

ESPN Thematic Report on Challenges in long-term care

Sweden

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ESPN Thematic Report on Challenges in long-term care

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Summary

Sweden has a comprehensive public long-term care (LTC) system for older people. In 2015, the number of LTC beds was 66.4 per 1,000 of the population aged 65 and over, which can be compared with the OECD31 average of 49.7 (OECD 2017). Expenditure on LTC was 2.9% of GDP in 2014 (Eurostat), which was among the highest in the EU. Services are highly subsidised in Sweden; users pay only 4 or 5% of the cost. Services are needs-based rather than means-tested.

The Swedish LTC system is decentralised, and municipalities are responsible for institutional care such as nursing homes, residential care facilities and group homes for persons with dementia, and home-help care and services. This decentralised structure gives rise to a number of important problems.

First and foremost, there are no national regulations on eligibility: local authorities decide on the service levels, eligibility criteria and range of services provided for home help and institutional care. Cash benefits (which play a very marginal role in the Swedish LTC system) for family carers are also decided upon locally and are not provided everywhere. In the national plan on quality in health and social care of older people (SOU 2017:21), the investigator suggests that the National Board of Health and Welfare (NBHW) should map out differences between municipalities in their guidelines and practice in granting access to institutional care, and the causes of these differences.

More recently, an 'ageing in place' policy has dominated the organisation and performance of LTC in Sweden. This policy has led to a gradual downsizing of institutional resources. Since the early 2000s, 30% of the beds in municipal institutional care have been closed. The downsizing of municipal institutional care has in practice lifted the threshold so that only the most dependent older people can access institutional care.

Another development in Swedish LTC is a strong marketisation trend (i.e. private forprofit provision of publicly funded care), including increased competition, freedom of choice and diversity of providers.

Integrated care is a national policy goal to avoid fragmentation and improve efficiency in care provision for older people by introducing coherent and coordinated LTC services, both within the care systems and between health and social care. Simultaneously, there is a striving for more competition under the umbrella of freedom of choice and diversity. The official goals of (on the one hand) equality and LTC systems of integrated care, and (on the other) freedom of choice, results in a political dilemma involving conflicting goals. At the political level, there is a need to prioritise.

1 Description of the main features of the country's long-term care system

Almost all Swedish welfare state programmes are based upon individual independence, springing from the high value attached to individual independence and the idea that family bonds should be voluntary rather than obligatory. Consequently, there is no legislation giving families the responsibility for caregiving. Sweden has a comprehensive public LTC system for older people. The guiding principle of eldercare policy is the provision of publicly subsidised, widely available services that can be used by everyone in need, regardless of financial and family resources (Sipilä, 1997).

The responsibility for the long-term care (LTC) of older people is divided between three governmental levels. At the national level, parliament and the government set out policy aims and directives by means of legislation and economic incentives/steering measures. The 21 county councils and regions are responsible for health and medical care. The 290 municipalities are responsible for social care, i.e. institutional care and home help. Homehelp services can be complemented by home health care services. The municipalities vary considerably in population and character and thus the conditions for managing the municipal tasks differ.

All citizens are, if needed, eligible for health and social care services. Access to social care is based on a needs-assessment, as opposed to being means-tested. However, there are no national regulations on eligibility. Eligibility criteria, service levels, and the range of services provided (for both home help and institutional care) are decided locally. Cash benefits are also decided locally. Hence, an evaluation of eligibility criteria for LTC services and benefits is difficult to make.

Both health and social care services are highly subsidised. Through taxation, county councils and municipalities finance around 90% of the cost of health and social care. Around 5% is covered by national taxes. Users pay only a fraction (4-5%) of the cost. Fees for LTC include care, rent, and meals. There is also a ceiling on fees. From 2017, the maximum amount charged for care, whether home-based or in an institution, is 2,068 SEK per month (219).

There are two types of municipal cash benefits available for family carers in Sweden. These are, however, not provided everywhere; each municipality may decide whether to provide this programme or not, and what the eligibility criteria, level of payment, etc. should be. One allowance is attendance allowance (hemvårdsbidrag), which is given on top of services provided to the care recipient. This is a net cash payment given to the care recipient, to be used to pay for help from a family member. The level of reimbursement is at most about 4,000 SEK per month (~450). The other benefit is carers allowance (anhöriganställning), which is actually not an allowance: the municipality employs a family member to do the care work. Carers allowance is taxed, and gives the same salary and similar social security as for home-help workers in the municipality's own services. It is not possible for a person who is 65+ to be employed.

