
Informal care of the elderly in Sweden – Carers’ situation

Björn Albin, Christina Siwertsson & Jan-Olof Svensson

Björn Albin, PhD is a senior lecturer at the School of Health Sciences and Social Work, Linnaeus University, Växjö, Sweden. Christina Siwertsson, MPhil is a university lecturer at the School of Health Sciences and Social Work, Linnaeus University, Växjö, Sweden. Jan-Olof Svensson is a RN Carers Consultant in the municipality of Växjö, Sweden and assistant project manager at the Swedish Family Care Competence Centre.

Abstract

Informal care of the elderly (often given by a relative or a spouse) plays an important role in most societies. This article describes the situation and support for carers that exist in Sweden today and how this may develop in the future. The description is partly based on the results from the evaluation of a government supported project ('Anhörig 300') aimed to develop support for carers in the county of Kronoberg as well as from information and documents. Four different typical situations for carers are identified and indicate how very different situations for carers can be. During the 21st century the Swedish Government has given great attention to support for carers, mainly through changes in the legislation and through economic grants to the municipalities.

In the future the support for carers must be given even greater attention and be developed further. The National Development Plan for Nursing and Care of the elderly in Sweden, from 2005, suggested increased support for carers as a complement to the public sector elderly care. From 2009 the Social Services Act has been changed in accordance with this plan. A key issue is to involve voluntary organisations to alleviate isolation and loneliness among carers.

An earlier version of the following article was first published in Japanese in *Chiiki Fukushima Kenkyu* (Studies of Community Welfare), 2008; 36; 72-83. It has since been revised and updated for publication in an English language journal.

Introduction

To care for somebody else is a common human activity in all types of societies. Care can be organised in an informal or formal way, can have the aim of focusing on different groups or covering the whole population and can be financed publicly or privately. Formal care in this article is defined as municipal care services while informal care is given by a close relative or a friend. In most societies informal care of the elderly plays an important role. This article describes the situation in Sweden for carers and the different types of support for carers that exist and how this situation may develop in the future.

This article is based both on the results from the evaluation of a project ('Anhörig 300') aimed to develop support for carers in the county of Kronoberg and on related information and documents. Data for the evaluation report was collected by two sets of interviews collected with a one-year interval. A total of 47 carers as well as project managers and politicians were interviewed. Information and documents have been collected by one of the authors, Jan-Olof Svensson, from the Social Care department at the Växjö municipality. He works in a national project in the Swedish Family Care Competence Centre as an Assistant Project Leader working on questions related to support of carers. He has also, through his work as a carers' consultant, contacted the carer who has contributed the case example.

History

Caring for persons, especially elderly, within the family or within small close personal networks is, in a historical perspective, the most traditional form of organising care and social welfare in a society (The National Board of Health and Welfare, 1993).

Different stages in the organisation of care and social welfare of elderly persons can be identified when a society changes and develops. In Sweden six different development stages can be distinguished: early and medieval period, the feudal and catholic period, the reformation period, the transition period, the liberal and philanthropic period and the welfare state period (Odén, Svanborg, & Tornstam, 1993).

Little is known about the care of elderly persons in the early and medieval period but based on the few sources we have we can assume that most of the care took place within the family (Odén, 1998). The situation for the 'free persons' and the 'slaves' differed, with the latter having very little protection from their families and being in the possession of the free person who owned them. During the feudal and catholic period (1200-1550s) the family still had an important role but the care of the elderly was also influenced by the Christian religion and supported by the Church. According to the catholic 'natural law' care for elderly parents was a duty and elderly parents should be cared for in the same way as mothers cared for their children (Odén, 1996). Care was a task for the family but also the church had a clear responsibility to cater for all people's needs according to the Bible (Odén, 1998).

The family, as a care 'unit', was strengthened during the period of reformation (1550-1700). New Mosaic laws from the central government, making it a crime to abuse parents (physically or verbally), were imposed with a penalty of capital punishment. There are indications that weak persons who were not family members were still cared for within the family. The transition period (1700-1800) was characterised by the disbandment of the religious influence on elderly care. The first laws about organising public care for weak persons in society were formulated during this period. The nuclear family became the ideal in society, and care of old persons became the responsibility of the local parish (Odén, 1988; Odén, 1998).

