found that on the recipient side, 38 percent of the ADL disabled receive approx. 2.6 hours care per day by an informal care provider. According to a report by Larsson (2005) in Statistics Sweden's own publication on the Survey on Living Condition (ULF) the proportion of elderly who received help with some type of chore or personal care have, in all age groups over 65 independent of gender, increased with 2 – 5 percent in 2003 compared to year 1998. Similarly, when the gender is not considered for

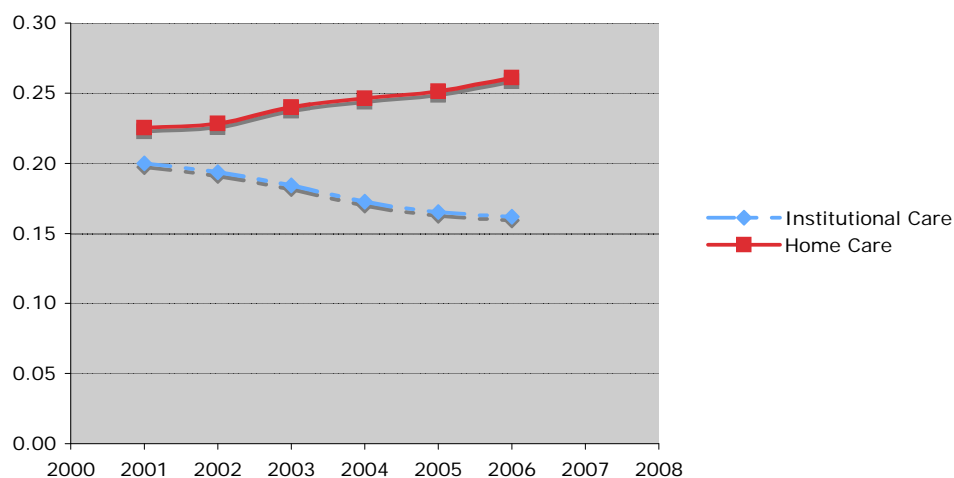
but the living arrangement is, it was found that informal care had increased with as much as 10 percent among single households but hardly any among the cohabiting elderly.

### *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, which was enough to survive on. At the outset of the social welfare reform, approximately 5 percent of Sweden's gross domestic product (GDP) was spent on the elderly, which included pension, housing subsidy, social services and health care. This share quickly escalated and reached about 14 percent of the GDP in the 1990s. But the recession in the 90s along with the introduction of Ädel reform in 1992 came to burden the already financially struggling local authorities and put an end to the rising expenditure on elderly care in Sweden. Many municipalities had to face a shrinking income due to the financial turbulence and were forced to increase the fee 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 possibility to live a self-contained life as long as possible, making this transition easier for the municipalities to justify. Institutional care was thus reserved for the most needed who required more professional and medical attention than is possible to provide in his or her own residence (Figure 1).

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), meals 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 4 lists the number of institutional care recipients in Sweden. The proportion of institutionalized persons 80 years and over was about 20 per cent in 1950 but saw its peak in 1975 when the corresponding number had reached 30 per cent (Sundström, G., et. al, 2002). The number has since steadily decreased reaching 16 per cent in 2007.

Table 4

**Institution:**

Year	1950	1975	2000	2001	2002	2003	2004	2005	2006	2007
Population 80+	106804	224610	452562	464211	469526	475938	482337	487163	490254	490962
Prop of 80+ institutionalized	0.20	0.30	0.21	0.20	0.19	0.18	0.17	0.17	0.16	0.16
Nr of 80+ institutionalized	21361	67383	95038	92807	90898	87697	83291	80468	79390	76143

Source: Author's own computation based on data obtained from Statistics Sweden, Sundström et. al (2002), National Board of Health and Welfare

In 2008, the number of elderly in institutional care was 95 600, out of which approximately 80 percent was 80 year or above and 70 percent of the care recipients were women. The number of places in institutional care have decreased with almost 10 per cent from 106 000 in 1998 to the 95 600 in 2008.

The average waiting time for institutional care (measured as 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 municipality (Öppna jämförelser, Socialstyrelsen 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 much longer period, reducing the need of care even further.

Nevertheless, increasing critical opinion about cuts in institutional care have lately caused the political discussions to change course and further reduction seems unlikely as of today. 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 move 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 issue of capacity is decentralized and the responsibility of 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 to provide any elderly or disabled in need of care with 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 would gradually extend to include time for socializing and personal care of heavier kind. Almost 50 years later, the responsibility of home care still remains with the municipalities and is regulated by the Social Services Act. However, the focus of home care is almost entirely personal care and does not include socializing activities.

Table 5

**Home care (HC):**

Year	2001	2002	2003	2004	2005	2006
Population 80+	464211	469526	475938	482337	487163	490254
Prop of 80+ with HC	0.23	0.23	0.24	0.25	0.25	0.26
Nr of 80+ HC	104538	107234	114146	118817	122484	127862

Source: Author's own computaion based on data obtained from Statistics Sweden, Sundström et. Al (2002), National Board of Health and Welfare

Note: Home care does not include home nursing care. However, the data includes individuals who receives home care and home nursing care simultaneously.