Because data on municipal cash benefits ceased to be part of official statistics in Sweden in 2006, the most recent figures are from that year. The figures showed that 5,300 persons received attendance allowance and almost 1,900 received carers allowance. The number of persons receiving allowances is assumed to have decreased since then. It is important to stress that cash benefits play a very residual role in the Swedish LTC system, as services in kind are prioritised over cash benefits.

In 1992, the community care reform programme shifted the major responsibility for the care of older people from county councils to municipalities. This reform spurred a reduction in the number of hospital beds for several decades afterwards. This reduction is part of a *deinstitutionalisation trend* in the Swedish LTC system. An 'ageing in place' policy dominates the organisation and performance of LTC in Sweden. This policy has led to a gradual downsizing of institutional resources. Since the 1992 community care

reform, the number of hospital beds has been reduced by more than 50% (National Board of Health and Welfare, 2017). In 2014, Sweden had the lowest per capita hospital bed rate in the European Union (EU): 2.5 beds per 1,000 persons, compared with an EU average of 5.2 beds per 1,000 persons (OECD, 2016a).

In the early 2000s, a wave of reductions began in the number of municipal institutional beds (i.e. nursing homes, residential care facilities, group homes for people with dementia). Since then, 30% of municipal places have been closed. Thus, over time, more and more people receive help at home rather than in institutions, in accordance with the 'ageing in place' policy. In 2001, 18.3% of those aged 80+ received home help, while 20.0% were living in institutions. In 2017, 22% of those aged 80+ received home help and 12.2% received institutional care. This development over the past decades is shown in Figure 1.

Moreover, there has been a shift in the allocation of home-help care: people with greater needs receive more comprehensive care, while those with less extensive needs are less likely to receive any home help.

Another development in Swedish LTC is a strong marketisation trend (i.e. private provision of publicly funded care), including increased competition, freedom of choice and diversity. There has been a dramatic increase in privately provided LTC, and the entire increase is the result of the growth of for-profit - in contrast to non-profit - provision. In 2009, the Act on System of Choice in the Public Sector (LOV) was introduced, and since January 2010 choice has been obligatory for primary care in all counties and regions. This means that county councils are obliged to introduce freedom of choice for patients, allow the establishment of primary care clinics by authorised private providers, and fund the latter's services from tax income. Thus, private providers do not necessarily need to be established in all counties, but there must exist opportunities for such establishments (Ekman & Wilkens, 2015). In effect, private actors are given the opportunity to start a clinic where they choose, and then send the bill to the county council. The county councils cannot decide where the clinics are located, for example where the need is greatest (Burström, 2015). This reform opened up the possibility for county councils and municipalities to, amongst other options, contract out services to private service providers. Today, the LTC sector is highly deregulated but remains publicly financed.

Another feature of the Swedish LTC system, similar to that in many other countries, is fragmentation. Specialist services are poorly designed to provide care for patients with multiple health problems and social needs.

The aforementioned cutbacks in formal eldercare, as well as the altered allocation of home-help services (focusing on those with the greatest care needs) have taken place along with an *increase in informal care* (refamiliarisation). The proportion of older people who received care from both home-help services and family members in order to manage their activities of daily living increased substantially during the early 2000s (Ulmanen & Szebehely, 2015). Moreover, the number of hours that relatives spend on caregiving has increased.

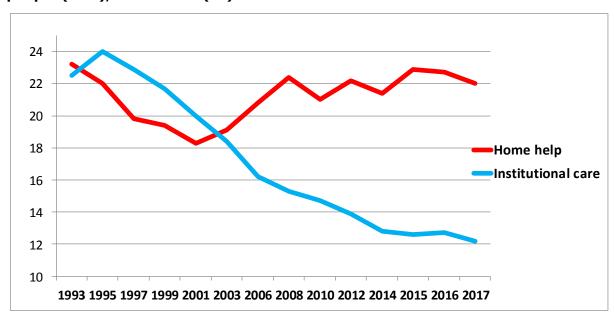


Figure 1. Development of access to LTC. Coverage ratio in the care of older people (80+), 1993-2017 (%).

Source: Social Services Registry (National Board of Health and Welfare) and population statistics (Statistics Sweden) (National Board of Health and Welfare).

