Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage

EUROFAMCARE

National Background Report for Sweden

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

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Main Findings

- Due to improved general living conditions, Sweden has a greying population. In 2003, out of a total population of almost 9 million inhabitants, 17.2 per cent was aged 65 years or older and 5.2 per cent has reached the age 80 years or older. In spite of the fact that ever greater numbers of elderly people live to an advanced age – or rather due to this fact – many suffer illness, handicap and become dependent on help from other people for their daily existence.
- Increased longevity also implies that an increasing number of old persons are living alone. The present socio-demographic situation among older people and their families is characterised by the vast majority of older persons living on their own. Among elderly 80 years and older, two thirds are living alone, i.e. very few cohabit with children or others.
- Care of the elderly in Sweden is a public responsibility, and in return for taxes, people are provided with a broad spectrum of welfare benefits that guarantee a minimum standard of living, service and care and redistribute income more evenly over lifetime and individuals. Public policies and programs providing health and social services are comprehensive.
- In Sweden, care of the elderly is divided between three levels of government. At the national level, the 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 are responsible for the provision of health and medical care. Finally, at the local level, the municipalities are legally obliged to meet the social service and housing needs of the elderly. Both the county councils and the municipalities have a very high degree of autonomy vis-à-vis the central government.
- Sweden has an extensive system for public service and care provision in elderly care. The most important services for making it possible for elderly to go on living in there old home are home help services. It contains help with daily activities, e.g. shopping, cooking, cleaning and laundry. It also includes personal care such as help with bathing, to go to the toilet, getting dressed and in and out of bed. Besides home help, there is also a comprehensive range of municipal services for the elderly, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, handicap aids, etc.
- The single individual could claim services but he / she has no automatic right or entitlement to services. If the elderly requesting services is dissatisfied with the care manager's decision, the case can be appeal in the administrative court. Data from nation wide studies, show that the number of appeals were residual. However, although the number of

appeals is very low, the right to appeal is considered as an important individual protection.

- For decades, the role of the family in care of the elderly has virtually been a non-issue Sweden. In fact, one of the cornerstones in the post-war welfare system has been that former family responsibilities should be taken over by the state. Then, in pace with the economic growth, the state should gradually extend and secure service and care, for children, disabled and elderly. And consequently, there are no statutory responsibilities for children to care (or to provide economic security) for their family members.
- In the 1990-ties the family was “re-discovered” in elder care. The major experiences in promoting home-based community care were that home care was often dependent on extensive family caregiving. Due to the economic recession, the interest in the informal care sector and its potential to substitute costly formal service provision has increased. Increasing research evidences also point to the crucial role of families, their care burdens and their need for support. Then, new data from national representative studies confirm the well-know fact, that in Sweden as in many other countries, the families and the next of kin are the major providers of service and care for the elderly.
- There are three layers of supportive services for the elderly and their families in Sweden. The first layer of service and care - home help - is targeting the person cared for. On top of services offered the person cared for – which of course also function as an indirect support for the carer – there is a second layer of support targeting directly the carer.The third layer, represent the increasing amount of help input provided by voluntary workers. It’s a fact that public support for carers is now more and more often intertwined with – and dependent of – voluntary efforts and the work of voluntary organisations.
- A three-year Action Plan (1999-2001) provided funding for local governments to develop an infrastructure of services targeting family carers. Municipalities were stimulated to expand services for carers e.g. by setting up caregiver resource centres that offer training, counselling, support groups, respite care and other programs. As a result, the number of support programs available has steadily increased. For example, respite services is now available in virtually all municipalities. There is also a substantial growth in counselling and personal support services provided in and by the municipalities.
- Local authorities have responded rapidly, in expanding their supportive services for carers. However, recent research and evaluation of current development show several shortcomings. The major problem is that we don’t have any data on the quality of the programs, neither we know how many carers they serve. Then, issues of targeting and quality of support for carers need to be addressed.

- In 2002, the Parliamentary Standing Committee on Health and Welfare commissioned the Government to analyse the economic consequences of a new legislation on carers´ right to service and support. A Governmental proposal is expected to be presented in 2004.
- The financing and provision of service and care to future cohorts of elderly is an increasing social-policy issue in a taxed-based system as in Sweden. The debate is focused on whether the public responsibility should be defined more narrow or not and / or whether a greater share of the costs for service and care should be shifted over to the individual user.
- There are two major and decisive future challenges; First, safeguarding basic standard and access to public services and care for the elderly. Second, the extend the formal services is able to respond to the needs and demands of the carers.

Introduction – An Overview on Family Care

The Swedish population is greying and in 2003, out of a total population of 8,9 million inhabitants, 17.2 per cent was aged 65 years or older and 5.2 per cent has reached the age 80 years or older. In spite of the fact that ever greater numbers of elderly people live to an advanced age - or rather due to this fact - many suffer illness, handicap and become dependent on help from other people for their daily existence. In return for taxes, people are provided with a broad spectrum of welfare benefits that guarantee a minimum standard of living, service and care and redistribute income more evenly over lifetime and between individuals. Therefore, in general, nobody has had to forgo service and care, due to economic reasons.

The aims for the care of the elderly in Sweden has since decades been to guarantee a secure financial situation, good housing, and service and care according to needs. Public help shall give care recipients freedom of choice and influence and maintain high standards. All the elderly shall have equal access to these welfare "products" regardless of age, sex, ethnicity, place of residence, and purchasing power.

According to the Social Services Act (1982) elderly has the right to receive public service and help at all stages of life. Anyone who needs help to support himself in his day-to-day existence has the right to claim assistance if his 'needs can not be met in any other way'. In 1983, the Health and Medical Services Act came into effect. According to this Act, health care and medical services aim to maintain a good standard of health among the entire population and to provide care on equal terms for all.