The deep-rooted tradition of children's responsibility for their parents came under debate during the liberal and philanthropic period (mid 1800-1930). A bylaw that stipulated children's responsibility to care for their elderly parents was abolished but reintroduced during the 1860s when a number of years of famine increased social problems. In 1913 the first law about pensions for the elderly was passed and this can be seen as the first and early step towards the welfare period (Odén, 1988; Odén, 1998).

The timing of the creation of the welfare state can be discussed but its foundations were laid during the 1920s in the political debate concerning the Swedish state as a 'People's home'. In 1956 a new Social Services Act was passed providing a guarantee for elderly persons, who could not support themselves, to receive help from the municipalities. For the first time children were not economically responsible for their parents and it was a collective responsibility for society to pay the costs for elderly persons and their right to a good old age (Odén, 2000). A new Social Services Act was approved in 1982 and clearly stated that elderly persons in Sweden should have the right to the same quality of life as every other person in society. Several revisions of the Social Services Act have been made since 1982 and the Act now also includes support for carers (Norström and Thunved, 2001). According to the Social Services Act, from 2001 the municipal Social Welfare Board *should assist, by way of support and relief services*, persons caring for next-of-kin who are suffering from long-term illness, are elderly or have a functional impairment (Ministry of Health and Social Affairs, 2001). The Act was reviewed again in July 2009 and now states, in chapter 5 section 10, that the Social Welfare Board *...has to assist, by way of support and relief services*' (Regeringens proposition, 2009 [Government Proposal, 2008/09:82]). These changes in the Act can be seen as an increased responsibility for the public sector to become more active to find carers who need support and to start the support as early as possible.

The population in Sweden, the elderly and the carers

Sweden, as is the case for many other industrialised nations, is a country with a large number of elderly. At present 17.8% of the total population of 9.3 million (approx.) is at least 65 years of age (Statistics Sweden, 2008). The prognosis for the coming years, estimates that the number of persons over 65 years of age will increase from 1,645,000 in 2008 to 2,448,000 in 2050. As a person grows old it becomes more likely that he/she will need support from society or from informal sources. Different types of functional decline, such as pain and mobility problems, are strongly related to ageing (National Board of Health and Welfare, 2005). The largest percentage increase of elderly persons will take place in the age group over 80 years of age. The number of persons in this group is at present 493,113 but by 2050 will have grown to be 892,000 persons (Statistics Sweden, 2008).

It is not easy to estimate how many people are carers for elderly persons in Sweden and similarly how much care is provided for the elderly by carers (Sundström, Malmberg, & Johansson, 2006). One of the problems is that there are no official statistics to be found concerning carers and the work carers do. Different studies, based on interviews with carers, have shown different results. Furthermore the kind of tasks the carers do, such as 'looking after', 'comforting' etc. are very difficult to assess in terms of hours and minutes (Szebehely, 2005). Despite these problems calculations are still done and in a study in 2005 it was estimated that 62% of all Swedish elderly care was provided from informal sources (Sundström, et al., 2006). In the age group 75 years or older 82% of the elderly in need of support for Activities of Daily Living (ADL) support were helped by a member or members of their families in 2000 (Sundström and Johansson, 2005).

Since the late 1970s a trend in Sweden has been that the support for elderly persons from public sources has decreased and at the same time been concentrated and focused on the most needy in the oldest age group, those over 80 years of age. This trend has thus also contributed to an increase in support from carers, especially to those in the age group 65

to 80 years of age (Eliasson-Lappalainen and Szebehely, 1998). An increasing support from female carers has also been a characteristic development during the 1990s. In 1994 29% of elderly single person households received help from a female carer and this had increased to 39% in 2000 (Szebehely, 2005).

A significant demographic trend is the increased number of elderly persons originating from a foreign country. In 1999, 130,000 persons, 8,6% of the population over 65 years of age, were foreign-born persons living in Sweden. Today nearly 50% of the foreign-born elderly come from another Scandinavian country but a total of 146 different countries are represented among elderly foreign-born persons. Challenges for future elderly care will be the mixture of different languages, different cultures and different religions (National Board of Health and Welfare, 2000).