2 Analysis of the main long-term care challenges in the country and the way in which they are tackled

Challenges in the Swedish LTC system are manifested in different ways at each level of the system and have to be understood within the context of the structure described above. LTC is predominantly financed and provided by independent local authorities (the municipalities). Challenges also differ between municipalities, due to variations in economic and demographic conditions, as well as in population size. However, some patterns can be discerned for most municipalities: difficulties in funding and recruitment of staff, and a shortage of institutional care. At the central state level, challenges are to some extent of a different character. Problems and complaints within LTC are often referred up to government, which relies on legislation and economic incentives to tackle the challenges. However, because of pronounced regional and local independence and the fact that county councils and municipalities finance the major part of LTC, priorities and decisions are still most often made at the local level. Thus, at central state level, the challenge is the lack of powerful tools to regulate the LTC system.

2.1 Access and adequacy challenge

As described above, Sweden has experienced social, demographic and economic changes in the last couple of decades, affecting the coverage ratio of persons receiving services, the amount and type of help provided, and the nature and intensity of support received by older people with LTC needs. According to the OECD (2013), the Swedish LTC system offers good coverage, and the range of services covered is wide. Not surprisingly, the Swedish LTC system is costly relative to the European average.

The downsizing of municipal institutional care (as described in part 1) has in practice lifted the threshold so that only the most dependent older people can access institutional care (National Board of Health and Welfare, 2016; Schön, Lagergren & Kåreholt, 2016). A consequence is that many frail older people are dependent on help in their own homes, both formal care (home help and home health care), and informal care provided by families. The cutbacks in institutional care have not been compensated for by an increase

in home-help services (National Board for Health and Welfare, 2017). As a consequence, a larger proportion of frail older people have to cope with less or no formal support. This places more responsibility on individuals and their families, and assumes that the individuals have sufficient capacity to take care of their health and to navigate the health and social care systems.

Although formal care provision is extensive in Sweden, the contribution of informal carers is substantial. Studies indicate that the proportion of older people relying on their family for care has increased over the years. The driving force behind this development has been the rapid reduction in municipal institutional care for older people, which evidently has had negative repercussions on middle-aged children's ability to work to the extent they would prefer. Awareness of the growing work-life balance problem is relatively new in Sweden. It was not until 2014 that the work-life balance issue was recognised in political discourse, when the government pointed out that more than '140,000 persons have quit their jobs or reduced their working hours to care for their aged parents' (National Board of Health and Welfare, 2012; Szebehely, Ulmanen & Sand, 2014; Schön & Johansson, 2016). The lack of knowledge about the effects of present policies on support to informal carers was also highlighted in the national plan on quality in health and social care of older people (SOU 2017:21). At national level, there is no up-to-date knowledge on whether support to informal carers is provided, to what extent information about available support reaches carers, or how carers value the support provided.

Another challenge is that there are variations between municipalities regarding the intensity, content and quality of the LTC services provided. In a recent government-commissioned inquiry (SOU 2017:21) it was suggested that the National Board of Health and Welfare (NBHW) should map out differences between municipalities in terms of their guidelines and practices in granting access to institutional care, and the causes of substantial differences.

In sum, public responsibility for LTC has become more narrowly defined in Sweden, and more responsibility for care is placed on persons in need of care and on their families.

2.2 Quality challenge

High quality is an important feature of the Swedish LTC system. The idea behind the universalistic nature of the Swedish welfare system is to make services affordable for the poor, but of such high quality that the same services are attractive for those who are wealthier (Szebehely, 2005).

However, quality is a complex matter and hard to measure, especially in primary care and LTC, where services often lack standard definitions. To get an idea about the efficiency and quality of Swedish LTC, there has to be something to compare it with. Analyses from both the OECD (2013; 2016b) and the Swedish Association of Local Authorities and Regions (SALAR) (2015) show that, in an international comparison, the Swedish LTC system stands up excellently and is high-performing in many areas. Several shortcomings can, however, be identified. Primary care is supposed to play a central role in care coordination in Sweden, but there is a poor formal structure around the nature of this function/role. The highly decentralised care system and the large number of independent care providers has, amongst other things, led to multiple data journal systems. County councils often have different journal systems, and so do municipalities. These systems are not always compatible. Fragmented data systems prevent effective data sharing and can thereby undermine care. A lack of reliable quality indicators holds back efforts to improve primary care and LTC services (OECD, 2016b).