In Sweden, the responsibility for the elderly welfare is divided between three principals or levels of government. At the national level, the 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 (21 in all) are responsible for the provision of health and medical care. Finally, at the local level, the (290) municipalities are legally obliged to meet the social service and housing needs of the elderly. Both the county councils and the municipalities have a very high degree of autonomy vis-à-vis the central government. Both have elected assemblies and have the rights to levy taxes. The county councils and municipalities may, within the limits prescribed by the existing legislation, decide the degree of priority they will give the elderly over other groups.

Care of the elderly in Sweden is a public responsibility, and consequently, there are no statutory requirements for children to provide care for (or economic support to) their elderly. Public policies and programs providing health and social services, as well as pensions and other forms of social insurance, are comprehensive. The high percentage of women in the labour market (76 % in 2003) presupposes a formal system of care for the elderly, as well as the

fact that few children (about 2-3 %) cohabit with their elderly. However, Andersson and Sundström (1996) referring to comparative data from the Eurobarometer, conclude that in spite of the large proportion of elderly living alone the elderly in Sweden come out near the top in all network-relevant measures in the 13 country comparison.

In 2003, some 11 per cent of the total provision of elderly services was contracted out to private (for-profit) providers, mainly in the metropolitan areas.(National Board of Health and Welfare, 2003). It should be pointed out that the services provided by private providers are decided on and financed by the municipality. So private in this sense does not mean out-of pocket paid services. So far, and due to the fact that there exist affordable and available services and care for the elderly, there is no market for insurance based elderly care in Sweden.

Unlike in many other countries, voluntary organisations do not in generally take on the role as service and care providers in Sweden. Yet, recent studies show that many Swedes are involved in voluntary work, including helping elderly, to an extent that is comparable many other European countries (Lundström and Svedberg, 2003).

While the formal service system has been an important component of policy designed to help the elderly manage at home, there has been increasing awareness that most families provide some informal care and many older persons prefer informal care. Several studies have during the 1990-ties reaffirmed what is well known from other countries, that informal care plays a dominant role in care of the elderly. It is conclusive, that in many cases elderly care could not function without the help provided by the informal care system.

So far there is no evidence that the development of an extensive formal care system, as in Sweden, will impose a decrease in informal care giving (Johansson, 1991; Sundström, 1994; Herlitz, 1997; Johansson, 2000). Data from two national representative studies among elderly living at home, once again confirm that informal carers provide an increasing amount of necessary care for the elderly (Sundström et al., 2002; Johansson et al., 2003; Dahlberg, 2004).

The family has been "re-discovered" in elder care in Sweden. This "awakening" was reflected in a growing awareness that support for carers is a necessary precondition to mobilise the carers in the future, which in turn is of crucial importance for the whole system of elderly welfare. In 1998, a milestone was passed when a new paragraph was enacted in the Social Service Act, which stated, that "the local authorities should support families and next of kin, when caring for elderly, sick and dependent family members". The law, if not obligatory, carry a strong message to the municipalities to expand carers support.

Then, in 1999, the National Action Plan on Policy for the Elderly came into power, in which one of the major initiatives was a national grant to stimulate caregiver support, the so-called "Carer 300 project". From 1999 to the year

2001, a total of 300 MSEK (i.e. some 33 million Euro) was disseminated to the local authorities, in order to stimulate further development of supportive services. The outcome of the Carer-300 project has been systematically followed and evaluated, and the progress and setbacks was summarised in the final report as follows:

First the progress – obviously, the carers, their situation and needs for support has been recognised and highlighted. The "carers' issue" has been skyrocketing on the public agenda.

Second, the number and the scope of support programs available have increased impressively all over the country. For example, respite services is now available in virtually all of Sweden's 290 municipalities and especially in-home respite has expanded rapidly recent years. It is interesting to note that there has been a substantial growth in counselling and personal support services provided by the municipalities. Regarding the setbacks and shortcomings it obvious that there is very much work to be done to improve targeting and quality of the support offered the carers.

Looking ahead, the financing and provision of service and care to elderly in the future is an increasing social-policy issue in a taxed-based system as in Sweden. The debate is focused on whether the public responsibility should be defined more narrow or not and / or whether a greater share of the costs for service and care should be shifted over to the individual user. This "mega-problem" has also strong connections to the problem of recruiting and retaining care personnel and retaining Swedes in the workforce altogether.

Regarding cares, there are two major and decisive challenges for the future. The first issue relates to the problems of safeguarding the "first layer" in our system, that is the level of and access to public services and care in Sweden. The second has to do with whether the formal services are able to respond to the needs and demands of the carers. Taken together, this question the legitimacy of the system of welfare for older people in our country. And surely, there is a growing " carers' movement" that will stress national and local governments to provide easy accessible, flexible, tailor-made support.

In this perspective, to integrate caregivers support as a central aspect in the care management of formal services is a pivotal issue for the future. If relatives choose to take on the kind of major responsibility which the formal system could otherwise be obliged to assume, then those relatives must be able to feel that society actually supports their action, not only in official policy rhetoric, but also in practical terms. The challenge for future then, is to find a balance in optimising family and public resources, in a partnership of care.

1 Profile of family carers of older people

1.1 Number of carers

In Sweden, there are no data on carers, that is collected in a national representative and systematic way. Instead, we have to rely on other sources, which could give some indications on the national profile of carers. One example is the ULF-study (short for Level of Living among Swedes), that was carried out in year 2002 and which gives some indications of the volume care giving in Sweden for older persons living in the community. Data available show, among other things, the number of persons needing help with IADL and PADL, and whether help is provided by the family, the public home help or by a combination of family and public service provision.