Agencies and authorities responsible for policies and practices

The municipalities have the main responsibility for supporting carers of the elderly but other authorities also have an important role. At the national level, the Parliament and the Government influence elderly care through legislation and financial support and thus also the support for carers in Sweden. One example of such legislation for carers is the stated aim in the Social Services Act 2001 where the municipalities' Social Welfare Board has to provide support and relief for carers. (Regeringens proposition, 2009 [Government Proposal, 2008/09]).

The Swedish government has, through reforms concerning elderly care, also indirectly influenced the municipalities' responsibility for supporting carers. 'The Elderly Reform' in 1992 was a major reform and gave the municipalities comprehensive responsibility for long-term services, social services and health care for the elderly and disabled. One of the purposes of the reform was to create clear lines of accountability and to mark the municipalities as the organisation with the main responsibility for elderly care.

The government is assisted by the Ministry of Health and Social Affairs in carrying out its policies in the area of elderly care and support for carers. The Ministry is divided into seven divisions such as Public Health, Health Care, Social Services etc. The Ministry prepares legislative proposals for Government and Parliament and is involved in the central government budget process. The Ministry has the task of evaluating and monitoring policy implementation. In the case of care for the elderly and support for carers, the National Board of Health and Welfare (Regeringskansliet, 2009) has the major monitoring responsibility. A good example of how the Ministry and its agencies monitor the local municipalities concerning decisions taken in the Government and in the Parliament is the evaluation of the carers' support project Anhörig 300. More than 20 evaluation reports were published from 1999 to 2002 concerning different areas of support for carers within this project (National Board of Health and Welfare, 2002).

The Swedish Parliament and Government have a direct link to the regional level, the 21 counties/regions. The County Administrations have responsibility for monitoring the implementation of the policies and decisions from the national level including services for the elderly and carers. The main tools used by the Board are advice and information, supervision, regulatory duties, coordination of county resources and financial support (Sweden's County Administrations, 2009).

Voluntary organisations in Sweden do not have, as in many other European countries, a strong position in the area of social services and health care. The Parliament and the Government have deemed it important to strengthen the voluntary sector and their role in support of carers. One important part of the project, *Anhörig 300*, was to increase the co-operation between the municipalities and the existing voluntary organisations (National Board of Health and Welfare, 1999). The main voluntary organisations that were active in support for carers were identified in the evaluation report from the project. The Red Cross, the Swedish Church and Free Church communities, and pensioners' organisations were working actively with support for carers in more than 80 percent of the 290 Swedish municipalities (National Board of Health and Welfare, 2002). The same pattern was found in the evaluation in the county of Kronoberg (Albin and Siwertsson, 2002).

The situation for carers in Sweden

The Social Services Act 2001 stated that:

...the Social Welfare Board has to support, assist and relieve situations for those who care for relatives who have a long term illness, are elderly or have a functional impairment (Government Proposal, 2008/09:82).

The need for knowledge about carers and support systems for carers as manifested in the Social Services Act has increased at the same time as greater interest from society has been shown for their situation. In 1979 one of the first Swedish studies that paid attention to the importance of the role of carers for elderly people was carried out. It was a national interview study where people over 65 years of age who were living in their own homes were interviewed. The study revealed that the level of informal help from carers assessed in the number of hours of help, was three times greater than formal help (Sekretariatet för framtidsstudier, 1982). Johansson (1985) has, using national data from 1981, shown that elderly 65-84 years of age who were in greatest need of help received most of the help from carers. During the 1990s and early 2000s several research projects have focused on the carers' situation. Despite the major changes that have taken place in the Swedish welfare system during the 1990s, the main finding from these studies is that it appears that informal care is proportionately stable in terms of both size and content (SOU 2000, p. 38, Jeppsson Grassman, 2003).

Many studies show that carers have always had a major role as informal caregivers to elderly people. One example is the county of Stockholm where 39% of the population 18-84 years old regularly give help to somebody they do not live with (Jeppsson Grassman, 2003). The research also shows that there are no signs that the importance of the carers' role will diminish. It is more likely that the opposite situation will occur because of the changes in the welfare system during the 1990s (National Board of Health and Welfare, 2000).

