Quality and cost-effectiveness in long-term care and dependency prevention

COUNTRY REPORT

Sweden

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Introduction

In recent decades Sweden experienced social, demographic and economic changes affecting the nature and intensity of support received by people with long-term care (LTC) needs. In terms of service coverage, the Swedish old age care system peaked in the early 1980s. Since then, a dramatic reduction of institutional beds has spurred an intensive debate among older people, their families and the public, about eligibility and ‘the right to care’. Reforms in favour for a marketization of care, implying a fragmentation of care, have created problems for older people with complex health problems and severe needs who are dependent on coordinated service and care (Szebehely & Trydegård, 2012).

This report summarises emerging policy developments in Sweden in relation to quality and cost-effectiveness and dependency prevention in the long-term care area. It reviews recent key policy developments in the following four areas:

- health promotion
- measures to support carers
- use of innovative care models and new technologies
- strategies to improve care coordination.

Brief Overview of the Formal LTC System in Sweden

The Swedish LTC system – resting on an ‘ageing in place’ policy – is provided, managed and financed by the 290 municipalities and the 21 counties and regions. Care of children and sick, disabled and older people are a public responsibility. Public policies and programmes providing health care, social services and support, as well as pensions and other forms of social protection, are comprehensive. The Social Services Act (1982) gives all citizens 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’. Likewise, under the Health and Medical Services Act (1983), health care should be provided on equal terms for all.

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 and economic steering measures. At the regional level, the county councils and regions are responsible for the provision of health and medical care. At the local level, the municipalities are legally obliged to meet the social care and housing needs of older people.

In 1992, Sweden enacted the Community Care Reform, placing the major responsibility for care of older people on municipalities. Since then, the counties/regions are responsible for health and medical care and for in-hospital and outpatient health care, including advanced home nursing/palliative care. Sweden’s municipalities are financially responsible for medically treated patients; that is, for ‘bed-blockers’ in hospitals. Municipalities are responsible for home help, including help with activities of daily living (ADLs) and personal care. They are also responsible for providing home health care, assistive devices, day care, and short-term institutional care and offer additional services, such as transportation, meals on wheels, security alarms, and housing adaptations. Since 1992, municipalities have been responsible for all types of institutional care, including nursing homes, residential care facilities and group homes for persons with dementia.

Both health and social care services are subsidized, with the recipient usually directly paying only a small part of the actual cost. The overwhelming part of the cost of health and social care, about 90%, is financed by local government – the counties and municipalities – though taxation. The user pays only a fraction (4% or 5%) of the cost and the remaining 5% is covered by national taxes. Taxation is based on individual income and likewise fees for services and care. Family or household economic resources are not considered and there is also a cap on fees for both health care and social services. Local
governments have a very high degree of autonomy from central government. They have the power to levy taxes and can decide to what extent they will prioritize elderly people over other groups.

All Swedish citizens are eligible for services and care and access to services is needs based, not means-tested. Care provision is based on a single-entry system; older people in need of help claim it from the municipality in which they live. Likewise, access to institutional care is decided through needs assessment process carried out by a municipal care manager. There are no national regulations on eligibility: local governments decide on the service levels, eligibility criteria and range of services provided, for home care and institutions. Health care is accessible at primary health care centres with everyone free to choose what centre or GP they prefer to visit. Finally, there are no statutory obligations for children to provide care or economic security for their elderly relatives.

Policy Developments

The 1992 Community Care Reform triggered a rapid reduction of hospital beds and during the ensuing 25 years hospital bed numbers have declined by more than half. A second wave of closures, of municipal institutional beds (i.e. nursing homes, residential care facilities, group homes for people with dementia), started at the beginning of the new century. Since then, 30% of municipal places have been closed. Studies show that the length of stay in institutional care has decreased, with a rapid increase in the proportion of people who moved into institutional care and died shortly afterwards (Schön, Lagergren, & Kåreholt, 2016). These changes have increased the pressure on primary health care centres with everyone free to choose what centre or GP they prefer to visit. Finally, there are no statutory obligations for children to provide care or economic security for their elderly relatives.

Since the freedom of choice reform, there are several options open to municipalities: to provide services in-house; to contract out services to private providers; to introduce a customer choice model; or to use different options for different services at the same time. Relationships between the municipality and service providers – private or public – are governed by means of contracts. In the contracting-out and customer-choice model, the municipality (or the county) can set quality standards and prices and inspect providers.

Older people with complex health problems and severe needs who live alone at home are often dependent on 24-hour service and care. A consequence of marketization of old age care has been a rapid increase of the number of providers of health and social care. Many private providers use (several) subcontractors to able to provide the necessary services.

People needing care round the clock will inevitably need multiple carers, with the challenges for continuity and security which this implies. There is an increased risk that they will be unable to continue at home and more older people in this situation will need emergency hospital care.

In 2010 to 2015, the government launched a programme to improve care coordination for older
people with complex health problems and severe needs. It contained a vast number of initiatives, backed by state grants and other economic incentives. Developmental projects were provided with earmarked resources to develop new models of integrated care. The counties and municipalities were remunerated according to numbers of people in various categories: for every person diagnosed with dementia registered in the Swedish Dementia Register; for people included in the Senior Alert Register (which records data on the prevalence of pressure sores, falls and malnutrition); and for people included in the Swedish Register of Palliative Care.

A performance-related payment system was introduced to reduce hospital admissions and readmissions among elderly people. It provided financial rewards to county councils, regions and municipalities for reducing such admissions. Another performance-related payment was tied to the reduction of inappropriate drug use among elderly people.

The governmental programme on care coordination 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 older people with complex health problems in collaboration with municipal social care services. Routines and methods need to be developed to identify older people at risk in order to provide service and care at the earliest possible stage. Another experience was that older people with complex health problems should not have to go to a GP clinic. Instead, the GP, nurse, or occupational/physical therapist should go to the elderly person, offering the necessary care at home. And, as many elderly people are heavily dependent on their families, support to the families must be integrated with the support provided to the elderly person (Stockholm Gerontology Research Center, 2014).