In 2008, the government initiated the user satisfaction survey, which since then has been conducted annually by the NBHW. In the first years, the survey was based on a sample of older persons receiving LTC, but was broadened in 2013 to include all older persons receiving home help or institutional care. The user satisfaction survey is the most widely used instrument for measuring quality in Swedish LTC. The results from the user satisfaction survey have a large impact, as they are embraced and used by the

government, the NBHW, the SALAR, municipalities, private and public LTC providers, researchers, and the media. The survey has been criticised for having serious shortcomings; one of the biggest problems is the extremely low response rate, in particular among those living in institutional care. A large majority of those living in institutional care are unable to respond by themselves, due to physical and/or cognitive impairments. In 2016, only 6.7% of those living in institutional care responded to the survey unaided (without proxy) and gave their view on the quality of the care they received (Johansson, 2017).

Another important aspect of quality in LTC is the working conditions and quality of jobs offered in this sector. Szebehely and colleagues have studied how working conditions in eldercare changed between 2005 and 2015. They found a notable increase in the number of care recipients that a home-help worker meets in one working day, and a decrease in care workers' autonomy and opportunities to get support from colleagues and managers. Care workers in institutional care perceived their work as much more mentally and physically demanding and with greater time pressure in 2015 than in 2005. In addition, more than half of the respondents (care workers) in 2015 reported that they had seriously considered quitting their job – again a considerable increase since 2005. The readiness to quit the job is clearly associated with workload and lack of support and autonomy. This raises important questions about recruiting and retaining care personnel (Szebehely, Stranz & Strandell, 2017).

Despite the fact that there are no legal obligations or statutory requirements for children to provide care or economic security for their elderly parents, a family that by its own choice wishes to care for a family member should be given recognition and support in line with the Social Services Act (SoL). According to the Act, 'the social services are obliged to provide support to persons who care for next of kin with chronic illnesses, older people, or people with disabilities'. All those who identify themselves as an informal carer who cares for next of kin can apply for support. There are no directives on the amount of help a caregiver has to provide to qualify for such support, and neither is there any legislation that specifies the content and quality of the support that municipalities are obliged to provide (Johansson, Long & Parker, 2011; Johansson & Schön, 2017).

The above-mentioned inquiry (SOU 2017:21) proposed a national plan for quality in health and social care for older people. The aim was to ensure high quality in future eldercare through long-term investments in strategically important areas. The proposed plan focuses on six different themes in LTC (with suggestions for further development): improving quality and effectiveness; improving health promotion and rehabilitation; recruiting and retaining care personnel; reviewing institutional care for older people; flexible forms of needs assessment; and the use of welfare technologies in old-age care. To what extent the recommendations in the inquiry will be implemented is, by and large, yet to be seen.

2.3 Employment challenge

A strong welfare state and policies have facilitated women's participation in the labour market, the rate of which in Sweden today is one of the highest in Europe. In 2016, female labour force participation was 79.2% in Sweden and 65.3% in EU-28. Only Iceland had a higher rate, of 84.4% (Eurostat). The high percentage of women in the labour market necessitates a formal system of care for the elderly, as does the fact that very few older people share their homes with their grown-up children. The pension system ensures that few people have to abstain from service and care due to economic reasons (Schön & Johansson, 2016).

The proportion of persons in Sweden who provide informal care for a dependent relative is lower than the EU average. In 2016, the proportion of the population aged 15-64 who were inactive in the labour market due to informal care obligations (looking after children

or incapacitated adults as the main reason for not seeking employment) was 4.1%

(females 7.2%, males 0.4%), and the EU average was 9.7% (Eurostat).

Szebehely (2010) studied the association between middle-aged women's participation in paid work and the extent of LTC provision in different countries. The association was weak among most countries, but Sweden, Finland and Denmark showed both high participation in the workforce and more public resources for LTC. Thus, it could be argued that public LTC for older people is also a precondition for female labour force participation, and thereby a precondition for a broader tax base to finance public welfare services.

There is a clear association between professional skills and quality in care. Today, there exist quality deficits that can be related to a lack of professional skills among LTC staff. Compared with other OECD countries, Sweden has a high number of staff in relation to the number of older people in the population. However, there is currently a lack of professionally trained staff within several care occupations. In the national plan on quality in health and social care for older people (SOU 2017:21, 2017), the investigator was commissioned to suggest measures in strategically important areas to improve quality in LTC. Ensuring efficient and secure staffing was one of the areas.

2.4 Financial sustainability challenge

2.4.1 Assessment of recent or planned reforms and how they address the described challenges

From a European perspective the Swedish LTC system performs well in many respects. It offers high financial protection, covers a wide range of services, and is staffed with a higher number of care workers in relation to the number of older people in the population than other OECD countries (OECD, 2013). Expenditure on LTC was 2.9% of GDP in 2014 (Eurostat), which is among the highest in EU. However, not least due to the developments described above — such as deinstitutionalisation, fragmentation, informalisation, and marketisation — important future challenges remain.

