

Summary

Support for carers (RiR 2014:9)



Support for carers

The Swedish National Audit Office has examined whether the government has created the conditions for support to carers that meets their needs.

Audit background

At some point in our lives, most of us provide care or assistance to someone in our family who has suffered from illness, a disability, or who may need help due to old age. We then become carers. There can be as many as 1.3 million families in Sweden who provide care. Most family members provide care of their own free will and are in good health. However, studies reveal that the health, finances, work situation and leisure opportunities for family members may be adversely affected by providing care. Usually these carers live together with the person they provide care for, a husband/wife/partner, child or a sibling, and the care they provide is substantial.

As a carer, providing care should be a voluntary commitment and act as a complement to existing formal services. However, according to the government, in practice formal services are a supplement to the care carried out by family members. A good support for carers is important in order to avoid negative consequences related to informal caregiving both for individuals and for society as a whole.

The aim has been to examine whether the government has created the conditions for support to carers that meets their needs. The government has mainly chosen to meet carers' needs for support by amending the Social Services Act, 1998 and 2009, with the aim of clarifying the municipalities' responsibility to support carers. Following the amendment in the law in 2009, municipalities must offer support to carers. In the bills prior to the amendments of the Social Services Act, the government made it clear that the support should be characterised by individualisation, flexibility and quality.

The audit is based mainly on interviews with carers, carer and patient non-profit organisations, researchers and representatives of authorities and the Swedish Family Care Competence Centre (SFCCC) (Nationellt kompetenscentrum anhöriga). The interviews were supplemented with research results and quantitative studies.

Audit results

The Swedish National Audit Office's general conclusion is that the government has not created good conditions for support to carers that meets their needs. The audit highlights that carers' needs



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for support are often a question of their family member/significant other receiving good health and social care, but it is also about an individualised and flexible support for themselves as carers.

The municipalities' carer support needs to be developed

One of the opportunities for individualised support emphasised by the government in 2009 was that carers should apply for aid/assistance for themselves. During the audit, it emerged that this is rare and that the extent to which this occurs is difficult to follow up due to a lack of documentation. The audit also indicated that inadequacies in the quality and flexibility of carer support leads to carers choosing not to take advantage of the support offered.

According to the National Board of Health and Welfare Sweden's surveys, there are major differences within and between municipalities with regards to the support offered to carers and how carer support is governed. The support in the majority of municipalities is most developed within care for older people based on situations where older spouses provide care to one another. According to the Swedish National Audit Office, this means that older spouses are offered support that meets their needs to a greater extent than for example, working carers, carers of disabled people or people with mental ill-health. Since 2009, municipalities have also started to form other support services based on the needs of other carer groups.

Municipalities have also organised, controlled and financed carer support differently. In most municipalities, however, carer support has mostly been conducted in project form, operating beside the ordinary line organisation. It is also unusual to find regulatory documents that contain procedures with a carer perspective.

The Swedish National Audit Office considers that the municipalities' carer support needs to be developed to fulfil the intentions of an individualised, flexible, and quality support. According to the Audit Office, the support offered so far has not been sufficiently adapted to carers' shifting needs and the differences indicate that the municipalities, have chosen to prioritise carer support to a varying extent.

The government should provide better conditions for municipal carer support

The municipalities have received a great deal of scope to decide which carer support they should offer as the liability of the municipalities has been regulated with a legislative provision in the Social Services Act. In the preliminary work, the government clarified that the support should be characterised by individualisation, flexibility and quality. Since the municipalities have chosen primarily to offer carer support as a municipal service, there are limited opportunities for the courts to clarify what support the municipalities must offer through guiding legal cases.

The government has commissioned the National Board of Health and Welfare Sweden to guide municipalities in the implementation of the provisions in the change in law and has established a national competence centre (SFCCC) in order to improve the state of knowledge in the area. Despite these measures, the intentions of municipal carer support have yet to be realised and the



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support carers are offered differs within and between municipalities. Consequently, the Swedish National Audit Office believes that further guidance to municipalities is probably not sufficient to ensure carer support that meets these intentions.

The Swedish National Audit Office considers that the State has not created sufficiently good conditions for a municipal carer support that meets these intentions. The Swedish National Audit Office therefore recommends that the government considers whether chapter 5 §10 of the Social Services Act needs clarification.

The government's instruments of control can be used in a better way

Since 1999, the State has invested a total of about 2 billion Swedish Crowns on developing carer support in the municipalities. The Swedish National Audit Office's review reveals that it is partly unclear which results have been obtained through State initiatives regarding municipal carer support. One obstacle with respect to knowledge about the initiatives is the lack of national statistics relating to what support the municipalities offer carers and that carers make use of. This is explained by the lack of documentation of carer support.