The Swedish Government has since the late 1980s indicated that carers and support for carers are important questions for the future. By international standards the Swedish municipalities have a high level of autonomy in terms of shaping and developing services for the population in their areas. The Government's attempts to influence the development of support systems for carers and activities for carers within the municipalities have been via the

distribution of direct funding. For example, in 1988 20 million SEK was directed to develop the support for carers and in 1996 7.5 million SEK was made available in grants from the Government to be used by the municipalities. The largest research funding in this field was introduced in 1998 as a national project Anhörig 300. Three hundred million SEK, from the Government, was distributed to the municipalities and was to be used during a three-year period (1999-2001). The specified conditions were that the municipalities were to design a special plan for their support for carers of the elderly and evaluate the results (Albin and Siwertsson, 2002; National Board of Health and Welfare, 2002). The Government grants have continued and are planned to increase (Regeringens Proposition, 2006). In 2005, 25 million SEK was distributed to the municipalities; an additional 100 million SEK was distributed from the Government during 2006-2007. A total of approximately 114 million SEK has been allocated from the Government during the period. Besides this the Government allocated five million SEK per year to organisations for pensioners and relatives and five million SEK for the development of the Swedish Family Care Competence Centre (Socialdepartementet, 2008; Regeringens Proposition, 2009).

The various studies and evaluation reports indicate that the carers' situation in Sweden differs in relation to their unique circumstances. 'If you have 10 carers they will have 10 different needs' (Albin and Siwertsson, 2002, p.54). In an evaluation report of Anhörig 300 in the county of Kronoberg, based on two sets of interviews, with a one-year interval, with 47 carers, the following four typical examples for carers were identified (Albin and Siwertsson, 2002):

Carer example 1

I have to get up early in the morning and I have to give him his medicine at 7.30 am. Then it is time for food and all the other things he needs. It is difficult to measure how many hours. I get up at 7.30 am and then I work all day as a carer. It goes on to the evening when the home helpers come and help him to bed. Usually about 8-8.30 pm. It can be work 24 hours a day.

Carer example 2

She is not so old but there are certain things she can't manage. I help out when there are problems with the language, she doesn't speak Swedish and it is always me that acts as the interpreter. It is when she goes to the doctor, the dentist or shopping. I also do some practical work in the household. For example she can't manage to clean the windows. She can cook her food and take care of her self. 1-2 times a week we go shopping. On average I help her 7-8 hours a week.

Carer example 3

I help my old father now and then. He is 90 years old, has dementia and has problems understanding what's going on. I have given help now for 4-5 years but it has become more and more because he is now so old that he can't manage of his own. I don't help him so much but I do all the paperwork and I do the garden. I drive him to the doctor and the dentist and everything else that he needs.

Carer example 4

She has been sick a very long time. I remember when we were on vacation ten years ago and I noticed she couldn't walk as usual. I didn't like it when she moved to a nursing home, but I manage. I visit her every day and the children visit her sometimes. The small things I can do I will do, like cleaning the table, and helping the staff because they have a lot of things to do. Sometimes I go to the nursing home at 2.30 p.m. and go back home when they put her in bed and sometimes I go at lunch time.

Practices – public support for carers in Sweden and in Växjö municipality

The care of the elderly is a public responsibility. Very few adults live together with their parents in Sweden and there are no statutory requirements for children of elderly parents to provide care or financial support for them. Sweden thus needs a formal system of care and support for carers. Caring has traditionally been the responsibility of women (Odén 1998) but despite the fact that a large proportion (74%) of adult women work today (Statistics Sweden, 2006), it is still mostly women who have the role of being carers (Jeppsson Grassman, 2003; Regeringens Proposition, 2009).

