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Lennarth Johansson

The Long-Term Care System in Sweden

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1. Country Overview

Source: https://ontheworldmap.com/sweden/ (Accessed: May 20, 2021)

- Sub-Region: Northern Europe
- Capital: Stockholm
- Official Language: Swedish
- Population size: 10,099,265 (UN, 2021; 2020 estimation)
- Share of rural population: 12.3% (UN, 2021; 2019 estimation)
- GDP: 530.88 Billion US$ (World Bank, 2021; 2019 value)
- Income group: High Income
- Gini Index: 30 (World Bank, 2021; 2018 value)
- Colonial period and Independence: N/A

2. Long-Term Care Dependency

a. Population statistics

Table 1. Older population in Sweden, 2020

Age	*Total number*	*Share of total population (per cent)*
60+	2,657,312	25.6
70+	1,551,352	15.0
80+	543,720	5.2

Source: Statistics Sweden, 2021

Table 2. Health status of older population in Sweden, 2019

Share of older population with "very good" or "good" perceived health (per cent)		
Age	*Sweden*	*EU 28*
65+	62.7	41.7
75+	54.2	32.3
85+	39.9	24.5
Share of older population having longstanding illness or health problems (per cent)		
Age	*Sweden*	*EU 28*
65+	55.2	60.9
75+	59.2	67.5
85+	62.9	72.6

Source: Eurostat database

b. National definition and measurement of long-term care dependency

In Sweden, old age care (äldreomsorg in Swedish) is the umbrella term embracing both home care (home help and home health care) and care homes (institutional care), which are the two major services provided by the municipalities within the framework of the Social Services Act.

There are no national definitions or measurement criteria for long-term care (LTC) dependency in Sweden. Dependency and the need for services and care is determined through a needs assessment procedure and eligibility for services is decided by the local government.

3. Public Schemes on Social Services and Health, including Long-Term Care

There is no legislation that is explicitly concerned with social protection for LTC in Sweden. However, social protection, including benefits for LTC dependency for older people, is covered in two pieces of legislation, the Social Services Act and the Health and Medical Services Act.

a. Social Services Act

Name and type of law	Social Services Act (1982:30)
Date the law was passed	28th June 1979
Date of *de jure* implementation	1st January 1982
Brief summary of content	The law emphasizes the right to receive public services and help at all stages of life. Everybody has the right to claim public services and help to support themselves in their day-to-day existence "if their needs cannot be met in any other way". According to chapter five, the municipalities are obliged to provide home care and care homes for needy older people.
Socio-political context of introduction	The law replaced previous laws relating to child welfare, social assistance, and treatment for alcohol abuse. The act provides a framework for the coordination of social services within the municipalities. It emphasised the importance of respect and autonomy for the individual and a clear public responsibility for care of older people based on the principles of independence and "aging in place".
Revisions of law	The Social Services Act was revised and modernised in 2001 (2001:430) and enacted on 1st January 2002.

b. Health and Medical Services Act

Name and type of law	Health and Medical Services Act (1983:40)
Date the law was passed	30th June 1982
Date of *de jure* implementation	1st January 1983
Brief summary of content	The aim is good health and equal access to health services for everyone according to their needs and on equal grounds, and provided on equal terms for all. Health care – both inpatient and outpatient care – must be provided to everybody according to need.
Socio-political context of introduction	The Swedish health care system is a socially responsible system with an explicit public commitment to ensure health care provision for all citizens. Three fundamental principles are intended to apply to all health care in Sweden. These are: human dignity i.e. all human beings have an equal entitlement to dignity, and should have the same rights, regardless of their status in the community; need and solidarity, i.e. those in greatest need take precedence in medical care; finally, cost-effectiveness – when a choice has to be made between different health care options, there should be a reasonable relationship between the costs and effects, measured in terms of improved health and quality of life.
Revisions of law	The Health and Medical Services Act was revised and modernised in 2017 (2017: 30) and enacted on 1st April 2017.

c. Brief comparisons of the two laws

Name	The Social Services Act	The Health and Medical Services Act
Coverage	The whole population	The whole population
Service provision	Municipalities	Regions
Financing	Municipalities	Regions
Regulation	National government	National government

4. Subsequent Major Reforms in Long-Term Care

a. Major reform I

Name and type of law	Community Care Reform
Date the law was passed	13th December 1990
Date of *de jure* implementation	1st January 1992
Brief summary of content	The reform implied a major decentralisation and deinstitutionalisation of old-age care, a development that continued throughout the 2000s, resulting in a new structure for old-age care in Sweden.
Socio-political context of introduction	To integrate and consolidate financial and care responsibilities it was decided that the responsibility for the care of the elderly should be borne by one level of local authority, namely the municipality.
Brief summary of characteristics of the programme	The 1992 reform – based on an "aging in place" policy - implied that the municipalities were given the major responsibility for elderly care.