Neither the National Board of Health and Welfare Sweden nor the Health and Social Care Inspectorate have so far conducted a targeted inspection of the municipalities' obligation to offer carer support. The Swedish National Audit Office believes that inspection within the current circumstances is not an appropriate control instrument in order to address the problems in the municipalities' carer support.

The Swedish National Audit Office recommends that if the government wishes to enable follow up, increased knowledge and inspection of carer support in the municipalities, the government should consider how carer support that is given as a service and as aid/assistance shall be documented by the municipalities.

More knowledge is needed about informal care

Today there are no comparable studies about the development of informal care over time. The surveys that do exist have been carried out by different actors and with different questions and samples. Thus, the results are difficult to compare. Furthermore, there are no surveys of the extent of minors' provision of care to family members/significant others. All-in-all, this means that there is also a lack of data to assess the socio-economic implications and costs of informal care on an individual and societal level.

The Swedish National Audit Office recommends that the government commissions an authority to monitor the extent of informal care and the consequences for individuals and society over time. One step should be to conduct a socio-economic analysis of the consequences of informal care for individuals and society. The equality aspects are particularly noteworthy in such an analysis.



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It should be easier to combine paid work and care

Working carers are largely dependent on their employer's generosity in order to remain in the labour market. This is because the benefits that exist, carer's allowance and statutory leave for family (informal) care and pressing family reasons, only covers part of the carers' needs and is only used to a small extent. Working carers in many cases have to be self-reliant and be able to control their working hours themselves and take time off at short notice. A number of carers also take out holiday leave and use flexitime in order to care for their family members/significant others.

The Swedish National Audit Office recommends that the government considers whether parts of the social security system and labour laws should be adapted to carers' needs to make it easier for carers to combine paid work and care.

The best carer support is good health and social care services

The Swedish National Audit Office considers that quality enhancing measures in health and social care would be the most effective option to make things better for carers. In interviews it has emerged that the best carer support is good health and social care for their family member/significant other. It is a question of social care services such as sheltered (special) housing and home help services, health care services such as treatment and hospital beds, but also staff with the right education and expertise. The Swedish National Audit Office has not audited health and social care for the family member per se, but has chosen to report how important the health and social care of the family member is for the carers' situation and support needs.

It should be optional to provide informal care in Sweden. The Swedish National Audit Office believes that a pre-requisite for informal care being optional is that there is an alternative to carers' informal care provision in the form of good public health and social care services. The Swedish National Audit Office's assessment based on interviews during the audit is that many carers take on more responsibility than they actually want to due to shortcomings in existing health and social care services. Many carers feel that one of the heaviest burdens they have to bear is the co-ordinating role they often have to take on board. If the carer does not take on the role of co-ordinator a great deal would fall through the cracks. The Swedish National Audit Office believes that this is a difficult problem to solve that is linked to the commissioning and organisation of existing health and social care services.

In the interviews carried out by the Swedish National Audit Office it emerged that the carer's need to be recognised and receive information and knowledge is rarely met in contacts with health and social care services. In addition, the interviews conveyed that care planning was a situation where many carers felt invisible. The Swedish National Audit Office recommends that the government should ensure that education is provided to disseminate information to municipal and county council employees about the significance of carers for the health and social care sector and how



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health and social care practitioners can support carers via for instance, information and a caring approach.

The carers whom the Swedish National Audit Office interviewed felt that they have had to fight to get the services that their family member/significant other requires from the municipalities and that they are at a disadvantage in relation to the municipalities when it comes to knowledge about which service/s their family member is entitled to. Carers also describe that it is difficult, time consuming and stressful to appeal decisions. The Swedish National Audit Office recommends that the government commissions the National Board of Health and Welfare Sweden to inform citizens about their rights to support and services in the Social Services Act and the Law regulating Special Support and Service to persons with certain functional disabilities and what the situation looks like in practice, if the government wants to make it easier for carers.

According to the Swedish Family Care Competence Centre, Carers Sweden and the National Board of Health and Welfare Sweden, county councils currently lack a structured approach with regards to the provision of support to adult carers. The Health and Medical Services Act is only a general public health preventive mission and a mission to provide support to minors in some situations.

The Swedish National Audit Office recommends that the government considers whether the responsibility of county councils to support carers needs to be clarified in the Health and Medical Services Act.