Between 2010 and 2015, the government launched a programme to improve care coordination for older people with complex health problems. A vast number of initiatives backed by state grants were launched. The programme showed that it is possible to promote ageing in place. But to do so, primary health care must be strengthened and able to target and serve this vulnerable group of very frail older persons in collaboration with municipal LTC. Methods need to be developed to identify older persons at risk in order to provide care at an early stage. Older people should to a higher degree receive necessary care at home. Moreover, as many older persons are dependent on their families, support to the families must be strengthened and integrated with care provided to the older person (Stockholm Gerontology Research Centre, 2014).

On 1 January 2018, legislation on safe and effective discharge from inpatient care came into force (government bill 2016/2017:106; SOU 2015:20, 2015). One aim of the legislation is to improve care, with shorter lead times between inpatient care and municipal LTC. Another aim is to clarify the structures and forms for collaboration between the responsible authorities. Those who are embraced by the legislation are persons who, after discharge from hospital in-patient care, are in need of LTC financed by municipalities or outpatient care financed by county councils (Johansson & Schön, 2017). This legislation has not yet been evaluated. However, a concern is whether municipalities are ready and prepared to handle a faster discharge of older patients from hospitals. Another concern is whether the new legislation will result in increased pressure on the families concerned.

2.4.2 Policy recommendations to improve the accessibility, adequacy, quality and sustainability of the LTC system

The Swedish welfare model, where LTC is a public responsibility, has been shown to be successful in many respects. It has for example relieved the care burden of families, and is thus a precondition for women's labour force participation. It has been argued that a universal LTC system, like that in Sweden, needs the loyalty of the entire population for legitimacy and sustainability. Therefore, it is of great importance that the services are of high quality in order to satisfy all users, an idea referred to by Rothstein (2004) as 'the high-quality standardised solution' (Burström, 2015). If the Swedish LTC system of public responsibility for the care of older people is to endure, one of the major challenges is to secure financial sustainability.

Even though there has been a drastic reduction in municipal institutional care, Sweden still has a relatively high number and a high coverage ratio of beds in municipal institutional care from an international perspective. However, the cutbacks in institutional care have resulted in an increasing number of frail older people with complex health problems and cognitive impairments who are dependent on help in their own homes, both on formal care such as home help and home health care, and on informal help provided by families. Consequently, with more LTC delivered in older people's own homes, policies to support informal carers will become increasingly important.

Integrated care is a national policy goal to avoid fragmentation and improve efficiency in care provision for older people by introducing coherent and coordinated LTC services, both within the care systems and between health and social care. Simultaneously we see a striving for more competition under the umbrella of freedom of choice and diversity. The official goals of (on the one hand) equality and LTC systems of integrated care, and (on the other) freedom of choice, give rise to a political dilemma involving conflicting goals. At the political level, there is a need to prioritise.

A cornerstone for evidence-based policy making regarding LTC for older people is the provision of adequate data for monitoring and research purposes. In Sweden, there is a need for a better system of regular and representative statistics, together with a robust monitoring or evaluation system allowing questions to be answered about the targeting, efficiency and quality of LTC provision.

3 Analysis of the indicators available in the country for measuring long-term care

There exist an abundant number of indicators to measure LTC. An almost intrinsic problem with many of these is that it is very difficult to measure, or even define, quality within LTC in which services often lack standard definitions.

Commissioned by the government, the NBHW and the SALAR created the national monitoring system 'Open Comparisons' (*Öppna Jämförelser*) in 2007. This is a compilation of indicators drawn from several registers and surveys. Publications of results from Open Comparisons can be found at the NBHW website. The SALAR website provides both publications and a list of indicators and prevalences. The indicators in Open Comparisons are listed below.

The indicators in Open Comparisons cover a wide range of items. The indicators on, for example, polypharmacy and other indications on inappropriate drug use, waiting times in institutional care, risk preventions, and costs, can be viewed as quite robust. However, the Open Comparisons system also contains a number of items from the user satisfaction survey (described above in the section on quality challenges). As mentioned previously, this survey struggles with low response rates, and gives little understanding of the views of care recipients. It is therefore highly questionable whether such unreliable material can be used as a basis to measure quality — a concept that is inherently complex and hard to capture.