5. Description of Current Long-Term Care System

In 1992, the Community Care Reform came into force, thereby establishing the structure of LTC that is still in place in Sweden. The reform aimed to integrate and consolidate financial and care responsibilities by transferring the responsibility for the care of older people to the municipality.

Under the reform legislation, the municipalities were given the statutory responsibility for all types of institutional housing and care for older people, including responsibility for and operation of nursing homes and other care facilities for somatic LTC. This entailed a new municipal responsibility for some 31 000 nursing home beds which, prior to the reform, had been run by the regions, on the legal basis of the Health and Medical Services Act. These nursing home beds were "added to" the different types of residential care facilities for which the responsibility already lay with the municipalities within the framework of the Social Services Act. The municipalities were also responsible for providing health care (up to nurse level) to elderly residents in the institutions. However, the responsibility to provide health care does not include medical care provided by primary care doctors.

By agreement with the county, the municipalities were also able to assume responsibility for home health care. The Community Care Reform also stipulated that every municipality should have a Medically Responsible Nurse (MRN). Their area of responsibility was to ensure that municipality health care is appropriate and safe. The MRN is also involved in municipal health care planning, allocating resources and expertise, and is therefore a key person regarding health care in municipal service and care.

To address the long-standing problem with "bed blockers" in hospital care – patients occupying beds while waiting for care to be arranged after their hospital stay –, a new law was introduced giving the municipalities financial responsibility for bed blockers in hospital care, namely the "Act (1990: 1404) on the municipalities" responsibility for payment for certain health and medical care". This law was updated and replaced by a new law, "Law (2017: 612) on collaboration in discharge from hospital care", that came into force on 1st January 2018.

The Community Care Reform entailed changes in the division of responsibilities between the municipality and the county council (today's regions). The municipalities took over a certain operational and financial responsibility from the county. These changes in responsibility resulted in certain amendments and additions to the Health

and Medical Care Services Act and the Social Services Act, followed by changes in financing through a tax change between counties and the municipality.

a. Organisational structure

In Sweden, responsibility for health care and social services is divided between three levels of government. At the national level, parliament and the government set out policy aims and directives by means of legislation, economic incentives and supervision. The Social Ministry is responsible for both health and social care at the national level. The regions (21 in all) are responsible for the provision of health and medical care. At the local level, the (290) municipalities are legally obliged to meet the social service, home health care, and institutional care needs of older people. Regions and municipalities have a very high degree of autonomy vis-à-vis central government. Both have elected assemblies and the right to levy taxes. At regional and local level, each region and each municipality decide, within the framework of legislation, over their own matters.

b. Service provision

The provision of (municipal) long-term service and care is based on a single-entry system; persons in need of help turn to their local municipality in order to claim for help. Need is determined through a needs assessment procedure, which is carried out by a municipal care manager. Eligibility to services is not means-tested and there are no national regulations. The municipality decides on the service level, eligibility criteria and range of services provided. Individuals can claim services but they have no automatic right or entitlement to services. If the elderly person requesting services is dissatisfied with the care manager's decision, he or she can appeal the decision in the administrative court.

Access to institutional care is decided in the same way as for home help services, i.e., through a needs assessment procedure carried out by the municipal care manager. Eligibility and access criteria may and do vary considerably from one municipality to another. However, the level of dependency and degree of cognitive impairment is often decisive.