The findings of the evaluation report of the project *Anhörig 300* by Albin and Siwertsson (2002) showed what kinds of support that had been developed in the municipalities in the county of Kronoberg 1999-2001 in order to meet the carers' needs as expressed in the interviews. The municipalities needed to know how many carers they had and in some municipalities the first stage of the project was an inventory. These findings also included important developments that had been made during the project period. One of these involved some of the municipalities who had employed carers' representatives or contact persons to co-ordinate information, meetings, carers' groups and other types of support. A system with 15-25 hours per month of social services (e.g. home help) for free was developed in most municipalities. If the carers need any sort of social services an assessment is carried out and then help can be provided free of charge.

There is no tradition in Sweden of municipalities cooperating with voluntary organisations and as part of the project efforts were made to encourage cooperation with voluntary organisations, such as the Red Cross, churches, various associations for senior citizens and those for particular illnesses such as dementia, stroke and schizophrenia. Better information and education projects were developed and realised in each of the eight municipalities in the county of Kronoberg. Examples of these were: special websites with information and support from Primary Health Care Centres, Nurses and Home Helpers, and education about health problems such as stroke, disabilities and dementia. Support that had existed to some extent earlier, for example, day care, home care, night care etc. was further developed during the project. One conclusion in the report is that it will be important in the future to focus more on the carers at an earlier stage. A system of early visiting and preventive activities should be developed and carried out on a continual basis (Albin and Siwertsson, 2002).

Due to the high level of municipal autonomy the level of support for carers can differ between municipalities. It is important to notice that most of the different types of support for carers have been developed since the 1980s (Jeppsson Grassman, 2003). Though the following examples are taken from one middle-sized Swedish municipality they would normally be found in most of the 290 municipalities in the country and reflect needs expressed by the carers in the project *Anhörig 300* (Albin and Siwertsson, 2002).

Carers in a municipality can receive the following support:

- A no cost relief service, which entails staff from the municipality replacing the carer for a certain number of hours, normally 15-25 hours per month.
- Different kinds of group activities for carers. Study groups, with the aim of giving the carers more information about legislation, illness, technical aids etc, or meetings where

carers can discuss and share their experiences. There are special group activities for persons that care for people with dementia.

- Places for short-term accommodation and care for the person receiving care (in Sweden or abroad) in order that the carer can get some time for him/herself.
- Meeting place for carers once a week providing the opportunity for the carers and old people to meet in an informal way. Today 17 meeting places exist in the municipality and in these activities the municipality co-operates with voluntary organisations.
- Day care centres for elderly people, for example for people with dementia, can be both support for the carers but also a possibility for activating the person with dementia. From 2009 there has been a new day care centre for younger people with a stroke diagnosis.
- Three-day residential courses for carers organised by the Swedish Red Cross as a complement to the study groups.
- Relief places for the relative is something that the carers can be helped with when they themselves become acutely ill and cannot provide the normal support.
- Nurses specialised in the care of dementia and a special coordinator for carers within the municipality. These persons provide support, advice and are responsible for different arrangements such as meeting points, co-operation with voluntary organisations and education for carers. A special education programme has been started for carers for persons with early stage dementia.
- A structured information system that helps the carers to find out about what support for carers the municipality can offer. Modern technology, such as websites and IT-technology, is used but also brochures and other written material. The special coordinator for carers is an important person in the information system.
- A 'home visiting service' developed by the Red Cross with a focus on carers.

During the last three years the eight municipalities in the county of Kronoberg have trained people who should act as carers' representatives. One municipality has contacted a large number of different voluntary organisations and offered training for members who in the future will have special responsibility for giving information to carers.

The examples above show the variety of support provided, but the use of the support differs between different carers. Some carers may still not know what types of support are available or they may not see the support as necessary in their situation (Jeppsson Grassman, Forssell, Jegermalm, Orsholm, & Withaker, 2003).

Case example – a carer's experiences

This example presents the personal experiences as told by one of the carers in Växjö municipality. The support satisfied his needs and he has a very positive experience of the support from the municipality. From research studies we know that not every carer has the same positive view (Forssell, 2004).