At the national level, in January 2016, a commission presented a white paper (Government bill 2016/2017:106), proposing that the legislation from 1992 should be changed, giving municipalities (a maximum of) three days to arrange for necessary services at discharge. This legislation has not yet been passed, but is expected to come into force on 1 January 2018.

In March 2017, a government-commissioned white paper proposed a national plan for quality in health and social care for older people (SOU 2017:21, 2017). This 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.

Health Promotion

A variety of initiatives to improve public health have been implemented in Sweden over the years. In the early 1980s the policy was based on the idea that by expanding public service and care for the elderly, health status and thereby life quality among the elderly should gradually improve. Contributing to this development was the improvement of general living conditions among older people. At that time, there was also scepticism as to the effects of preventive health activities among older people. Later, and continuing into the 1990s, there was a gradual increase of research and development work. Pilot projects, based on outreach activities or surveys of elderly people living at home attempted to identify elderly people at risk, needing services and care. The understanding was that there could be elderly people that for various reasons had no contact with the public authorities, which could substantially benefit from public support. However, several local attempts to reach ‘elderly at risk’ provided poor returns; few such people were in fact identified. The initiatives were not cost-effective. Against that background, the general conclusion was that public services and care catered for almost everybody in need for help. This rather negative
standpoint has over time been replaced by a more pragmatic attitude, where more direct illness prevention activities were initiated. Local developmental schemes, such as fall prevention activities, drug reviews among elderly people living at home and flu vaccination programmes were started.

From the late 1990s until now, Swedish policy for older people incorporates an ‘active ageing philosophy’ (Government bill 1999/2000:149). At the executive level, this policy is reflected in current legislation. The Social Services Act (1982) and the Health and Medical Services Act (1983) underline the importance of participation in community planning. Social services are required to familiarise themselves with the living conditions in their municipality and promote healthy environments in partnership with other societal bodies, organizations, associations and individuals. Health and medical care services should promote good health for the entire population.

Local conditions and requirements determine to what extent older people can cope with daily life. Disability becomes a problem when requirements exceed ability, for example when it is too far for an older person to walk to the shop or when the steps on the bus are too high to get on and off. Community planners should aim to design a society in which older people can live an independent life for as long as possible.

Non-governmental organizations and organizations for retirees play an increasing role in promoting healthy ageing. They represent a considerable resource and can prevent social isolation among older people who have a poor social network and have been struck by failing health. They are also directly involved in promoting ‘health classes’ to prevent strokes and heart disease and to improve general health in old age. These organizations constitute a very large movement, promoting a wide variety of social activities, among them senior university classes, arts and crafts courses, dancing or Nordic walking classes, and the shared preparation and enjoying of meals. The numbers of people reached by the activities of these organizations all over the country outnumber those involved in activities provided by the public authorities.

Strategies for Health Promotion

From time to time different initiatives have been made in Sweden to offer home visits or health check-ups with the aim of preventing illness among elderly people. Until recently, special health promotion programmes for the elderly have not been prioritised. Now, however, there is an increasing interest in developing methods of supporting an increasing number of healthy elderly people in maintaining their health and functional ability.

In 1999 municipalities and primary care districts were invited to apply for financial support from the government to participate in a prevention project which started in autumn 1999 and was concluded at the end of 2002. The target group for this national home visit programme was those elderly people without ongoing public help and support.

Twenty-one municipalities with different geographic and sociodemographic profiles were included in the project. Over 4000 older people (mostly 75 and over) participated, receiving regular home visits over a two to three-year period. The visits were carried out by district nurses, care managers, physiotherapists and occupational therapists. The visits also became an intervention to varying degrees. The visitors gave information and advice about health care and eldercare systems and on health promotion, depending to the lifestyle and individual needs of the subjects. Fall prevention and nutrition were two important topics. All subjects were encouraged and supported to participate in physical, mental and social activities. At baseline, most participants were satisfied with their present health and functional ability. Even so, one in ten reported that they had problems with loneliness, anxiety, depression, pain or fatigue. Two out of three home visits resulted in interventions to promote health. Simple measures, such as technical aids, new spectacles or hearing aids helped to improve functional ability and quality
of life. Visitors referred subjects to primary health care for drug reviews or health check-ups. Assessments of need for home help, transportation services or housing adaptations were other common interventions. For sedentary or isolated older people, activities were suggested and contact was established with voluntary organizations and befriending services (National Board of Health and Welfare, 2002).

Nordmaling, a small rural municipality in the north of Sweden, is one example where home visits had clear effects on the need for home help and health care. The subjects who received home visits used home help to a lower degree, and made fewer visits to hospital care and GPs than a group of controls. Savings were estimated to be substantial regarding expenditures for home help. A general experience was that older people are open to lifestyle changes. The home visits also identified concealed problems such as frail older people caring for spouses with dementia. Several subjects reported improved health and wellbeing. Small investments in service support yield a good return in independence. The conclusion from this national demonstration project is tentatively that preventive home visits were a successful strategy in promoting wellbeing among older people (Sahlen, Dahlgren, Hellner, Stenlund, & Lindholm, 2006).

Preventive home visits are nowadays common in municipal services, although it is not known how many systematic preventive home visit programmes are operated by the municipalities. In a recent dissertation work, positive effect of health promotion also among very old people has been reported (Behm, 2014).

In the 2000s, several prevention policies were developed, sometimes implemented with the help of state grants in the municipalities. One example was the development of drug therapy for elderly people. In Sweden 25% of all prescription medicines are taken by people 75 years and older. This creates substantial risks of inappropriate drug use and problems such as adverse reactions, hospitalizations and mortality.

In the late 1990s, the development of quality indicators started, resulting in 2004 in a first set of national agreed indicators. The next year the Swedish prescribed drug register was initiated. This contains data with unique patient identifiers on all prescription drugs dispensed to the entire population in Sweden. The registry made it possible to evaluate the quality in drug therapy among older people, or those receiving home help or institutional care. Several evaluations have been made, and the results have been used in local development work and in training of doctors and care personnel. Pensioners’ organizations have also been active, developing a ‘guide for smart drug use’ as an important information resource about drugs for their members, for example when they see their doctor.