Area	Variable name	Definition	Source	Years available
Ordinary housing and institutional care	Consideration of own opinions and preferences in home-help services. (Hänsyn till åsikter och önskemål i hemtjänsten)	Share of older people who report that staff always or often take into consideration their opinions and preferences on how care should be carried out.	NBHW	2012-2016
(Ordinärt och särskilt boende)	 Sufficient time in home-help services. (Tillräckligt med tid i hemtjänsten) 	Share of older people who report that staff always or often have sufficient time to carry out their job.	NBHW	2012-2016
	 Action plan and participation in homehelp services. (Genomförandeplan och delaktighet i hemtjänsten) 	Share of older people in ordinary housing who have participated in establishing an action plan.	NBHW	2012, 2014, 2016
	4. Continuity of staff in home-help services.(Personalkontinuitet i hemtjänsten)	Mean value of number of different members of staff that a home-help recipient meets during a period of 14 days.	Municipal survey	2007-2016
	5. Home-help services as a whole.(Hemtjänsten i sin helhet)	Share of older people who, on the whole, are very satisfied or moderately satisfied with home-help services.	NBHW	2012-2016
	 Consideration of own opinions and preferences in institutional care. (Hänsyn till önskemål och åsikter i särskilt boende) 	Share of older people who report that staff always or often take into consideration their opinions and preferences on how care should be carried out.	NBHW	2012-2016
	7. Sufficient time in institutional care. (Tillräckligt med tid i särskilt boende)	Share of older people who report that staff always or often have sufficient time to carry out their job.	NBHW	2012-2016

Area	Variable name	Definition	Source	Years available
	8. Action plan and participation in institutional care.(Genomförandeplan och delaktighet i	Share of older people in institutional care who have participated in establishing an action plan.	NBHW	2012, 2014, 2016
	särskilt boende)			
	 Food in institutional care. (Maten i särskilt boende) 	Share of older people who answered 'very good' or 'quite good' to the question: 'How does the food normally taste?'	NBHW	2012-2016
	10. Institutional care as a whole.(Särskilt boende i sin helhet)	Share of older people who, on the whole, are very satisfied or moderately satisfied with institutional care.	NBHW	2012-2016
Integrated care	11. Waiting time for institutional care.(Väntetid till särskilt boende)	Waiting time (number of days) from date of application to the date when the person is offered a place in institutional care.	www.kolada.se, RKA	2007-2016
(Sammanhållen vård och omsorg)	12. Risk prevention measures in ordinary housing.(Riskförebyggande åtgärder i ordinärt boende)	Share of older people aged 65 and older who have home health care with prevention measures when there is a risk of falls, malnutrition, bedsores, and poor oral health.	Senior Alert	2014-2016
	13. Risk prevention measures in institutional care.(Riskförebyggande åtgärder i särskilt boende)	Share of older people aged 65 and older who receive health care in their institutional dwelling with prevention measures when there is a risk of falls, malnutrition, bedsores, and poor oral health.	Senior Alert	2014-2016
	14. Number of injuries due to falls per 1,000 inhabitants aged 80+.(Antal fallskador per 1000 invånare 80 år och äldre)	Number of injuries due to falls per 1,000 inhabitants aged 80+ who have been admitted to hospital. Mean values for the years 2008-2016.	patient register	2008-2016

Area	Variable name	Definition	Source	Years available
	15. Functional ability 12 months after stroke.(Funktionsförmåga 12 månader efter stroke)	Share of people aged 56+ in the municipality who 12 months after stroke incidence (insjuknandet i stroke) were independent of help to move about, visit the toilet, and get dressed and undressed. Mean values for the years 2011-2016.	Riks-stroke	2011-2016
	16. Discussions at a palliative turning point.(Brytpunktssamtal)	Share of persons deceased at age 65 or older who before death had a conversation in which they were informed about their situation.	The Swedish palliative register (Svenska palliativregistret)	2012-2016
	17. Assessment of pain during the last week of life.(Smärtskattning sista levnadsveckan)	Share of persons deceased at age 65 or older who had an assessment of pain during their last week in life.	The Swedish palliative register (Svenska palliativregistret)	2012-2016
	18. Three or more psychotropic drugs. (Tre eller fler psykofarmaka)	Share of persons with concurrent use of three of more psychotropic drugs. Presented both as share of people with home help and institutional care, and share of the general older population.	NBHW, the Swedish prescribed drug register and the social services register (läkemedelsregistret, registret över socialtjänstinsatser till äldre och personer med funktionsnedsättning)	2007-2016
	19. Inappropriate drug use. (Olämpliga läkemedel)	Share of people with inappropriate drug use according to at least one out of four indicators of inappropriate drug use. Presented both as a share of people with home help and institutional care, and share of	NBHW, the Swedish prescribed drug register and the social services register (läkemedelsregistret, registret över	2007-2016