Among those elderly living at home (65+) and needing *daily* help with service (IADL) and / or personal care (PADL), some 157 000 persons received help with daily activities (IADL) and some 28 000 received personal care (PADL) from the family solely. There are of course overlaps among these groups. Altogether then, some 13 per cent of those elderly living at home (and not institutions) that needs daily help, are helped by their families and next of kin.

As mentioned, there is shortage of data, with some exceptions. In 1994 and repeated in the year 2000, the National Board of Health and Welfare initiated a survey of elderly 75+ living in their own homes. These are representative, in-person interviews (N = 1,379 and N = 1,466 respectively). Subjects are weighted, as men and the oldest segments were over-sampled (no upper age-limit). The surveys, that covered a wide range of issues are in all important respects similar in design and using the same items. The data presented below give some further indications of family caregiving in Sweden.

Table 1: Sources of care for Swedish elderly, residing in the community, by household structure, 1994 and 2000, aged 75+ (%)

	All		Live alone		Co-resident	
	1994	2000	1994	2000	1994	2000
Family / informal care only	59	66	33	47	85	88
Informal care & Home Help	13	16	17	24	9	7
Home Help services only	28	18	51	28	5	5
Sum	100	100	100	100	100	100
N	538	642	266	338	275	303

Source: Sundström et al. 2001

In the 1994 and 2000 surveys, needs for help were assessed with ten ADL-items (see Note to Table 2). For each need, it was established who was providing help. The helper's gender and relationship to the interviewee was regis-

tered and it was established whether home help was provided with these tasks. The total number of hours of public home help was also determined.

Clearly, a growing fraction of the elderly relies on informal care only and a shrinking fraction depends on public help, be it alone or in combination with informal care. Among co-resident elders little shift has taken place in care patterns: now as before, most find their carer in their own household. This is usually the spouse, and there are in absolute numbers about as many men caring for a wife as women caring for a husband.

The surveys undertaken in 1994 and 2000 can also help us assess the volume of hours provided to elders by various sources of care. To this end, needs for help with various ADL-tasks were converted for all interviewees into a straightforward index, where a higher value indicates that the person managed more ADL-functions on his / her own.

It was assumed that elders who needed help but used no home help received at least as many hours of help from informal carers at their respective ADL-level, as they would have received in home help at that level, had they used this public service. This will not inflate informal care and will give a conservative estimate of decline in public services, if anything (very few persons reported needs that were not provided for). Subjects who both used home help and received informal care are assumed to have used the same number of hours of both kinds. Calculations are based on the actual hours of home help reported.

Under these assumptions, it emerges that public home help provided 40 percent of the total amount of help hours in 1994 and 30 percent in year 2000. One can also use these survey-data to estimate the annual amount of help for all elders in the population and convert the weekly figures to annual ones, the Swedish municipalities in 1994 'produced' 36 million home help hours for the 75+. In the same way, 28 million home help hours were provided in year 2000. Likewise, under these assumptions, informal carers raised their 'output' from 50 million hours in 1994 to 61 million hours in year 2000.

As mentioned earliar, many elderly are living alone and cannot rely on their spouse when needing help. In table 2, help provided to the elderly by children is presented from the surveys.

Table 2: Care for elderly people 75+ who live alone, help from children and home help, 1994 and 2000 (%)

Help from	All		Has off-spring		Off-spring within 15 km		Childless	
	1994	2000	1994	2000	1994	2000	1994	2000
Children	12	22	16	28	16	33	-	-
Home help	25	20	24	18	23	19	27	29
N (weighted)	716	843	547	670	371	414	170	173

Sources: Johansson et al. 2003.

Note: Home Help is a needs-assessed public service that in Sweden provides help with *household tasks* (primarily shopping, cooking, cleaning and laundry) and / or with *personal care* (getting into / out-of bed, bath, toileting, eating, un / dressing, outdoor walks etc.). The average client uses 32 hrs / month, with large variations. There is no upper limit to the number of hours, but very few (1% of all users) use more than 200 hrs / month.

Finally, regarding the gender of the carer, data from the two surveys, is shown in the next table below.

Table 3: Gender of informal carer for elders who live alone and need help with one or more ADL-functions, 1994 and 2000 (%)

Help given by	1994	2000
Female family	29	39
Male family	15	24
Daughter(s)	22	33
Son(s)	12	13

Sources: a. a.

In conclusion; it emerges that increased input from families match declining public services, that is, a 'reversed' substitution process took place. Most of the expanding informal care for elders was provided by daughters, but sons also help. A problematic aspect of these shifting patterns of care are the many family carers that now stand alone with their increasingly heavy commitments, whereas carers in the recent past could expect that their responsibilities were at least to some degree shared with the state.

1.2 Age of carers

As mentioned before, data on carers of older persons are scarce. What was presented in the last section covers very much available, national representative data. Of course, there is a general knowledge about, e.g. spouses being major carers among the young-old and that care of the old-old is provided by a daughter or daughter in-law living nearby.

However, data such as level of education, income, employment among carers is not known. We presume that there are few carers that actually have stepped-out from the work force, to take care of an older family member. There is an possibility to be employed as a carer by the municipality, but this is a rare solution. Among families with older immigrants, this opportunity is used more frequently.

1.3 Gender of carers

No available information.

1.4 Income of carers

No available information.

1.5 Hours of caring and caring tasks, caring for more than one person

No available information.

1.6 Level of education and / or Profession / Employment of family carer

No available information.

1.7 Generation of carer, Relationship of carer to OP

No available information.

1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc.)

No available information.

1.9 Working and caring

Again, there are no data available, but this is an issue that is now gradually entering the public discourse. Especially carers of persons with an early onset Alzheimer's disease have voiced the opinion on the need for measures to be able to stay in work, even if they also have a caring responsibility.