There has been an impressive improvement in terms of reduction in drug use: almost 40% between 2005 and 2013. This is interpreted as a direct result of the use of quality indicators and the feedback to both professionals and responsible authorities, which in turn has probably led to better knowledge among prescribing doctors about drug therapy among the elderly. This development paved the way for new regulations on drug utilization reviews. Now, if you are 65 or over and prescribed five or more drugs, you also have the right to a review of your drug therapy (Fastbom & Johnell, 2015).

Health promotion among older people is a rapidly growing political issue in Sweden. The challenge is to develop affordable and sustainable measures, and there is debate as to whether general or targeted implementation strategies are preferable and cost-effective.

Policy Measures to Support Carers

Almost all Swedish welfare state programmes are based on the independence of the individual. Swedish culture places a high value on individual independence; family bonds should be voluntary and not obligatory. The underlying philosophy has been to promote maximum independence from the family, even if individuals need support for daily living.
Sweden has a well-developed welfare system, providing health care and social services as well as pensions and social protection to the citizens over the life course. The general principle behind LTC policy is to provide publicly subsidised, widely available in-kind services based on the individual's needs, regardless of economic means and family resources, thereby removing the burden of providing services from the family (Sipilä, 1997).

Family Care of Older People

Over the years, studies have repeatedly showed the crucial role of the family as caregivers of needy family members. Approximately two-thirds of all care for community-living older people is provided by informal caregivers, and the proportion of older people relying on family for care has increased over the years (Johansson & Sundström, 2006; National Board of Health and Welfare, 2015; Sundström, Malmberg, & Johansson, 2006; Szebehely & Trydegård, 2012).

Until recently, population-based data on informal caregiving has not been available. In 2012, the National Board of Health and Welfare was commissioned by the government to carry out a study of informal caregiving for persons with disabilities and older people, covering the whole country and for the adult population. The study showed that 18% of the population 18 years and older provides help, support and care on a regular basis, corresponding to over 1.3 million people overall. More than 400,000 people (6%) provide daily help, more than 600,000 (8%) weekly, and some 300,000 people (4%) provide help at least once a month.

Those aged 45 to 64 years are most likely to be caregivers: 24% of those in this age range identified themselves as caregivers (which represents some 580,000 in the population). Older people (65+) are also frequent caregivers, with 19% (just over 325,000 in the population) saying they provided care. Older caregivers give more intensive help than younger caregivers.

The results also showed that 8% of the caregivers (almost 70,000 persons in the population) reported they had reduced working hours due to caregiving duties, and 3% (29,000 persons) had stopped working for the same reason. Among all caregivers, women reduce their working hours (9%) due to caring more frequently than men (6%) (National Board of Health and Welfare, 2012).

Carers’ Cash Benefits Provided Within the National Social Insurance

Table 1 outlines the various types of support available for family carers of older people. We provide more detail on some of these in the following paragraphs.

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<th>Cash</th>
<th>Benefits in kind</th>
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<td>paid leave</td>
<td>direct support</td>
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<tr>
<td>care leave</td>
<td>information and advice</td>
</tr>
<tr>
<td>allowance</td>
<td>counselling</td>
</tr>
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<td>attendance allowance</td>
<td>training/education</td>
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<td>carers’ allowance</td>
<td>support groups</td>
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<td></td>
<td>in-home respite</td>
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<td>assistive devices</td>
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<td>institutional care</td>
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<td></td>
<td>indirect support</td>
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<td>home help</td>
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<td>institutional short-time respite</td>
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<td>housing adaptations</td>
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Family members who take care of another family member in a terminal care situation can claim time off work (care leave) with compensation from national social insurance. The benefit (up to almost 80% of the sickness benefit) requires a doctor’s certificate, is taxable, and is paid for up to 100 days for each cared-for person. The employer is legally bound to hold the employee’s position open while they are on leave. The leave claimant does not have to be providing all the necessary care themselves. ‘Family’ has a broad definition and includes neighbours, friends and others who stand in for family members. In 2016, some 15,700 persons used care leave. As there are some 90,000 deaths in Sweden annually (Swedish Social Insurance Agency, 2016), there is room for a larger uptake.

Carers’ Cash Benefits Provided by Municipalities

Caregivers can receive attendance allowance: this is a net cash payment that is given to the dependent person, to be used to pay the family member for the help. The monthly payment is a maximum of about 4,000 SEK per month (€450). Eligibility is usually based on assessed level of dependency. As there is no relevant federal or national regulation, each municipality will decide whether to provide this programme, and if they do, decide on eligibility, level of payment, etc.

Another option is the carers’ allowance which means that the municipality employs a family member for the care work. It provides a similar salary and social security protection as for the care personnel in the formal services and is taxed, but is not payable for people 65 years or older. Again, this is not covered by federal or national regulation and municipalities can choose whether or not to offer the allowance. Carers’ allowance can be a preferable arrangement in some circumstances, for example when an older person lives in a remote part of the municipality and has a child living nearby or to provide services and care to older immigrants, where the municipality does not have care personnel with the necessary language and culture competence. Data on municipal cash benefits was no longer collected for Swedish official statistics after 2006. That year some 5,300 persons received attendance allowance and almost 1,900 persons caring for an older family member received carers’ allowance. This kind of support plays a very residual role now, as services in kind are prioritised over cash benefits.

Description of Carers’ Benefits In-Kind

Direct support for carers is service and care provide for the carer directly (e.g., information and advice, counselling, support groups, in-home respite) while indirect support is targeted at the person cared for (home help, institutional care, day care, short-term respite care, etc.). Direct support is offered by all municipalities as a general service, and not based on a needs assessment. The intensity, content and quality of the provided support can, however, vary between the municipalities.

All persons in Sweden with care needs, irrespective of age and type of disabilities, are covered by the Social Services Act (1982). The Act gives the 290 municipalities the ultimate responsibility for ensuring that all residents in the municipality obtain the support and help they need. Indirect support is accessible after a needs assessment. The main service is home help, which includes help with daily activities, e.g. shopping, cooking, cleaning and laundry, as well as personal care such as help with bathing, going to the toilet, getting dressed and getting in and out of bed. There is also a comprehensive range of additional services, e.g. home health care, transport services, meals on wheels, security alarms, housing adaptations, assistive devices, etc.