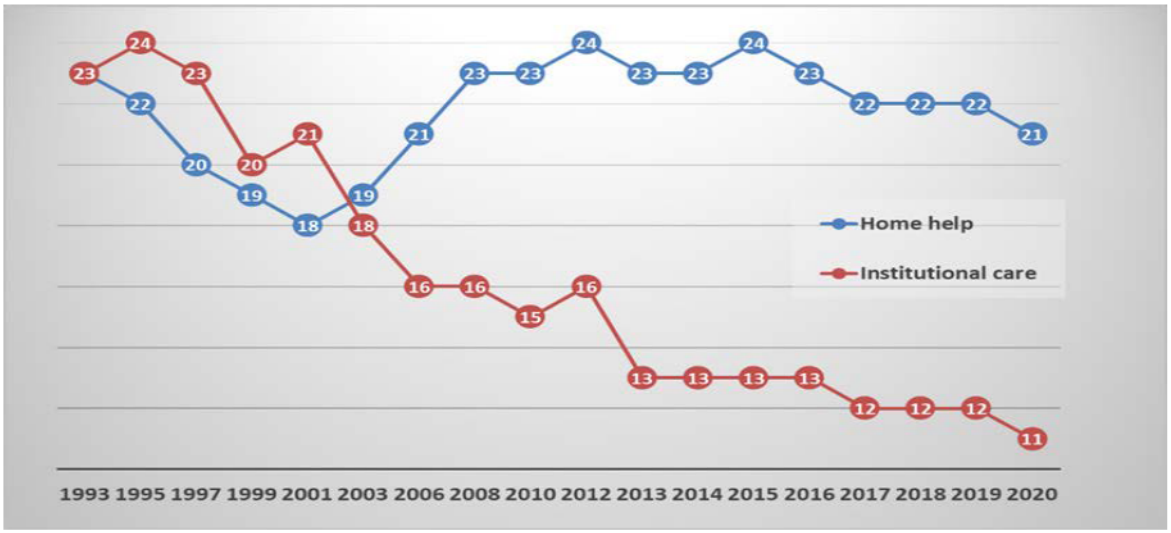
Home care (home help and home health care) benefits are provided in kind. There are altogether some 3,000 home help units in Sweden (SALAR, 2020) providing help to some 167,000 older people (NBHW, 2021). This includes help with daily activities, e.g. shopping, cooking, cleaning, and laundry, but also covers personal care such as help with bathing, going to the toilet, getting dressed, and into/out of bed. Today's users may get help many times per day, during the evenings, in the night-time and at weekends – features unavailable just a couple of decades ago. Another example is to offer supervision at night-time, via a web camera, as an alternative to visits by the night team. On average, clients use about 39 hours/month, but the distribution is skewed, with most clients using fewer and a smaller group using very many hours.

Besides home help, there is also a comprehensive range of other municipal services for elderly people, such as transportation services, meals-on-wheels, security alarms, housing adaptations, assistive devices, etc. Municipalities also offer day care, often providing respite for families caring for their elderly relatives at home. An additional care alternative is short-term institutional care, which is often provided to older persons after a hospital stay. The municipalities are responsible for home health care (except in the Stockholm region), which is part of the municipal elderly care, both in the individuals' homes and in the institutions. Many of the elderly receiving home health care are also in need of help from the municipal home help services. In 2017, some 70 per cent of all elderly people receiving help had both home health care and home help, i.e., many elderly people in this situation are highly dependent on daily help and supervision.

Out-patient health care is accessed at the primary health care centres (PHC), most of which are publicly run, and sometimes privately (reimbursed with public money). The region is responsible for PHC; at these centres, health care is provided by doctors, nurses, occupational therapists and physiotherapists who serve the whole population, including elderly people. LTC facilities don't have resident doctors, but residents get planned regular visits from PHC doctors, and when an acute medical need arises.

As the care of older people is a public responsibility in Sweden, there are no legal obligations or statutory requirements for adult children to provide care or economic security for their aging parents. Swedish welfare state programmes are based upon individual independence; family bonds should be voluntary and not obliga-

Figure 1. Coverage ratios in home help and institutional care among people 80 years and older, 1993 – 2020 (per cent).



Source: National Board of Health and Welfare, Statistics on Care and Services for the Elderly, each year

tory. The underlying philosophy has been to promote maximum independence from the family, even if you need support for your daily living. However, given the public responsibility to cater for older people's service and care needs, it is still the family and next of kin who are the major providers of help to older people.

c. Financing

Regions and municipalities have a very high degree of autonomy vis-à-vis central government. Both have elected assemblies and the right to levy taxes. The regions and municipalities may, within the limits prescribed by existing legislation, decide to what extent they will prioritise older people over other groups.