1.10 General employment rates by age

Table 4: Labour force participation in Sweden 2003, by age and gender (%)

Age	Men	Women	All
20–24	69.0	62.6	65.9
25–34	88.0	81.6	84.8
35–44	90.9	86.7	88.9
45–54	89.3	86.6	88.0
55–59	83.0	79.2	81.0
60–64	64.0	56.1	60.0

Source: Statistics Sweden, 2004

1.11 Positive and negative aspects of caregiving

As there is no systematic identification or targeting of carers in the public services, with still don't have necessary knowledge of the carers situation. However, local studies show that carers in general, find caring rewarding. At the same time they also point to problems such as psychological stress, social isolation and health problems. Both among spouses and nearby living children (daughters), caring is creating mixed feelings and tension, which over time could lead to a burn-out situation.

In pace with caring for older people and the carers' issue is entering the public discourse, more and more evidences for the burdens of caring is brought forwards.

Elder abuse is a reality in Sweden, as in many other countries. Our knowledge is vague and scarce and more research is needed (Saveman, 1994). Of course, there is a risk for abuse within the family, especially if quality of the relation between the carer and the cared is poor and if the caring situation is a „forced choice" for both parties. The risk for abuse is also increasing given the fact that many municipalities are forced to recruit care personnel, lacking necessary training and skills.

1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand

No available data.

1.13 Other relevant data or information

No available data.

2 Care policies for family carers and the older person needing care

The Social Service Act (Socialtjänstlagen) is a framework law that emphasises the right of everybody to receive social services. Anyone who needs help to support himself in his daily living has the right to claim assistance if his needs "cannot be met in any other way". The services provided by the municipal social services are based on an assessment of the individual's housing, services and care needs. The assessment is carried out by a case manager employed by the municipality. If the individual is not satisfied with the decision, he / she can appeal against it in the administrative court.

According to the Health and Medical Services Act, health and care shall be available to all members of society to ensure a high standard of health and care for everybody on equal terms.

Compared with most other countries, the Swedish municipalities and county councils have an unusual autonomous position towards the state. Local politicians are directly elected at general elections and both municipalities and county councils levy taxes. Consequently, service and care is financed by local governments. The laws on social services and health care give the municipalities and the county councils very great freedom to plan, organise and to decide over eligibility and service levels on their own. The autonomy of the local governments also implies that services for the elderly are organised differently in different parts of the country. Thus, the number of institutional beds related to the population and the scope of the home help and the home nursing services, for example, vary considerably especially between urban and rural areas.

The availability of care resources also varies greatly in different parts of the country. According to Berg and colleagues (1993), the proportion of elderly people 80+ receiving home help ranged from 17 to 80 per cent in different municipalities, while the utilisation of long-term institutional care and old age homes could range between 9 and 37 per cent. Further, there are no evidences in support of the idea that a low utilisation (and supply) of institutional care is generally offset by an increased utilisation of home care (Trydegård, 1998). Consequently, support targeting carers directly, also vary in scope and quality the same way.

2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people

2.1.1 What are the expectations and ideology about family care? Is this changing?

There are no statutory requirements for children to provide care or economic support for their elderly. However, if a family by own choice, wish to care for a family member, they should be given recognition and support. The underlying philosophy in the Swedish system is that public support should target the person in need for care. The aim is to promote maximum independence (from others, the family and next of kin), even if you need service and care for your daily living.

2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental?

No, in Sweden there is no national binding definition of dependency. Instead, each municipality could decide on their own how to define dependency and eligibility for services.

2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living

The county councils are responsible for the provision of health and medical care. And, at the local level, the municipalities are legally obliged to meet the social service (including personal care) and housing needs of the elderly. Also, if the elderly do not have enough economic resources for his / her everyday living, he could claim social assistance from the municipality where he lives.

2.1.4 Is there any relevant case law on the rights and obligations of family carers?

There are 2 cases that have reached the Supreme Administrative Court recent decades regarding caring for older persons. Both cases had to do with situations, when the carer claimed economic reimbursement for his care work.

2.1.5 What is the national legal definition of old age, which confers rights (e.g. pensions, benefits, etc.)?

The new pension scheme (enacted in 1999) carries a flexible retirement age. To enable people, who so wish to work beyond the age of 65, the pension agreement contains a clause allowing people to work until they reach the age

of 67. It is also possible to retire from the age of 61, but then with a reduced yearly pension. However, the official age for retirement is 65 years.

2.2 Currently existing national policies

2.2.1 Family carers

A milestone was passed in 1998, when a new paragraph was amended to the Social Services Act, stating that “the municipalities should support families caring for elderly or disabled in their own home”. In the preparatory work, the motives for this new legislation were presented as following: it represented a recognition of the carers, it aimed to prevent burnout and to increase life quality among carers.

2.2.2 Disabled and / or dependent older people in need of care / help?

In the National Policy for the Elderly, decide on in 1998, the overall goal is that: “Older persons shall have access to good caring services”. This means a focus on „aging-in-place, institutional care when needing, individualised service and care, access to health care on equal terms, services and care of good quality, and be able to end one’s life in dignity and peace“.

2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job sharing, part time work, etc)?

As will be presented in paragraph 5.5, there is the Care Leave Act, that could be claimed by people in working age (< 65), in order to be able to leave work (for 60 days in total) to support a family member in a terminal stage of life. Beyond that, there are no legal measures or special programs, supporting carers who are working. Usually it is up to negotiations between the employer and the employee, to make the practical arrangement. As a great proportion of the women has part-time employment already, there are possibilities to care and work at the same time.

2.3 Are there local or regional policies for carers and dependent older people?

Local governments have great freedom within existing legislation, to decide and prioritise service and care to elderly in relation to other needy groups in the municipality. As a consequence of the independent position of the local governments, they could develop “a local profile“ of service provision (levels, quality and mix of service programmes) both targeting the elderly and the carer.

2.4 Are there differences between local authority areas in policy (and thus provision) for family carers and / or older people?