Direct and indirect support complement and sometimes overlap each other. It is not unusual that the person cared for receives both home help and a carer respite service at the same time. Direct and indirect support is of course also provided by the health care services and many carers also receive help from voluntary organizations. It is known that the priority of carers themselves is for high quality and accessible service and care for the person cared for: i.e. indirect support.
Evaluation of the Legislation

In 2009, the Social Services Act was amended with a paragraph stating that ‘social services are obliged to provide support to persons who care for next of kin with chronic illnesses, older people or people with disabilities’. Anyone who identifies themselves as being ‘a person who cares for next of kin’ may apply, and there are no regulations regarding the amount of help a caregiver must provide to qualify. Nor does the law specify the content or quality of the support that the municipalities are obliged to provide (Johansson, Long, & Parker, 2011; Schneider, Sundström, Johansson, & Tortosa, 2016).

In 2014, the National Board of Health and Welfare presented a review of the 2009 legislation. It stated that the reduction of institutional care provision had implied that an increasing proportion and number of frail older people are now dependent on help in their own homes – both on formal home help, and on informal help provided by their families. One example is that most people with dementia are now cared for at home in Sweden. The reductions in formal LTC institutional care have then been accompanied by a ‘re-familiarization’ of care, i.e. the proportion of older people relying on family for care has increased in recent years.

As eligibility and access to services have been tightened, one could question whether the net effect has been negative for carers, despite legislation promoting support for them. However, in a macro or system perspective, there are signs of rapid development of support, especially support for carers of older people. Municipalities all over Sweden have expanded the availability, access and the diversity of support. In a micro and carers’ perspective, the results are more ambiguous and contradictory. In Sweden, direct support to carers, e.g. information, advice and respite services, is offered as a general service, and not based on a needs assessment. Also, carers’ organizations have raised critical voices. They point to instances of poor quality support, with a lack of tailoring and poor timing. They complain about training and professional skills among care workers in the municipalities, of them not being able to understand the diversity of caring and of the carers’ situation. In conclusion, outcomes in terms of support to individual carers and families are difficult or impossible to assess, as there is no system of documentation or statistics concerning support for carers.

During recent years, there has been a spotlight on the fact that families are forced to reduce hours or leave work due to caring obligations. This new recognition has led to more attention being paid to informal caregiving and work and care reconciliation. We can now see a negative interaction between less generous services for families with disabled persons and reduced working hours due to caring responsibilities. The driving force behind this development in old age care has been the rapid reduction of institutions for older people (as well as hospital beds), which has clearly prevented their grown-up children from working to the extent that they would prefer. The declining coverage of eldercare services has been followed by an increase of family care (Rostgaard & Szebehely, 2012; Szebehely & Trydegård, 2012; Ulmanen, 2015).

The Nordic welfare model, where care for disabled and older people is a public responsibility, has been shown to be an effective way to relieve the care burden of families. Despite cutbacks in the public care system, Sweden still has a generous public care system compared to many other countries. But if the welfare system dismantles, the care burden of families will increase. The cornerstone for evidence-based policymaking is the provision of adequate data, for monitoring and research purposes, concerning caring and carers. In Sweden, there is an urgent need for regular and representative statistics, and a robust monitoring or evaluation system, in order to answer questions about the targeting, efficiency and quality of the support provided.

The lack of knowledge about the effects of present policies to support carers was also highlighted in the National Plan on Quality in Health and Social Care of
Older People (SOU 2017:21). While support to carers was not the main focus, the plan commented on the state of the art in carer support. It stated that there is no updated information at the national level concerning whether support is provided, to what extent information about available support reaches the carers and how the carers valued the support provided.

Use of Innovative Care Models and New Technologies

Innovative Care Models

The drastic reduction of hospital beds since 1992 and the continuing reduction of municipal institutional beds has caused an imbalance in the LTC system. Moreover, 10% of hospital beds are out of action, due to increasing problems with nurse recruitment. The most obvious indicator of the imbalance is hospital tension, with increased queues in emergency departments and shorter hospital stays due to the shortage of beds. Increased readmittances among hospitalized older people create further tension in the system. The shortage of municipal beds (including institutional short-term care) creates problems when discharging older people who are not fit to go straight home.

Reducing the tension in hospitals has become prioritized question in recent years. In 2014, the government commissioned an investigation of the Act on municipal payment liability for patients in hospital who are ready to be discharged (1990:1404). Most of those who are covered by the act are older persons, 65 years and older. The aim of the investigation was to improve their care, with shorter lead times between inpatient care and health and social care in the own home or in institutional care and ensuring that unnecessary hospital stays for patients ready for discharge were, as far as possible, avoided. Another aim was to clarify the structures and forms for collaboration between the responsible authorities (i.e. the county councils and the municipalities).

The white paper ‘Safe and Effective Discharge from Inpatient Care’ (SOU 2015:20) was presented in February 2015, and a government bill (2017) was presented in February 2017. The bill proposed new legislation, the Act on Coordinated Discharge from Hospital Care, which is expected to be approved by Parliament in spring 2017. The aim of the proposed act is to ensure good health and social care of high quality for those who, after discharge from hospital in-patient care, need social and health care from the municipalities or outpatient health care. The new legislation will come into force by 1 January 2018.

To speed up discharge from hospitals while maintaining patient safety, several innovative models have been developed. For example, at many hospitals, a new function – the discharge nurse – has been put in place to improve care coordination between the hospital, primary care, municipal home help and the family. This represents an effort to plan, coordinate and manage a safe discharge from hospital. Likewise, several municipalities (especially in the big cities) have organised the discharge planning to be taken care of by a special care manager.

Different models of ‘safe return programs’ have been developed across the country. The general idea is to provide additional support (more hours of home help, visits by nurses/OT/PT and assistant nurses etc.) for the older person, immediately after returning home. Sometimes this work is organised in special ‘discharge teams’ (including a municipal care manager). Supported by the team and for two weeks, the older person can have extensive around the clock home help and nursing care, to overcome any temporary problems related to their hospitalization. Besides improving the chances of a good recovery, such schemes are also helpful for the family. Local evaluations point to less use of hospital care and lower costs from older ‘bed blockers’ in hospital. Whether safe return programmes lead to fewer readmittances is unclear.