Area	Variable name	Definition	Source	Years available
		the general older population.	socialtjänstinsatser till äldre och personer med funktionsnedsättning)	
	20. Antipsychotic drugs. (Antipsykotiska läkemedel)	Share of persons aged 75+ who have been treated with antipsychotic drugs.	NBHW, the Swedish prescribed drug register and the social services register (läkemedelsregistret, registret över socialtjänstinsatser till äldre och personer med funktionsnedsättning)	2013-2016
Background indicators	B1. Deviation from standard cost. (Avvikelse från standardkostnad)	Shows how the actual costs for eldercare in the municipality are related to the costs that the municipality is expected to have, based on the structural conditions (e.g. demographic structure and level of ambition). A positive deviation indicates a higher cost than expected.	SALAR	2007-2016
(Bakgrundsmått)	B2. Cost per inhabitant, home-help services. (Kostnad per invånare, hemtjänst)	The municipality's total cost for home-help services divided by the number of people aged 65+ in the municipality. A high cost is often due to a high number of older people in the municipality receiving home-help services.	Statistics Sweden	2007-2016
	B3. Cost per user, home-help services (Kostnad per brukare, hemtjänst)	The municipality's total cost for home-help services divided by the total number of persons who receive at least one kind of service offered in home-help services. A high	Statistics Sweden	2007-2016

Area	Variable name	Definition	Source	Years available
		mean cost is either the result of recipients being granted a high number of services, or the fact that the cost of providing the home- help services is high in that municipality.		
	B4. Cost per inhabitant, institutional care. (Kostnad per invånare, särskilt boende)	The municipality's total cost for institutional care divided by the number of people aged 65+ in the municipality. A high cost is often due to a high number of older people in the municipality living in institutional dwellings.	Statistics Sweden	2007-2016
	B5. Cost per user, institutional care. (Kostnad per brukare, särskilt boende)	The municipality's total cost for institutional care, including costs for premises, divided by the total number of people living in institutional dwellings. The indicator shows the mean cost for a recipient of institutional care in the municipality.		2010-2016
	B6. Proportion aged 80 and older. (Andel 80 år och äldre)	Share of the municipality's population aged 80+.	Statistics Sweden	2007-2016
	B7. Proportion aged 65 and older with home-help services. (Andel 65 år och äldre med hemtjänst)	Proportion of the municipality's population who are 65 and older and receiving homehelp services. A high proportion of older people receiving home-help services can indicate that care needs are greater among the municipality's inhabitants than in the country at large. A high proportion may also indicate that the municipality has a lower threshold for granting home-help services, i.e. is more generous.	Statistics Sweden and NBHW, the social services register	2007-2016
	B8. Proportion aged 65 and older in	Proportion of the municipality's population who are 65 and older and are granted		2007-2016

Area	Variable name	Definition	Source	Years available
	institutional care. (Andel 65 år och äldre i särskilt boende)	institutional care.	services register	
		As above, a high proportion may indicate either a greater need or a lower threshold for granting institutional care.		
	B9. Proportion aged 65 and older with home health care services in home help. (Andel 65 år och äldre med hemsjukvård i hemtjänst)	Proportion of the municipality's population aged 65+ who receive both home-care services and home-help services.		2014, 2015
	B10. Median age at time of moving into institutional care. (Medianålder vid inflytt till särskilt boende)	Median age at the time of moving into institutional care.	NBHW, the social services register	2014, 2015