Yes, there exist great differences between local governments and how they interpreted their responsibility to provide service and care to the elderly. Service provision could differ several hundred per cent from one municipality to another.

3 Services for family carers

There are three layers of supportive services for the elderly and their families in Sweden. The first layer of service and care - home help - is targeting the person cared for.

On top of services offered the person cared for – which of course also function as an indirect support for the carer – there is a second layer of support services targeting directly the carer. However, the carer has no legal right to service, but could claim services on there own behalf, in order to able to help the person cared for.

The third layer, represent the increasing amount of help input provided by voluntary workers. It's a fact that public support for carers is now more and more often intertwined with – and dependent of – voluntary efforts and the work of voluntary organisations.

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)			X	X				
Counselling and Advice (e.g. in filling in forms for help)			X		X			
Self-help support groups			X		X			
„Granny-sitting"		X					X	
Practical training in caring, protecting their own physical and mental health, relaxation etc.			X		X			
Weekend breaks		X		X				
Respite care services			X	X				
Monetary transfers			?					
Management of crises		X			X			
Integrated planning of care for elderly and families (in hospital or at home)			X	X				
Special services for family carers of different ethnic groups		X			X			
Other								

3.1 Examples

3.1.1 Good practices

In table 5 below, the coverage of different types of support programs for carers is presented.

Table 5: Availability of support programs for carers (percentage of municipalities providing)

Type of programme	Available in 1999	Available in 2002
Economic support	66	63
In-Home respite care	69	87
Institutional respite	99	97
Day care	80	92
Carers support group	28	83
Carers resource centres	7	56
Carers consultant	5	68
Counselling	47	77

3.1.2 Innovative practices

Data in table 5 above, reflect recent developments in developing carers support in Sweden. The most popular type of support programmes are:

- Respite programs
- Counselling programs
- Information and training programs

4 Supporting family carers through health and social services for older people

4.1 Health and Social Care Services

4.1.1 Health services

4.1.1.1 Primary Health Care

The shortage of doctors in PHC, has since the Community Care Act was implemented (1992), been a constant problem. The county council has the responsibility for health care provided by doctors serving the whole population, including the elderly. The shortage has direct and strong repercussions on care of the elderly and their carers.

In half of the Swedish municipalities, the municipality has taken over the responsibility for home nursing care. In the other municipalities, home-nursing care is provided by the primary health care organisation. There are also hospital-based home nursing organisations, often specialised in e.g. palliative care, home rehabilitation care, care of cancer patients in their own home and so on. Home rehabilitation teams could also have their (organisational) base in PHC or the home help services. From a carers point of view, PHC services are fragmented and not easy accessible. One example is the constant problems to have home visits from doctors.

4.1.1.2 Acute hospital and Tertiary care

Table 6 below; give some vital data on the number of hospital beds etc. in Sweden.

Table 6: Number of hospital beds and average length of stay in hospital care in Sweden 1992, 1996, 2000 and 2002

	1992	1996	2000	2002	Change 1992–2002
Medicine	14 106	11 148	10 916	10 659	-24,4
Surgery	15 367	10 603	9 314	8 371	-45,5
Geriatrics	7 983	4 699	3 189	2 432	-69,5
Psychiatry	11 846	7 276	5 565	4 831	-59,2
Total	**49 212**	**33 726**	**28 984**	**26 293**	**-46,6**

Source: National Board of Health & Welfare, 2004

The reduction of hospital of hospital beds has implied a faster ”through-put” of patients in acute hospital care. Today (2002), the median stay in days in internal medicine is down to 4 days for patients aged 80 years and older. This has

also consequences for the carers, as they nowadays cannot expect long time of ”respite” before the elderly is discharged back home again. And as the number of beds / apartments has been cut down recent years, this in combination create an increased pressure on the carers.

4.1.1.3 Are there long-term hospital care facilities (includes public and private clinics)?

As can be seen in table 6 above, the number of beds and consequently the average length of stay has been dramatically reduced in hospital care recent decade. Especially geriatric care has been affected and this trend of closing down beds seems to continue. The compression of hospital stay means of course that a substantial part of caring – sometimes advanced nursing – is being transferred to the next level of care; primary health care and the municipality. Then, since the Ädel reform came into power, a steady increase of care-load, both in institutional and home-based care has been identified. Not surprisingly on the other hand, given the fact that service and care resources have to give priority to the most frail and needy elderly. This means that elderly moving to special housing today are more frail and dependent both in terms of functional and cognitive capacity.

4.1.1.4 Are there hospice / palliative / terminal care facilities?

Palliative care is offered all over Sweden. In general, palliative care is primarily targeting persons with cancer. There are a handful hospital-based palliative care units in Sweden, but for the vast majority of elderly, terminal care is provided in municipal nursing homes or at intermediate care unit. Some municipalities have arranged so that a special ward in the nursing home is used as a “palliative unit”. Other municipalities have no „ear-marked“ palliative beds, but instead use the beds in intermediate care units more flexible, all according to current needs.

4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?

There is no “obligatory expectations” of families to visit, help and support their family member when in hospital or in institutional care. But families do that frequently out of love and compassion. This is basic ethics in our society. In fact, many families do provide a number of “services” and support, especially for the elderly living in special housing facilities.