Another initiative in this area is Ambulatory Emergency Geriatric teams, serving older people at home. The teams are typically called in by
ambulance personnel to treat an older person at home, instead of ‘load and go’ to hospital. There are interesting results from these teams, showing that substantial reductions in hospital admissions could be achieved (Johnson, 2015). A further extension of ambulance services are ‘assessment cars’, staffed by nurses, who make emergency visits to older people in cases given a lower priority by the regular ambulance services. The nurses assess the older person’s care needs and if it is necessary for them to go to hospital, help to arrange the transfer.

Primary health care is often not successfully addressing the needs of very old people with complex health problems or severe needs. However, initiatives have emerged recently to target this problem. For example, special out-patient clinics for older people (75+) have opened in many places (as a part of the ‘regular’ primary care clinic), trying to provide for older people with complex health problems, offering increased access, GP continuity, planned home visits by a nurse, more time per patient and more visits. An increasing number of primary care clinics across the country also offer acute home visits during weekdays to older patients.

Sweden has a long tradition of providing ambulant health care to different target groups. For example, palliative care teams and advanced home health care, are types of services that are available all over the country. The teams are substitutes for hospital care and located at the hospital. There are also teams based at PC clinics, catering for basic home health care needs in collaboration with the municipal home help services.

During recent years, a few case management programmes for LTC of older people have been trialled in Sweden, for example the experimental scheme evaluated by Sandberg (2013) (which has not been implemented in regular LTC services).

Personalization – Matching of Resources to Needs

Since the Swedish old age care peaked in 1980s and the Community Care reform was implemented in the 1990s, the system has been downsized considerably, making the issues of eligibility and assessment of needs central. The introduction of market-oriented reforms in Swedish LTC during the 1990s further focused the care management processes on the assessment of needs and the commissioning of services. The tightening of eligibility criteria spurred an intensive debate among older people, their families and the public, about eligibility and ‘the right to care’, and so also the assessment procedure.

The (strong) pensioners’ organizations particularly questioned the assessment procedure, which they felt was discriminating and undignified for older persons who were simply claiming their rights to services. In response to this and as measure to make basic services more accessible, some municipalities introduced a ‘simplified’ assessment procedure in the late 1990s. Under this measure, those citizens of a municipality who are over 75 years can claim help with daily tasks up to a certain number of hours per month, without any formal (traditional) assessment. The Swedish Agency for Health and Care Services Analysis (2013) reported that in 2009, 50 municipalities (out of 290) offered a simplified assessment procedure as compared to 110 municipalities in 2012, indicating a rapid development. Some municipalities now provide a facility to claim through this simplified assessment online. The white paper ‘National Plan on Quality in Health and Social Care for Older People, presented in March 2017 (SOU 2017:21, 2017), focused among other issues on the legality of present forms of ‘flexible’ or simplified forms of needs assessment. However, there were no final suggestions presented, rather the conclusion was that the legal aspects needed further investigation.

Increased marketization in LTC in Sweden places an emphasis on customer choice and the ‘personalization’ of service delivery. In Sweden, this means that the customer has the right to choose the provider of the services once the user has been found to be eligible. Sweden has encouraged LTC users’ freedom of choice since the early 1990s, but this was further reinforced in 2009 under the act on ‘System of Choice in the Public Sector’, giving the municipalities the option of contracting providers.
The aim of this legislation was to make it easier for different actors to enter the commercial market in care for older people. In 2010 similar legislation was extended to out-patient primary health care services.

Some fundamental acceptance criteria for providers are defined by the act and all applicants meeting these criteria must be officially accepted. If a municipality decides to introduce such a freedom of choice system, it is required to announce this decision on a national website, including details about the providers, acceptance criteria, quality information and contracts. Municipalities have an obligation to inform LTC customers about their freedom of choice and their right to change providers. They are also responsible for maintaining the same price levels across providers. Individual users have the right to opt out of the voucher system and are then guaranteed an alternative publicly-provided service (Meagher & Szebehely, 2013).

As mentioned in an earlier section, legislation was enacted in 2007 making state-subsidised service and care accessible for everyone. Older people can turn to a private firm for help with ‘household services’, for example, cleaning, washing, shopping and also personal care (health care services are excluded). The customer pays the full cost for the service, but can make tax deductions of up to a maximum of SEK 50,000 per person per year. This tax deduction could be an extra incentive for private providers to offer this kind of services, although the tax deduction can also be claimed by family members who pay for the services provided to their parents. Older persons receiving home help can also ‘top-up’ by purchasing tax-deductible services of their own choice.

The opportunity to buy tax-deductible services has been very popular. According to the Swedish Tax Agency roughly one third of the users are over 65 years of age and the number of older users is growing annually. The municipalities frequently refer to and actively publicize the option to buy out of pocket services this way, to divert users from public services to the private market, with the state tax-deduction as an incentive.

The ‘personalized’ models, as they are known in England, where users and carers are given the opportunity to act as the budget holders and commissioners of their own care, are not available as such in Sweden. Of course, cash benefits (i.e. attendance allowance, a net cash payment that is given to the dependent person, to be used to pay the family member for the help) have been available since the 1960s in Sweden. The monthly payment is, however, very modest, at most about 4,000 SEK per month (€450), and not enough to live on or to buy necessary services. Eligibility is usually based on assessed level of dependency or amount of caregiving, reckoned as hours of help needed, or given, per week. The Swedish LTC system still rests on the policy of offering public services for older people in need (Schön & Johansson, 2016).

New Technologies

Sweden has a long tradition of providing aids for disability or technical aids to older people as part of the structure making it possible to age in place. An illustrative example is security alarms, available in a handful municipalities in the 1970s, and now provided in every municipality in Sweden. In 2015, 179,000 people aged 65 and older received security alarms. From the beginning of the 2000s a shift from analogue to digital technology added new dimensions to security alarms and made them a key service among ‘welfare technologies’ in LTC. By 2016, however, only half of alarm users had digital security alarms; the government has set a goal to provide this service to all.