The division of responsibility is reflected in funding responsibilities. Care of older people is almost totally financed by local taxes. The user only pays a fraction of the cost (4-6 per cent). The largest share of the cost (about 85-90 per cent) is covered by local taxes. National taxes cover the remaining part of the cost (about 5 per cent). The fact that health and social care services for older people are primarily funded by local taxes confirms the independent role of the local authorities, i.e., their independence of national government.

The costs for LTC for older people – according to the OECD definition – were 3.2 per cent of GDP in 2017 (OECD, 2019).

d. Regulation

National government is responsible for laws and regulations in health and social care. However, within the framework of these laws, eligibility criteria, staffing ratios, bed capacity and quality standards in old age care is decided by each municipality. The Health and Social Care Inspectorate is the government agency responsible for supervising health care and social care, health care and social care staff, social services and activities in accordance with the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS).

The Health and Social Care Inspectorate is also responsible for certain permit applications. Companies, foundations, associations and other private actors who wish to run an individual business in accordance with the Social Services Act must have a permit before the business begins operating. The application is made to the Health and Social Care Inspectorate, who decide in this matter. Finally, the National Board of Health and Welfare is responsible for licensing health care personnel.

6. Summary of additional relevant laws

a. Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS 1993:387)

The LSS is a law that sets out rights for persons with considerable and permanent functional impairments. Its ten measures for individualised special support and service are to provide such persons with good quality living conditions in the community, rather than institutional care. Those covered by the LSS are persons with:

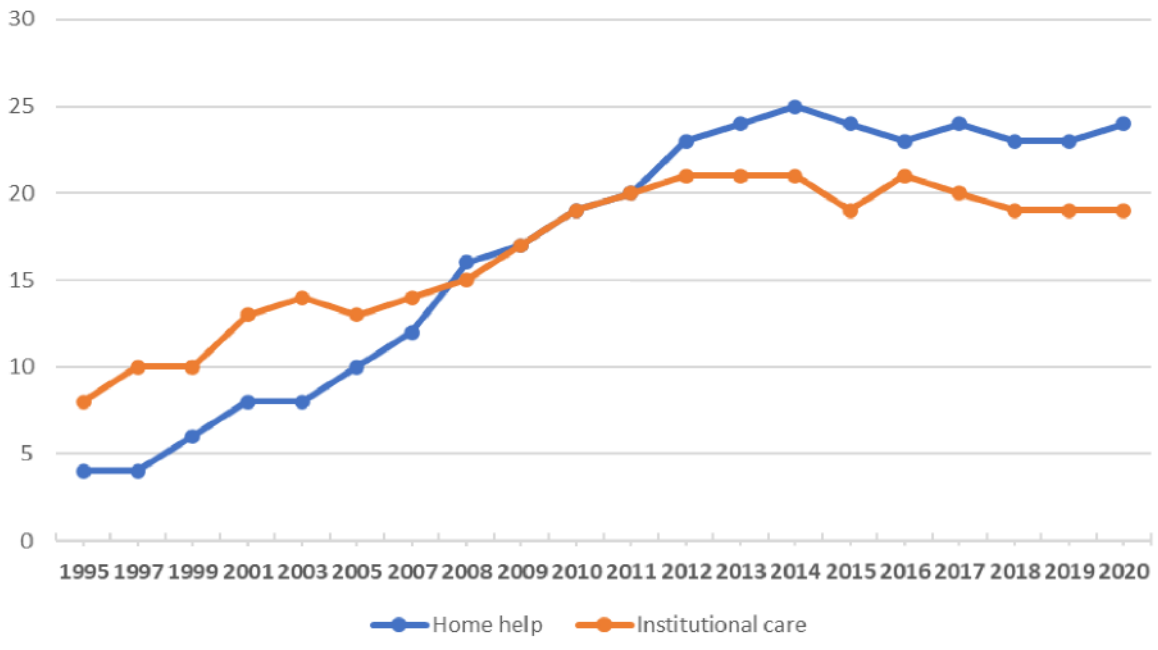
1) Intellectual impairments, autism or conditions similar to autism.
2) Significant and permanent intellectual disabilities following brain damage in adulthood. The injury has to have occurred through physical violence or physical illness.
3) Other permanent physical or mental disabilities that are not due to normal aging. The disabilities have to be so severe that they constitute serious impediments to activities of daily living.