4.1.2 Social services

Table 7: Use of home-based and institutional care among elderly in Sweden 1993–2003 (%)

Year	Persons aged 65 years and older[1)]			Persons aged 80 years and older[2)]		
	Home help	Institu-tional care	Total	Home help	Institu-tional care	Total
1993	10.6	8.4	19	23	24	48
1994	9.8	8.7	18.5	23	24	47
1995	9.3	8.7	18	22	24	46
1996	8.9	8.7	17.6	21	24	45
1997	8.4	8.5	16.9	19.8	22.8	42.6
1998	8.2	7.7	15.9	19.5	21	40.5
1999	8.2	7.6	15.8	19.4	20.2	39.6
2000	8.2	7.9	16.1	19.0	20.7	39.7
2001	7.9	7.7	15.6	18.3	20.0	38.3
2002	8.2	7.5	15.7	18.7	19.4	38.1
2003	8.3	7.2	15.5	19.1	18.4	37.5

1) Per 100 aged 65 years and older in the population
2) Per 100 aged 80 years and older in the population

In 2003, about 8 per cent of the population (65 years and older), received home help services. Of these, about one third also received home nursing care. Of those aged 80 and older, almost 19 per cent of this age group, received home help (National Board of Health and Welfare, 2003). In summary; the number of persons receiving home help, has constantly decreased in relation to population growth. However, the volume of service input (contact hours) has increased successively. In other words, fewer persons get more help (Agüro Torres et al.,1995; Sundström and Tortosa,1999).

Home help has been made available increasingly during weekend, evening and night hours. In 1988, 16 per cent of those with home help received it in the evenings and at night; in 1997 this had increased to 28 per cent. In 2003, about 4 per cent all elderly, having home help, received more than 120 hours of home help per month.

Besides home help, there is also a comprehensive range of municipal services for the elderly, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, handicap aids, etc.

4.1.2.1 Residential care (long-term, respite)

The development in the area of special housing (institutional care) is quite similar to what has happened in the home help services, as showed in the table above. As a result of the Ädel reform, all types of institutional care have been gathered under one ”umbrella” heading; ”special housing” with service

and care for elderly. This concept then comprises: nursing homes, old age homes, service houses, group homes etc. Until the early 1980s, institutional care expanded in pace with changes in the population. However, since then, this expansion has successively stagnated. In 2003, some 110 900 persons were living in different forms of institutional care or in ”special housing” for the elderly in Sweden (National Board of Health and Welfare, 2004). This corresponds to a service coverage of 7.2 per cent of 65 years and older and 19 per cent among those 80 years and older.

Since the Ädel reform came into power in 1992, all types of institutional care have been gathered under one ”umbrella” heading; ”special housing” with service and care for elderly. This concept then cover nursing homes, old age homes, service houses, group homes for persons with dementia etc. As a consequence, there is no statistics collected and available at the national level, of different types of institutional care. Out of the 111 000 beds / apartments available in 2003, it could be estimated that some 30 000 were nursing home beds, some 25 000 beds in group homes for demented and 55 000 beds or apartments could be found in residential care facilities (old-age homes and service houses).

4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of residential care (sheltered housing, residential homes)

Average age at admission to institutional care is 83 – 84 years, 3 out of 4 persons are women.

4.1.2.1.2 Criteria for admission (degree of dependency, income etc.)

Access to institutional care is decided in the same way as for home help services in general, i.e. through a process of needs assessment, carried out by the municipal care manager. Access criteria may and do very much differ from one municipality to another. However, the level of dependency and degree of cognitive impairment is often decisive. Admission is not based on means-testing.

4.1.2.1.3 Public / private / NGO status

Institutions could be run by private entrepreneurs, commissioned by the municipality, which then decide over the placement of the elderly. Private institutions, where the resident pay out of his own pocket do exist, but they are utterly rare. In 2003, almost 13 per cent of the elderly in institutional care, where provided this accommodation and care by private entrepreneurs.

4.1.2.1.4 Does residential care involve the participation of carers or work with carers?

In residential care (and other types of institutional housing and care facilities) carers and other family members and friends are frequent visitors. When visit-

ing, they do take part of the daily life of their family member. Traditionally care personnel have kept a certain distance to visiting family members. However, in recent years there is a shift in attitudes and care personnel are more and more focusing on the (former) carer, to collaborate and create “carer- friendly institutions”.

4.1.2.2 Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)

The prime services for the elderly in the municipality, is home help. It contains help with daily activities, e.g. shopping, cooking, cleaning and laundry. It also includes personal care such as help with bathing, to go to the toilet, getting dressed and in and out of bed. Besides home help, there is also a comprehensive range of municipal services for the elderly, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, handicap aids, etc. Data of the provision and use is collected on regular basis for some of the services. In other cases, one has to rely on special studies. In table 6, data on home help service coverage was presented. Below, the number of recipients or uptake of services on a monthly basis, is presented.

Table 8: Number of elderly receiving different types (in-home) of municipal social services in Sweden 2003

Type of services	No of recipients 65+
Home help	128 000
Meal service	60 000
Transportation services	331 000
Day care	13 000
Home nursing care	34 000
Home adaptations	33 000
Technical aids (wheel–chairs / rollers)	325 000

4.1.2.3 Care management and quality of care: systems of evaluation and supervision of (both home and other support) care services

4.1.2.3.1 Home-help

The Social Service Act (Socialtjänstlagen) is a framework law that emphasises the right of everybody to receive social services. Anyone who needs help to support himself in his daily living has the right to claim assistance if his needs "cannot be met in any other way". The services provided by the municipal social services are based on an assessment of the individual's housing, services and care needs. The assessment is carried out by a case manager employed by the municipality. If the individual is not satisfied with the decision, he / she can appeal against it in the administrative court. According to the Health and

Medical Services Act, health and care shall be available to all members of society to ensure a high standard of health and care for everybody on equal terms.

The municipality should according to laws and regulations, continuously monitor the quality and outcome of the services, as well as client satisfaction. Moreover, the elder care services in Sweden is constantly supervised by two authorities; the National Board of Health and Welfare (focusing health care issues) and the county Administrative Board (focusing social service issues).

This system of care management, evaluation and supervision hold for all types of municipal social services for the elderly.

4.1.2.3.2 Personal care

See above.

4.1.2.3.3 Meals Service

See above.