The digital technology in security alarms allows a GPS function to be included, making it possible for example to track people with dementia who get lost. The technology also makes it possible to track data, registered by sensors, about the person’s health status, and to surveillance or monitor older persons’ whereabouts. New possibilities and functions of technology have led to ethical discussion and pointed to ‘blank spots’ in current legislation regarding people who not able to give proper consent, due perhaps to cognitive impairment.
The use of another application of technology, an internet-enabled camera installed in the older persons’ bedroom, is currently the subject of lively debate in Sweden. Some municipalities offer night-time monitoring services using these cameras as an alternative to visits by the municipal night patrol. Some older people needing night-time checks prefer this service, instead of having care personnel visiting their home during the night; others prefer the old type of service. The key issue is whether the older person has the capacity to decide on their own and give an informed consent to the services. The experience so far is that users appreciate the increased privacy this new technology offers.

Digital-based technologies have many other appreciated applications in everyday care work in the home help services. For example, care workers visiting older people at evening or night times need to have the key to the user’s home. This means that a care worker must carry and be responsible for the keys to up to ten people’s homes. Technology makes it possible to install digital locks, benefiting both users and care personnel.

Further, different types of E-rostering tools are frequently used in the home help services to plan staffing requirements for providing services to the user and management reports on overtime, sickness, annual leave, etc. The tool can be used to ensure that staff are employed where most needed and enable efficiency improvements.

Studies have also pointed to the benefits for carers of access to support via ICT (Blusi, 2014). Taken together, there is great potential in the use of ICT, and corresponding interest among the municipalities to include this in mainstream services. The hope is that ICT services can substitute for more costly services and thereby improve cost-effectiveness in old age care.

Older people’s use of the internet is relatively low: one in two of those aged 75 years and older do not make use of it at all (Arvidsson & Finndahl, 2016). Against that background, ICT-based services are still both underdeveloped and unevenly spread in Sweden’s 290 municipalities (National Board of Health and Welfare, 2016). However, as the cost of new technologies falls, widescale adoption of technology is becoming increasingly viable and may provide a significant tool contributing to the sustainability of the health and social care systems.

The National Plan on Quality in Health and Social Care (SOU 2017:21) outlines a comprehensive programme for the development of a national strategy for ICT based services. The strategy should include the views of the users, families, and the care personnel. Further it should scrutinize legal problems and with regard to personal integrity, point out necessary changes in legislation. A national strategy should also include standards for ICT technologies, build an evidence and knowledge base for future development and identify possible joint ventures with the industry.

**Strategies to Improve Care Coordination**

The Community Care Reform of 1992, represented for Sweden the major policy initiative in modern times to define responsibilities and accountability in old age care. The aim was to improve the collaboration between the health and social care authorities, as well as care coordination for individuals.

The reform entailed new legislation making Sweden’s 290 municipalities financially responsible for medically treated patients; that is, for ‘bed-blockers’ in hospitals. The reform contributed to a rapid reduction in the number of beds in county council hospitals, halving in the period from 1992 to 2016. The reduction of hospital beds has led to a faster ‘turnover’ of patients in acute hospital care and in turn, this has meant a reduction in the average length of stay in acute hospital care. This also has consequences for families, as they can no longer expect a period of respite before the elderly person is discharged back home.

Geriatric care has been particularly affected and the trend of closing beds seems to be continuing. The shortening of hospital stays of course means that a substantial part of caring – sometimes advanced
nursing – is being transferred to the next level of care: municipal and primary health care. Since the Community Care Reform came into force, a steady increase in workload in both institutional and home-based care has been observed. The older people moving into institutional care today are more frail and dependent both in terms of functional and cognitive capacity than before (Schön & Johansson, 2015).

One tool for coordinating care which has a long history in Sweden is diagnosis-related national guidelines. They are intended to support decision-making concerning the allocation of resources within health and social care services and contribute to ensuring that patients and clients receive a high standard of medical and social care services. The National Guidelines in Dementia Care were first published in 2010, and represent a significant step forward in the care of people with dementia and their families: their needs are highlighted in the guidelines as is best available knowledge and practice. The guidelines are being implemented nationwide; often they are adopted into local guidelines or care programs. The guidelines are reviewed at intervals, and several indications suggest that they have been successful in raising the quality of dementia care (National Board of Health and Welfare, 2014).

In 2010, the Health and Medical Services Act and the Social Services Act was amended with a paragraph, stating people who need help from both health and social care should be offered a joint individual care plan. The plan should show how service and care will be delivered in a coordinated way, to ensure best possible service continuity and patient safety. How far and how successfully this legislation has been implemented is not yet known. However, the forthcoming legislation, the Act on Coordinated Discharge (2018) from hospital care, stipulates that patients needing social and health care after discharge from hospital should be provided with an individual care plan. This is likely to increase the use of individual care plans.

Integrated health and social care, especially for older people with complex health problems and severe needs, have repeatedly been on the policy agenda in Sweden. Older people often suffer from multiple morbidities due to chronic conditions and disabilities and a continuum of care and follow-ups at different levels of care provision, must be secured. Also, as many older users move from health care to municipal care, back and forth, the need to create a seamless system of elderly care is evident, both to reduce or delay hospital admissions and at the same time, to help elderly people to stay at home. However, local autonomy means that the national government, has no power to enforce these kinds of structures for care coordination at a local government level.

Local Programmes

Skaraborg county in the west of Sweden, covers six municipalities with some 100,000 inhabitants altogether. These municipalities have a history of collaboration between health care and social services, starting at the beginning of the 2000s. These network discussions involved a great number of stakeholders: politicians, professionals, older people and their families and patient organizations. The aim was to develop person-centred integrated care of very frail older people though close collaboration between health care and social services authorities.

Two specialised teams were started in 2008-2011: the mobile palliative care team and the integrated home care team. These serve patients in all six municipalities and are financed by the county (i.e. the health care authorities). The palliative team primarily provides services for younger people with cancer. The integrated home care team have the responsibility for elderly people with extended needs who are unable to visit the outpatient clinic. The teams have an average caseload of 24 people, providing ‘a hospital ward at home’. Further, in Lidköping, there is a ‘mobile doctor’, primarily making home visits to older people in need. Since 2009, municipal home help services and home nursing care in Lidköping have been organised in home care teams (home helpers, OT, PT, nurses) with the goal offering elderly people proactive
rehabilitation services at home and to work in close cooperation with the integrated home care team and the mobile doctor.