These are some of my experiences of being a carer for a relative who suffers from Alzheimer's disease:

Being an inexperienced carer for a relative one needs a lot of help of many different kinds. When I look back at my situation many thoughts pop up about how quickly one's life can change from having security, companionship, happiness and much more that one takes for granted into feeling uncertainty, loneliness, helplessness, frustration, grief, tiredness etc. The

first help is the most important, I think, the help one receives from the health services. My first contacts with the Social Care services took place even before I felt the need of any help. I listened attentively to what the local authority nurse, specialised in dementia, could tell me and received a number of information pamphlets. The positive part was that I was able to talk about my situation and listen to the good and bad things that three other carers spoke about as well as listening to the nurse's calmly presented, objective comments on our descriptions of everyday events. I felt reassured after that and I worried less about the future, I did not take in the information that at the time appeared not to be relevant for me. It was important to have that contact at such an early stage because it takes a long time to adapt to the new situation. I am very grateful that the nurse did not forget about me after this first time and kept contact by ringing a few times to ask how I was getting on with everyday life.

The processing of services was efficient without any awkward administrative procedures when I needed help with relief services, short-term placements, daytime activities and finally a residential home from 2003-2005. This shows that the municipality's administration and home care services are integrated services in Växjö. In the periods that my wife was utilising the short-term placements 2002-2005, I had daily contact with the staff. They catered for my needs of help in a positive way and were willing and helpful even when unforeseen things happened. The relief service (12-15 hours per month) that we received free of charge between 2003 and 2005 was very useful. There were many young members of staff who came to our house to be with my wife while I was away and when I returned home it was most often a happy spouse who spoke positively about the relief staff.

The daytime activities at the day centre that my wife visited between 2003 and 2005 was the service I felt was the most positive. There was a happy and healthy atmosphere there that was communicated to both the guests and the carers. My wife was always happy when I was taking her there and more often than not even happier when I picked her up after a pleasant day with a varied programme of suitably taxing activities.

In the gentleman's club of male carers who had their wives at the day centre there was a sense of kinship. The municipality arranged these meetings and we appreciated them a lot. I felt that we developed our skills as carers together and gained greater knowledge of ourselves. Despite the change in care situation for my family I still take part in the group meetings.

When my wife moved to the residential home in the autumn of 2005 it was a major change in our joint lives. I usually visit her every other day at lunch time to help her and so that we can meet. I feel that there is a happy atmosphere at the residential home that is passed on to the residents. The staff are enthusiastic and take good care of temporary staff, trainees and students. My experience is that the staff are gentle, caring and show empathy in their approach to the residents.

I have participated in three courses that the municipality of Växjö and the Red Cross have arranged. These residential courses with overnight stays some distance away were important for me as I received a lot of essential information there. It is a pity that many carers hesitate to take courses themselves. The mental strain of caring for a relative makes one 'disordered' that one does not have the energy to plan ahead. It is difficult to take in information about problems that will have to be faced in the future. The information feels important when one is faced with the problem. The many discussions about our common problems were worth a lot to me. It can appear to be a waste of money to allow a number of carers to be away for almost a working week and allowing the municipality to pay for the care for our relatives in the meantime, but it is really worth it. Before we are able to actually absorb the information we must be able to switch off our thoughts about the daily care at home. It takes about a day for me to feel relaxed enough to be able to long for learning something new that I can have use for in the future. Another useful aspect is that we get to know important people in the municipal

Social Care services, the Red Cross and the Relative's Association. New friendships are created that can give strength and perhaps happiness in the difficult work ahead. Just the thought that one is not alone can be a comfort.

In conclusion I would like to say that the Social Care services for the elderly in the municipality of Växjö are of a very high standard after having seen different aspects of them during a five-year period.

Challenges and realities

In March 2006 the Swedish Government presented a National Development Plan for the nursing and care of the elderly for the next 10-year period (Regeringens Proposition, 2006). The plan emphasises some areas such as better nursing and care for the elderly with the greatest needs, safe living conditions, social care, equal levels of service provision for the elderly throughout the country, preventive work and issues related to staff development. Increased support for carers in the future was suggested by the Government as a part of the National Development Plan. Carers are still seen as supplementing the public sector elderly care services. New Government funding for voluntary organisations and funding for more long-term activities as a part of everyday work instead of short-term projects are examples of areas of future support. Furthermore the National Board of Health and Welfare received an assignment to develop a plan to create a centre for research and development concerning carers. Furthermore Statistics Sweden is to collect data on a national basis concerning the amount of care produced by carers in terms of sex, foreign-born persons and minorities (Regeringens Proposition, 2006). During 2006 and 2007 the Government allocated 10 million SEK for the development of the Swedish Family Care Competence Centre which started in 2008. The aims for the centre are to contribute to a long-term capacity building in issues related to carers' situations and carers' support. The centre should also contribute to higher quality and productivity in the care of elderly persons throughout Sweden (Nationellt Kompetenscentrum Anhöriga, 2009).