4.1.2.3.4 Other home care Services (transport, laundry, shopping etc.)

See above.

4.1.2.3.5 Community care centres

See above.

4.1.2.3.6 Day care ("protective" care)

See above.

4.1.2.4 Other social care services

Counselling, technical aids, home adaptations are services that managed the same way as social services for elderly in general. Training of carers and paid care personnel is not a matter of service provision. However, municipalities do frequently offer training, as a part of recruitment efforts or to retain care personnel by “in-job” training opportunities.

4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modelling of both home and other support care services

4.2.1 Who manages and supervises home care services?

Swedes have a statutory right to claim service and care whenever needing. But the municipality decides on their own on the service level, eligibility criteria and range of services provided. Elder care provision is based on a single-entry system; the person in need for help turns to the municipality where his lives, to claim help. One precondition for receipt of care and service is that a need is assessed to exist. Need determination takes place through a process of need assessment, carried out by a municipal care manager. In some municipalities, the use of interdisciplinary care planning teams for assessment and coordination of eldercare services is frequent, especially when the decision is about a permanent move to institutional care.

The single individual could claim services but he / she has no automatic right or entitlement to services. If the elderly requesting services is dissatisfied with the care manager's decision, the case can be appeal in the administrative court. Data from national representative study carried out in 2001, showed that the number of appeals were residual. Although the number of appeals is very low, the right to appeal is considered as an important individual protection.

The assessment usually starts with a home visit (or e.g. a meeting with the elderly at the hospital) for a review of the request and need for services. The process also includes discussions with the family and consultations with other professionals to collect necessary information and data. In more than half of all municipalities, care management is based on a purchaser – provider model. In those municipalities, another part of the organisation takes on the actual provision of services after the care manager has done the assessment and decided on what care package is needed. Private service providers could also be contracted in. In the traditional care management system, the care manager is responsible both for the assessment and to organise the provision of help.

4.2.1.1 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorized to run these quality controls?

The municipality should according to laws and regulations, continuously monitor the quality and outcome of the services, as well as client satisfaction. Moreover, the elder care services in Sweden is constantly supervised by two authorities; the National Board of Health and Welfare (focusing health care issues and based on the Health Care Act) and the county Administrative Board (focusing social service issues and based on the Social Services Act).

4.2.1.2 Is there any professional certification for professional (home and residential) care workers? Average length of training?

For nurses, occupational therapists and physiotherapists, a three-year university education is needed, to receive professional accreditation.

4.2.2 Is training compulsory?

In 2002 some 192 000 persons (home helpers / nurses aids) were employed in the home help services. Almost one quarter were full-time employed, nearly 60 per cent worked part-time and the rest were on an hourly basis employment. Only about bout half of the care personnel has at present the requested training for the work (upper secondary school-level), primarily due to difficulties to recruit care personnel with adequate training and skills. And, due to the problems to recruit personnel altogether, training is not a compulsory for basic care personnel (home helpers and nurse's aids) in care for the elderly.

4.2.3 Are there problems in the recruitment and retention of care workers?

Increasing problems to attract and recruit care personnel now challenges the caring services in Sweden. The problems relate to virtually all types of professions, from physicians to home-helpers and exist all over the country. This not a new problem, but seems to increase rapidly. The basic problem is that – even if you are granted a permanent job – care work in general and care work with elderly especially - is loosing its attraction.

Then, there is a constant need to recruit large numbers of care personnel to the services. It is estimated that there will be a need for 200 000 more care workers in care for the elderly and disabled in the municipalities, by the year 2015.

And another, bigger problem, is to maintain the care personnel that has been recruited. Today, care as a workplace, has an increasing number of "throughput", i.e. the care personnel choose to leave for other work opportunities. An additional problem is the skyrocketing numbers of care workers on sick leave. Together with increasing numbers of pre-retired persons, make the situation very problematic. And further, women in the caring services are over-represented here. The total costs for absence due to sickness and early exit from the labour market (pre-retirement) is expected to increase from SEK 93 billion, with SEK 50 billion the coming five years (2002–2007).

4.3 Case management and integrated care (integration of health and social care at both the sector and professional levels)

The Community Care reform from 1992, represent a step in the direction of integrating health care and social services. For example, the municipalities

were given the opportunity (after agreement has been reached with the county council) to take over the responsibility of home nursing care. By now about half of the municipalities have done so and thereby integrated home nursing and home help services in the same organisation.

4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?

Yes, one could say that this is the general attitude today, but there is another thing how this work in practice. Many carers complain over being „invisible“, others argue that they have too little say in care planning and so. In the contact with the services, many carers feel that they are „under-dog“, with little say or power to be able influence the caring situation.

5 The Cost – Benefits of Caring

GDP for year 2001 was 2 267 million in Sweden.

5.1 What percentage of public spending is given to pensions, social welfare and health?

Table 9: Public spending on social protection for the elderly (65-w)in Sweden (2001)

GDP	2 266,6 BSEK
HEALTH CARE – Hospital care – Out-patient care – Pharmaceutical – Municipal health care	66,7
SOCIAL SERVICES – Special housing – Home help – Handicap aids	71,4
Σ HEALTH CARE SOCIAL SERVICES	138,1 (6.1 % of GDP)
PENSIONS – Basic pension – Supplementary pension – Housing supplement	202,4
Σ SOCIAL PROTECTION	340,5 (15.0 % of GDP)

The total public spending on social protection for the elderly – pensions, health care and social services - in Sweden, amounted to some SEK 340 000 million or 15 per cent of GDP in 2001. The costs for health care and services for the elderly in 2001 was estimated at some SEK 138 000 million or about 6,1 per cent of GPD. Most of this – two thirds – goes to various forms of institutional care, such as acute hospitals, nursing homes and old-age homes. The remaining third stands for outpatient health care and home help. Roughly 6–8 per cent of the cost refer to administrative costs.