The municipal home care nurse is the human ‘hub’ and contact person both for the integrated home care team and the mobile doctor, orchestrating the collaboration regarding the patient. As the nurse is also a partner in the home care team, she is able to coordinate services to the elderly people. Local evaluations have showed positive results in terms of less use of hospital care and improved quality of life among the older people as well as their families (Health Care Management, 2013; Lifvergren, Andin, Huzzard, & Hellström, 2012).

The most prominent example of an integrated care model in Sweden, internationally known, is the TioHundra organization in Norrtälje. This municipality is part of Stockholm county and is geographically the largest municipality in the county. The population in Norrtälje municipality amounts to nearly 57,000 inhabitants, of whom one-third live in the regional central city while the other two-thirds live in other urban and rural areas. The population triples during the summer months. Norrtälje municipality is to a large extent a backcountry community (Schön, Hagman, & Wånell, 2011).

TioHundra was initiated by Norrtälje municipality and Stockholm County Council in 2006 with the objective of improving efficiency, quality and coordination in care provision while still controlling the costs. The project became permanent in 2016. TioHundra is a comprehensive integrated system with a high degree of structural and financial integration of health and social care for the general population in Norrtälje. The integrated care organization consists of a joint health and social care board with politicians from the municipality and Stockholm county council. The main function of the joint board, which has its own administration, is to purchase care services from a jointly owned stock company – Vårdbolaget TioHundra.

Vårdbolaget TioHundra is responsible for managing the hospital, specialist care, primary care, home nursing, and social care for older people and people with disabilities. A local government federation owns the stock company, which in turn has the county council and the municipality as the sole members.

Although the process started in 2006 the work of full integration has been continuously improved along the way and is still ongoing. Examples of positive achievements are:

- Simplified financing through the joint organization has facilitated the coordination of care.
- Introduction of an innovative customer choice model that improved cooperation and integrated care services (home help services, home care and home rehabilitation as a unit) which offered older people the opportunity to get all their home-based care services from one provider.
- Coordinating the discharge of patients from hospital and following-up care planning in the home has been successful. A joint organization gave an opportunity to organise, prioritize and make follow-ups from a bottom-up perspective, i.e. the older persons themselves.

The Norrtälje model is probably the most promising attempt in Sweden to develop an integrated ‘one-stop-shop’ organization. On the negative side, extensive cost-savings and thorough restructuring of elderly care was not an encouraging start for the personnel involved. The introduction of reforms in health and social care – including increased competition, freedom of choice and diversity – led to increasing numbers of service providers, which complicated the integration process. The goals of integrated care and freedom of choice are potentially conflicting goals. Further, the reforms may not lead to cost-saving, but to increased cost-effectiveness.

To conclude, the Norrtälje model has not been implemented elsewhere in Sweden, which illustrates local structural obstacles and conflicting interests between the authorities responsible for care. At the same time, it shows the power of a ‘bottom up’ approach to create integrated and coordinated care.
References


### Safe and Effective Discharge from Inpatient Care

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<td>Reducing long length of stays at hospitals</td>
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<tr>
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**Aims**
- One aim is to improve the care, with shorter lead times between inpatient care and health- and social care in the own home or in institutional care.
- Another aim is to clarify the structures and forms for collaboration between the responsible authorities.

**Implementation**
- A responsibility for the county councils and the municipalities.

**Target group**
- The general population. However, the majority of those who are embraced by the Act are older persons (65+).

**Eligibility criteria**
- Persons who after discharge from hospital in-patient care, are in need of social care, health care financed by the municipalities or outpatient care financed by the county councils.

**Resources**
- No extra resources.

**Performance assessment and monitoring**
- No announced national system for performance assessment and monitoring yet.
Evidence of success
(outcomes, quality, satisfaction, awareness)

Not in force yet.

Transferability /Uniqueness

Given the right circumstances the reform, contextually adjusted, ought to be possible to implement in other countries/regions.

Is this an emergent practice?

The Act on payment liability (1990:1404) was implemented as a part of the Community Care Reform in 1992, and stipulates the municipal payment liability for patients at the hospitals when they are ready to be discharged. Municipalities’ payment liability starts, at the earliest, five workdays after that the municipality has received the call to the care plan meeting. Reducing long length of stays at hospitals has been a prioritised question in recent years. The main reason for reducing length of stays at hospitals is a more effective use of resources, because in-patient care is the most costly form of care.

In 2014, the Government launched an investigation of the Act on payment liability (1990:1404). A government Bill (2016/17:106) was presented in February 2017, where the government suggests that a new legislation will be introduced, the Act on Coordinated Discharge from Hospital Care.

Key proposals from the government bill are:

- It is clarified that the social care services and outpatient health care as soon as possible shall start the discharge planning process from in-patient care. The in-patient care shall therefore, in certain cases, inform concerned units about the admission within 24 hours from the time the patient is admitted to in-patient care.

- The Act includes regulations about coordination between the county councils and the municipalities. The responsible authorities shall consult with each other and elaborate common guidelines about coordination according to the new legislation and are supposed to make agreements with each other about time point for the municipal payment liability and amount to pay.

- The Act also includes regulations about the municipal payment liability in certain cases for patients that are cared for within in-patient care after that they are ready to be discharged and an agreement between the county council and the municipality has not been reached. The new Act stipulates that municipalities’ payment liability will start three days (Saturday and Sunday included) after that the municipality has received information about that the patient is ready to be discharged.

- The government Bill is expected to come into force on 1 January 2018. The repealed Act shall however be in force until 31 December 2018 for patients that are treated in psychiatric in-patient care.
Sustainability

n/a

Critical assessment

A concern is whether the municipalities are ready and prepared to handle a faster return of older patients from the hospitals. Will the new legislation result in an increased pressure on the families?

Academic literature on this action

Documents


### Integrated Care: A National Policy Goal

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<td>Policy objective</td>
<td>To provide integrated care to older people with complex health problems</td>
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<td>Start date – End date</td>
<td>1 January 2006. Ten years later, 1 January 2016, the project became permanent</td>
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#### Aims
- Improve efficiency, quality and coordination in delivery of health and social care services for older people with complex health problems and severe needs while still controlling the costs.
- Integrated care has been politically promoted in order to improve quality of care, efficiency, enhance continuity and avoid fragmentation in care provision. The objective of integrated care is present in several Government Bills’ and policy reports.