According to the National Development Plan voluntary organisations are actors with a great potential for supporting carers and elderly people, in particular if they focus on areas and needs that are not catered for by the public sector. The role of voluntary organisations is seen as working to alleviate isolation and loneliness among the elderly and to create social networks and personal relations (Regeringens Proposition, 2006).

Plans are also developed for the future support on the local level in the different municipalities, The municipalities in the county of Kronoberg consider the following areas as being important for the future:

- Evaluating the current support, especially concerning day care and a relief service support free of charge,
- Developing activities aimed at getting contact with more carers such as visiting activities together with voluntary organisations, organisations for migrants and minority groups,
- Developing different types of information together with the voluntary organisations increasing accessibility of the support in particular in rural areas,
- Creating greater opportunities for carers to meet both in terms of places to meet and the frequency of the meetings,

-
- Developing educational programmes for persons supporting carers and seminars for the carers.

Authors' contact details

Christina Siwertsson, School of Health Sciences and Social Work, Linnaeus University, Georg Lückligs väg 8, S-351 95 Växjö, Sweden. E-mail: christina.siwertsson@lnu.se

Björn Albin School of Health Sciences and Social Work, Linnaeus University, Georg Lückligs väg 8, S-351 95 Växjö, Sweden. E-mail: bjorn.albin@lnu.se

Jan-Olof Svensson, Växjö kommun, Box 1222, 351 12 Växjö, Sweden. E-mail: jan-olof.svensson@kommun.vaxjo.se