Table 6

**Home nursing care**

Year	2001	2002	2003	2004	2005	2006
Population 80+	464211	469526	475938	482337	487163	490254
Prop of 80+ with HNC	0.023	0.019	0.019	0.018	0.019	0.017
Nr of 80+ HNC	10664	9140	9187	8756	9152	8504

Source: Author's own computaion based on data obtained from Statistics Sweden and National Board of Health and Welfare

Table 5 displays home care in the population group 80 years and over (the group with the highest home care) between 2001 and 2006. In 2008, 156 200, or about 9 percent of the population over 65 received home care in Sweden. About 70 per cent of the home care recipients are women.

Home nursing care only became significant in the 1990s after the Ädel-reform in 1992 that transferred the responsibility of medical care that does not require a physician to the municipalities. Table 6 presents home nursing care among the age group 80 and over between 2001 and 2006.

### *3.4.3. Semi-institutional Care*

Short-term care (Korttidsvård) is a semi-institutional setting that works as a complement to home nursing care, home care service and institutional care. The purpose of this institution is to provide a place for rehabilitation, care after hospitalization, and to act as a commutation facility for informal care providers. It is today, however, often also used as a “waiting-room” for those waiting for a permanent placement in an institutional care setting.

After years of investments in home care and followed by a dramatic decrease in the number of places available in institutional care, Sweden is now again taking steps towards investing in and reinstating institutional care. A new version of institutional care, called “safety residents” (Trygghetsboende), has recently gained much attention. The aim with safety residency 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 be considered care in an institutional care environment. The safety residents are an alternative to own-accommodation but with additional services such as staff that are on call around the clock, a common lounge, and possibility for the residents to dine together. The government currently contribute approximately SEK 500 million per year to support investments made in institutional care only. However from 2009 to 2012 the same amount will also cover any investments made in safety residents.

## **4. LTC Policy**

The massive expansion of institutional care settings that started in the 1950s was due to reasons such as cost efficiency and technical progress replaced by political emphases on home care system in the late 1990s. The efforts made to increase home care was to some extent at the expense of institutional care and Sweden witness a closer to 10 percent decrease in capacity in institutional care in the 10 years between 1998 - 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 at an institutional settings. Due to problems such as increasing waiting time for placement in institutional care and increasing attention brought to the

mismanagement of the elderly in institutional care due to economic retrenchments, policymakers have in the last couple of years favourably inclined restoration of institutional care (albeit somewhat modified and modernized to account for present circumstances). Demographic changes and cost awareness have also made policy makers to increasingly turn their attention to informal care as it is not only cheaper care solution than any service provided by the government, but is also considered to require less human resources.

#### *4.1 Policy Goals*

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

Currently, about SEK 2 billion of the government spending in 2010 is budgeted for elderly care from which closer to SEK 1 billion is financial contributions disbursed to the municipalities. In an attempt to improve the quality of the care provided in Sweden, the government have proposed a gradual shift from the simple proportional contribution of today to an incentivized system that will reward well performing municipalities for its achievements. Additionally, to enable any in depth analysis of the administration, a more comprehensive and thorough evidence based follow up on any policy changes and policy implementation is proposed. An 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 the elderly care, which in trials proven to improve the quality and efficiency along with some educational requirement for all staff in elderly care.

## 4.2 Current Policy Debates

As the social welfare system in Sweden is highly dependant on tax contribution 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 is today is the sustainability of long term care in Sweden faced with the changing demographic structure.

The issues Sweden is facing in a shorter time perspective are listed below (recently discussed and presented by the Ministry of Health and Welfare for an open audience in the parliament (Socialdepartementet, 2009)):

- Home nursing care services
  - 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 if care is provided by a county council or by a municipality.
  - No uniform description of the responsibilities covered by home nursing care results in unequal care in different regions.
  - Missing procedures, e.g. difficult to access medical records outside office-hours.
  
- The psychological wellbeing of the elderly in Sweden
  - A subject that has not been given enough attention although study indicate that one in three aged are depressed and the elderly are the most suicidal group in the country.
  - Lack of procedures and coordination necessary to treat an elderly between establishments such as psychiatry, geriatric care, primary health care and LTC.
  - 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 in institutional care who, on average, receives 10 different medicaments per day. In the general population an aged person over 80 receives 6 different drugs on average per day.

It is estimated that 30 % of the hospitalization among the elderly is due to side effects caused by drugs

- Plan of action – explicit stipulation for elderly to have an individually assigned physician who is directly responsible for the medical treatment of the elderly.

- Shortage of institutional care
  - The extensive decrease in number of places available in institutional care during the last 10 years have led to increasing waiting time and inadequate care.
- Individually tailored elderly care
  - According to the answer of the questionnaire, most care recipients are very satisfied with the quality of care of elderly today. The main dissatisfaction concerns lack of social activities in LTC today.
  - No strategy currently available in to how to accommodate care for elderly with foreign background and homosexual, bisexual and transgender individuals.
- Training of staff
  - 70 – 75 % of the total labour force has specific occupational training in LTC today. This is an increase with 10% compared to 10 years ago.
  - The proportion of staff with post-secondary school education has not changed in the last 10 years and is about 13 – 15 % of the labour force.
  - More support and attention ought to be offered to the middle management.
- Extend the support to informal care providers
  - Governmental grants have helped local authorities to increase its support to relatives and next in kin. It is now statutory for the municipalities to offer help to relatives who care for an elderly.

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# ANCIEN

## Assessing Needs of Care in European Nations



*FP7 HEALTH-2007-3.2-2*

**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>).*