References

- Burström, B. (2015). Sweden recent changes in welfare state arrangements. *International Journal of Health Services*, 45(1), 87-104.
- Ekman, B. & Wilkens J. A. (2015). Literature review of the regional implementation of the Swedish government's health care reforms on choice and privatization. *Health Economics Review*, 2015; 5:39.
- Eurostat: Employment and social inclusion indicators. http://ec.europa.eu/eurostat/web/employment-and-social-inclusion-indicators/social-protection-and-inclusion/health-long-term-care.
- Eurostat (2010). Reconciliation between work and family life. Metadata in Euro SDMX Metadata Structure (ESMS). Compiling agency: Eurostat, the statistical office of the European Union.
- Government bill 2016/2017:106 (2017). Samverkan vid utskrivning från sluten hälsooch sjukvård [Coordinated discharge from hospital care]. Stockholm: Ministry of Health and Social Affairs.
- Johansson, L. (2017). En koloss på lerfötter. Tidningen Äldre i Centrum. Nr 1, 2017.
- Johansson, L., Long, H. & Parker, M. G. (2011). Informal caregiving for elders in Sweden: An analysis of current policy developments. *Journal of aging & social policy*, 23(4), 335-353.
- Johansson, L. & Schön, P. (2017). Country Report Sweden. Report. CEQUA Long Term Care network, London School of Economics and Political Science. Brussels: European Commission: European Union.
- National Board of Health and Welfare (2012). Anhöriga som ger omsorg till närstående. Omfattning och konsekvenser [Informal care. Magnitude and consequences]. Stockholm: National Board of Health and Welfare.
- National Board of Health and Welfare (2016). *Statistik om särskilt boende [Statistics on municipal institutional care]*. Stockholm: National Board of Health and Welfare.
- National Board of Health and Welfare (2017). *Vård och omsorg om äldre. Lägesrapport* 2017 [Care and services to older persons. Report of the situation 2017]. Stockholm: National Board of Health and Welfare.
- National Board of Health and Welfare. Information on Open Comparisons. http://www.socialstyrelsen.se/oppnajamforelser/aldreomsorg.
- OECD (2013). OECD Reviews of health care quality: Sweden 2013. Long-term care in Sweden. OECD Publishing.
- OECD (2016a). Health at a Glance: Europe 2016. OECD Publishing. http://www.oecd.org/health/health-at-a-glance-europe-23056088.htm.
- OECD (2016b). OECD Better policy for better lives. Health policy overview. Health policy in Sweden. OECD Publishing.
- OECD (2017). Health at a Glance 2017: OECD Indicators. OECD Publishing, Paris.
- Rothstein, B. Vad bör staten göra? Om välfärdsstatens moraliska och politiska logik [What should the state do?] SNS Förlag, Stockholm, 2004.
- SALAR. Information on Open Comparisons. https://skl.se/tjanster/merfranskl/oppnajamforelser/aldre.9487.html.
- Schön, P. & Johansson, L. (2016). European Social Policy Network. Thematic report on work-life balance measures for persons of working age with dependent relatives. Sweden 2016. Report. EU network of independent experts on social inclusion. Brussels: European Commission: European Union.

Sweden

- Schön, P., Lagergren, M. & Kåreholt, I. (2016). Rapid decrease in length of stay in institutional care for older people in Sweden between 2006 and 2012: results from a population-based study. *Health & Social Care in the Community*, 24(5), 631-638.
- Sipilä, J. (1997). Social care services: The key to the Scandinavian welfare model: Aldershot, Avebury.
- Social Services Act (1982) (SFS 2001:453) [Socialtjänstlagen]. Sweden.
- SOU 2015:20 (2015). Trygg och effektiv utskrivning från sluten vård [Safe and effective discharge from inpatient care]. Stockholm: Statens offentliga utredningar.
- Stockholm Gerontology Research Centre (2014). Utvärdering av sammanhållen vård för de mest sjuka äldre. Äldrecentrums slutrapport [Evaluation of coordinated care for older people with complex health problems and severe needs. Final report from Stockholm Gerontology Research Centre]. Reports: Stockholm Gerontology Research Centre, 2014:6.
- Swedish Association of Local Authorities and Regions (2015). Swedish health care from an international perspective. International comparison 2015. Stockholm: Swedish Association of Local Authorities and Regions.
- Szebehely, M., Stranz, A. & Strandell, R. (2017). Vem ska arbeta i framtidens äldreomsorg? [Who is going to work in the future eldercare?] Working Paper/Department of Social Work, 2017:1. Stockholm University.
- Szebehely, M. & Trydegård, G. B. (2012). Home care for older people in Sweden: a universal model in transition. *Health & Social Care in the Community*, 20(3), 300-309.
- Szebehely, M., Ulmanen, P. & Sand, A-B. (2014). Att ge omsorg mitt i livet: hur påverkar det arbete och försörjning? [Informal care giving among middle-aged people: how does it affect work and breadwinning] Working Paper/Department of Social Work, 2014:1. Stockholm University.
- Ulmanen, P. & Szebehely, M. (2015). From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. International Journal of Social Welfare, 24, 81-92.