#### Implementation
- In January 2006, a project for integration of health and social care services was initiated by Norrtälje municipality and the county council of Stockholm – TioHundra. TioHundra comprises the general population (divided into three age groups: 0–18; 18–64: 65+. Here we focus on 65+).
- TioHundra operates as one comprehensive health and social care organisation, owned, financed and managed jointly by the Norrtälje municipality and the Stockholm County Council. Although the process started in 2006, the work of full integration has been continuously improved along the way and is still ongoing.

#### Target group
- The most severely ill older people. The National Board of Health and Welfare define the most severely ill as “persons aged 65 years or older who have substantial reductions in their functional state as a result of ageing, injury or illness”.

#### Eligibility criteria
- Eligibility is decided on the basis of a needs assessment.
Resources
No extra resources or state grants. This local project has been financed by the local authorities, Stockholm County Council and Norrtälje municipality restructured their resources, i.e. pooled budgets.

Performance assessment and monitoring
Robust evaluations of integrated care systems or models are rare (Goddard & Mason, 2017; Hopman et al., 2016). Although several reports have evaluated the organizational process as well as the satisfaction among staff and users and to some extend even utilization of certain services, there has been little focus on health outcomes and quality of care.

Evidence of success (outcomes, quality, satisfaction, awareness)
Examples of positive achievements are:
• Simplified financing through the joint organisation has facilitated the coordination of care.
• Introduction of an innovative customer choice model that improved cooperation and integrated care services (home-help services, home care and home rehabilitation as a unit) which offered older people the opportunity to get all their home based care services from one provider.
• Coordinating patient’s discharge from hospital and following-up care planning in the home has been successful.
• A joint organisation gave an opportunity to organise, prioritise and make follow-ups from a bottom-up perspective, i.e. the older persons themselves.
• The Norrtälje project is probably the most promising attempt in Sweden to develop a kind of integrated ‘one-stop-shop’ organisation.

On the negative side it was found that extensive cost-savings and thorough restructuring of the elderly care was not an optimal start to involve the personnel. The introduction of new social reforms, including increased competition, freedom of choice and diversity led to increasing numbers of service providers which complicated the integration process.

The goals of integrated care and freedom of choice can be seen as two potential conflicting goals. Further, the reform may not lead to cost-saving, but to increased cost-effectiveness.

These results emanate both from quantitative assessment and interviews with key persons at different organisational levels. The results build on ex post impact assessment (Schön, Hagman, & Wånell, 2011).

Transferability/Uniqueness.
Given the right circumstances the reform, contextually adjusted, ought to be possible to implement in many other countries/regions.
Sustainability

The Norrtälje model is considered to be a prime example of a well implemented integrated care system. According to the literature, the Norrtälje model is unique in its kind, both in Sweden and elsewhere (Øvretveit, Hansson, & Brommels, 2010). The ten first years TioHundra was carried out as a project, in 2016 the project became permanent.

Critical assessment

Academic literature on this action


## Supporting Carers

**Policy theme**
To provide support to carers of sick, older and dependent people

**Design and implementation level**
National legislation, local obligation

**Policy objective**
To provide support to carers

**Start date – End date**
1 July 2009

### Aims
The Social Services Act is a frame law legislation, with no definition of informal care/carers. When announcing the 2009 amendment, the government website used the phrase “legal rights to support for carers”. This gave an image, that the amendment was an entitlement to support. But, the amendment gives carers the right to an assessment of their needs, no more no less.

### Implementation
To provide support carers is a legal obligation for the municipalities the Carers Act.

### Target group
Anyone who identifies themselves as being "a person who cares for next of kin" may apply, and there are no regulations regarding the amount of help a caregiver must provide to qualify. Also, the law doesn’t specify the content or quality of the support that the municipalities are obligated to provide.

### Eligibility criteria
Eligibility criteria to support is decided by the municipality – no national regulations exist.

### Resources
Initially, SEK 450 million of state grants was allocated to the municipalities to stimulate the implementation of the new law. The funding of the services provided on the basis of the legislation is municipal responsibility.

### Performance assessment and monitoring
The legislation was evaluated by the National Board of health and welfare, 2009–2014. The assessment of the effects and performance, is the availability of adequate data, for monitoring and research purposes, of caring and carers. In Sweden, this does not exist today, so there is an urgent need for regular and representative statistics, and a robust monitoring- or evaluation system in place, to be able to answer questions about, targeting, efficiency and quality of the provided support. In other words, the effects and the consequences of the legislation for carers cannot be shown.
Evidence of success (outcomes, quality, satisfaction, awareness)

Given the difficulties to present data of the effects of the legislation, one could still argue for that it has resulted in a raised awareness of informal caregiving and carers need for support. This development could be attributed to many different actors, but carers organisations have meant a lot. There are increasing insights, about the diversity of carers, i.e. there are many more carers, apart from those caring for older people, and they are also in need for recognition and support.

Also, an increasing awareness that a sick family member, affect everybody in the family. The whole family is affected, and whether you are the prime carer or not, other family members – especially children – also needs information, advice and support, accessible for their needs.

Increased knowledge that recognition and support for carers must include not only social services, but also health care, schools, other public authorities. And, finally, that workplaces must be “carer-friendly”.

Transferability/Uniqueness.

Also in this respect, there are too few examples (documented) of effect of the legislation, which makes it difficult to draw conclusions about transferability, at least at this stage.

Is this an emergent practice? (degree of innovation)

The legislation has consolidated recent 10–15 years’ developments of an infrastructure of support to carers in many municipalities, by appointing a carer’ counsellor.

The carers’ counsellor is the “one-stop-shop” of support, offering information, advice, counselling and respite services.

Sustainability

The is a part of the Social Services Act and thereby expected to be self-sustaining. In the present situation in the Social Service Sector in Sweden, other urgent needs and groups of needy people tend to be prioritized over support to carers.

Academic literature on this action


Documents