A central part of the LSS is that persons with major functional impairments and an extensive need of support in their daily lives may be entitled to personal assistance. The municipality is financially responsible for those who need assistance for less than 20 hours a week. A person who needs assistance for more than 20 hours a week may be entitled to assistance benefit covered by the National Social Insurance. The right to this benefit is set out in the Assistance Benefit Act (LASS) (1993:389). The Social Insurance Administration makes the decision regarding eligibility for LASS (Schön and Johansson, 2016).

b. Act on Free Choice

Since the 1990s the introduction of market mechanisms or the "privatisation of care" has encouraged freedom of choice for LTC users. This was further reinforced by the introduction, in 2007, of tax subsidies for paid help with household chores. In 2009, the *Act on Free Choice* gave the municipalities another alternative option of contracting providers, used in about half of Sweden's municipalities today. After needs assessments, the entitled

Figure 2. Home help* and institutional care** by private providers 1995 – 2020 (per cent)



Notes: *Home help in hours ** Persons cared for in institutions

Source: National Board of Health and Welfare, Statistics on Care and Services for the Elderly, each year

person is free to choose between different (accredited) providers. Competition in this quasi-market is *not* driven by price, as the municipalities pay a fixed sum per hour for services to all providers. Thus, since 2009, there are several options for municipalities: first to provide in-house services, secondly to contract out services to private providers, or thirdly, to introduce a customer choice model, or use different options for different services at the same time. Relations between municipality and service providers – private or public – are governed by means of contracts. In the contracting-out and customer-choice model, the municipality can set quality standards and prices, and inspect providers (Meagher and Szebehely, 2013).
In 2010, corresponding legislation made it mandatory in Primary Health Care services to give patients the right to choose their primary health care centre. The legislation also gave providers the freedom to establish their services wherever they choose if they fulfilled certain fiscal and administrative criteria. Older people with complex health problems and severe needs who live alone at home are often dependent on service and care around the clock. A consequence of the marketisation of old age care has been a rapid increase in the number of providers both in health and social care. Many private providers use (several) subcontractors to be able to provide the necessary services.

c. Current legislative initiatives

The COVID-19 pandemic has meant an excess mortality in the population during 2020 in Sweden. Many older people have been exposed to the infection and about 70 per cent of those who died had various forms of old age care. Since the end of spring 2020, there has been a consensus among responsible politicians, authorities and the public that Sweden has failed to protect the elderly from the pandemic.

To evaluate the consequences of the Swedish COVID-19 strategy, the government appointed a Corona commission to investigate the events in the course of the pandemic. In December 2020, the Corona Commission presented their report focusing on and evaluating the Swedish strategy to protect "the old and frail" (https://coronakommissionen.com/). The report summarised:

> "The Commission's overarching assessment can be simply summed up as follows: apart from the general spread of the virus in society, the factor that has had the greatest impact on the number of cases of illness and deaths from COVID-19 in Swedish residential care is structural shortcomings that have been well-known for a long time. These shortcomings have led to residential care being unprepared and ill-equipped to handle a pandemic. Staff employed in the elderly care sector were largely left by themselves to tackle the crisis" (Johansson and Schön, 2020).

In a response to the Corona Commission criticism, the government launched a committee (Swedish Government, Dir 2020:142) with the following directive:

> "A special investigator is commissioned to propose an elderly care law. The concept of elderly care needs to be defined and the activities given a clearer mission and content. The ongoing COVID-19 pandemic has shown that patient safety in municipal care is lacking. The investigator is also instructed to consider and submit proposals on how medical competence can be strengthened in the operation and, if necessary, at municipal management level. The aim is to create long-term conditions for elderly care and to more clearly define the mission and content of elderly care, as well as ensure access to good health and medical care and medical competence in elderly care. The investigator shall, among other things:
>
> - propose an Elderly Care Act that supplements the Social Services Act (2001: 453) with special provisions on service and care for the elderly and which, among other things, contains provisions on a national care plan,
> - consider and, if necessary, submit proposals that strengthen access to medical expertise in elderly care. The assignment must be reported no later than 30th of June 2022."

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