References

- Albin, B., & Siwertsson, C. (2002). *Anhörig 300' – utvärdering av närståendestöd i Kronobergs län 1999 – 2001*. FOU – Kronoberg. Rapport 2002, p. 2.
- Eliasson-Lappalainen, R.-M., & Szebehely, M. (1998). Omsorgskvalitet i svensk hemtjänst – hotad eller säkrad av att mätas? In Eliasson-Lappalainen, R.-M., Szebehely, M. (Eds.), *Vad förgår och vad består?* Lund: Arkiv.
- Forssell, E. (2004). *Skyddandets förnuft. En studie om anhöriga till hjälpbehövande äldre som invandrat sent i livet*. Stockholm: Stockholms universitet. Akademitryck AB.
- Jegermalm, M. (2005). *Carers in the welfare state – On informal care and support for carers in Sweden*. (diss.) Stockholm University, Department of Social Work. Edsbruk: Akademitryck AB.
- Jeppsson Grassman, E. (2003). En bok om anhörigskap. In Jeppsson Grassman, E. (Eds.), *Anhörigskapets uttrycksformer*. Lund: Studentlitteratur.
- Jeppsson Grassman, E., Forssell, E., Jegermalm, M., Orsholm, I., & Withaker, A. (2003). Anhörigskap. In Jeppsson Grassman, E. (Eds.), *Anhörigskapets uttrycksformer*. Lund: Studentlitteratur.
- Johansson, L. (1985). *Informell kontra offentlig äldreomsorg. Några data från ULF-studien 1980/81*. Göteborg: Nordiska Hälsovårdshögskolan, Hälsa för äldre i Norden år 2000, Rapport NHV 1985:1.
- Ministry of Health and Social Affairs. *Social Services Act SFS (2001:453)*. <http://www.sweden.gov.se/content/1/c6/04/34/02/9d488738.pdf>. 2009 11 12, kl 11.00.
- National Board of Health and Welfare. (1993). *Health care and social services in seven European countries*. Stockholm: Modin-Tryck.
- National Board of Health and Welfare. (1999). 'Anhörig 300'. *300 miljoner för utveckling och stöd till anhöriga*. Socialstyrelsens meddelandeblad. Nr 2.
- National Board of Health and Welfare. (2000:4). *Äldreuppdraget slutrapport*. Stockholm: Socialstyrelsen.
- National Board of Health and Welfare. (2002). *Anhörig 300 – Slutrapport*. Stockholm: Kopie Center.
- National Board of Health and Welfare. (2005). *Sweden's Public Health Report*. (In Swedish.) Stockholm: Socialstyrelsen.
- Nationellt Kompetenscentrum Anhöriga 2009. *Homepage*. [http://www.anhoriga.se/sv/Om-oss/Mal/2009 11 18 kl. 12.48](http://www.anhoriga.se/sv/Om-oss/Mal/2009%2011%2018%20kl.%2012.48).
- Norström, C., & Thunved, A. (2001). *Nya sociallagarna*. Stockholm: Nordstedt juridik AB.
- Odén, B. (1988). The role of the family and state in old-age support: The Swedish experience up to 1913. *Comp Gerontol C*; 2: pp. 46-42.
- Odén, B. (1996). *Rätten till en god ålderdom i ett rättshistoriskt perspektiv*. Aldring og Eldre; 4.
- Odén, B. (1998). Omsorgsetik och kvinnosyn. In: Eliasson-Lappalainen R, Szebehely M, (Eds.). *Vad förgår och vad består?* (pp. 31-46). Lund: Arkiv.
- Odén, B. (2000). Rätten till en god ålderdom. In Andersson, L., Jansdotter, A., Persson, B., Tornbjør, C. Rätten. *En festskrift till Bengt Ankarloo* (pp. 82-100). Lund: Nordic Academic Press.
- Odén, B., Svanborg, A., & Tornstam, L. (1993). *Att åldras i Sverige*. Stockholm: Natur och kultur.
- Regeringens Proposition. (2006). *Nationell utvecklingsplan för vård och omsorg om äldre*. 2005/06:115 <http://www.regeringen.se/content/1/c6/06/06/65/ce333b06.pdf>.
- Regeringens Proposition. (2009). *Stöd till personer som vårdar eller stödjer närstående*. 2008/09:82. <http://www.regeringen.se/content/1/c6/12/15/24/af30ba9e.pdf>.
- Regeringskansliet. (2009). *The Ministry of Health and Social Affairs*. [http://www.sweden.gov.se/sb/d/12073/a/129494 2009 11 18, kl 10.45](http://www.sweden.gov.se/sb/d/12073/a/1294942009%2011%2018%20kl%2010.45).
- Sekretariatet för framtidsstudier. (1982). *Tid för omsorg. Slutrapport från projektet Omsorgen i sanhället*. Stockholm: Liber.
- Socialdepartementet. (2008). *Stöd till anhöriga som vårdar och stödjer närstående*. Ds 2008:18). Stockholm: Fritzes.
- SOU (2000:38). *Välfärd, vård och omsorg. Antologi från kommittén välfärdsbokslut*. Stockholm: Fritzes.
- Statistics Sweden. (2006). *Andel förvärosarbetande 1980-2003*. http://www.scb.se/templates/tableOrChart___106405.asp 20060915 kl 13.50.

-
- Statistics Sweden. (2008). *Statistisk årsbok för Sverige*. Stockholm: Statistiska Centralbyrån.
- Sundström, G., & Johansson, L. (2005). The changing balance of government and family in care for the elderly in Sweden and other European countries. *Australasian Journal on Ageing*, 24, 5-11.
- Sundström, G., Malmberg, B., & Johansson, L. (2006). Balancing family and state care: Neither, either or both? The case of Sweden. *Ageing and Society* 26, 767-782.
- Sweden's County Administrations. *What is the County Administration Board?* <http://www.lst.se/lst/en/> 2009 11 18, kl 10.50.
- Szebehely, M. (2005). Anhörigas betalda och obetalda äldreomsorgsinsatser. In SOU 2005:66. *Forskarrapporter till jämställdhetspolitiska utredningen*. Stockholm. Fritzes.
-