5.2 How much – private and public – is spent on LTC?

As is shown in table 6 above, the costs for long-term care provided by the municipalities amounted to some 71 billion in year 2001 (and in year 2002, 75 billion Swedish crowns). How much elderly people pay out of their pocket for long-term care is not known, but probably residual in a population perspective.

5.3 Are there additional costs associated with using any National Health Service?: What costs exist for carers in accessing public health services?

Both the health care and social services are subsidised, with the recipient usually paying only a fraction of the actual cost. At the present, the fees (out-of-pocket costs) for health care and social services are increasing. But, to limit the cost for the recipient (for out-patient care), there exist a "high-cost-limit", which means that no one has to pay more than a total of 2, 200 SEK per year for health care (including prescriptions), regardless of the type and amount of care received.

Thus, the fee for long-term hospital care may not exceed SEK 80 per day. Dental care for children under the age of 18 is free, as is insulin. Subsidies are payable for preventive dental care and a charge limitation protection limits the cost of dentures. The patient must pay the first SEK 400 for medicines in a twelve-month period, but there is a ceiling for the patient of SEK 1,300 per year. For other health care there is a maximum limit of SEK 900 over a twelve-month period for patient charges. Pensioners staying in hospital shall not pay more than a third of their pension in patient charges.

5.4 What is the estimated public / private mix in health and social care?

Some 200 000 Swedes have a private health insurance – utterly few elderly(mostly top-executives or top-managers). Private, out of your own pocket paid health care is extremely unusual among the elderly. But it happens that elderly pay their way through the waiting line, to get a cataract operation.

5.5 What are the minimum and maximum costs of using residential care, in relation to average wages?

The cost for residential care is divided into three different parts: housing, meals, and care. Average net-income among elderly (single) is 8, 500 SEK per month. The average cost for housing is estimated to 2, 500 SEK, food / meals to 2, 400 SEK and cost for care at 500 SEK per month. The low cost for care is explained by a general reduction of the fee, due to this person low income. Altogether this “average elderly” would pay some 5, 400 SEK for residential care per month or almost two thirds of his income.

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)? Is it funded through taxation or social contributions?

Care of the elderly is almost totally financed by taxes. Only the user pays a fraction of the costs (5-6 %). The largest share of the costs (about 82 – 85 %) is covered by local taxes. National taxes cover the remaining costs of elderly care (about 10 %). The fact that health care and social services for the elderly is primarily funded by local taxes, further confirm the independent role of the local governments versus the national government.

This is a rough overview of the financing of elderly care. However, the mix of contributions from the different sources of financing, often vary from one type of service programmes to another. From the taxpayer point of view, about 20 per cent of the (local) tax paid by on average work-income, is used by the local authorities to finance services and care for the elderly.

5.7 Funding of family carers

5.7.1 Are family carers given any care benefits? Are these means tested?

Table 10: Economic support programmes for carers (2003)

	Attendance allowance	Carers´ allowance	Care leave
Restrictions	No	< 65 years	< 65 years. Max 60 days
Who is paid?	Care recipient / Patient	Carer	Carer
Taxable	No	Yes	Yes
Who pays?	Municipality	Municipality	Nat. Social Insurance
Pension credits	No	Yes	Yes
Levels of / month	Varies ~5 000 SEK	Varies ~14 000 SEK	80 % of income
Number of recipients in 2002	5 542 persons	2 002 persons	9 432 persons

5.7.2 Is there any information on estimated needs and the take up of benefits or services?

See table above.

5.7.3 Are there tax benefits and allowances for family carers?

There are three programs for economic support available for family caregivers caring for older people in Sweden. The first and the oldest one is:

On top of services provided to the person cared for, caregivers can receive an attendance allowance: this is an untaxed cash payment that goes to the dependent, to be used to pay the family member for her help. The monthly payment is rather modest – at most about SEK 5 000 / month (~ 550 Euro). Eligibility is usually based on level of dependency / amount of caregiving, "measured" in hours of help needed / given per week. Many municipalities have 17 hours of caregiving / week as cut-off criteria to receive the allowance. Each municipality have the right do decide on their own, whether to provide this program or not, eligibility criteria, level of payment, etc. There is no federal or state regulation. In year 2003, some 5 500 persons received this kind of allowance in Sweden.

Another option is the carers allowance (actually not an allowance) which means that the municipality reimburse or salary the family caregiver for her work Carers allowance provides similar social security protection as for the care personnel in the formal services and this income is taxed. The salary amounts to the same as a home help employed by the municipality in their own services. This program is also a matter for the local municipality to decide own, i.e. no national / federal regulation exists. The opportunity to be employed as carer by the municipality is far from a first-hand suggestion from the municipality. But in certain circumstances, e.g. elderly living in a remote part of the municipality and have a daughter living nearby, this could be a preferable arrangement for all involved. However, it is not possible to receive carer's salary if you are 65 years or older. In year 2003, some 2 000 persons – caring for an elderly family member – received carer's salary in Sweden.

Relatives who take care of an elderly family member in a terminal care situation, can receive payment from the National Social Insurance - the Care leave (enacted 1989). It is possible for relatives (with gainful employment, i.e. under 67 years of age) to take time off work, with compensation from the social insurance, for up to a total of 60 days per relative. The number of days refer to the person being cared for. The carer and the person cared for must both be registered at the social insurance office (i.e. the carer must be under 65 years of age), and the care must take place in Sweden. Payments are payable at full, half or one quarter rate. Starting the 1st January 1998, the level of payment is 80 per cent of the income qualifying for sickness benefit.

5.7.4 Does inheritance or transfers of property play a role in caregiving situation? If yes, how?

No, inheritance or transfer of property has no “official” role in caregiving in Sweden. But off course, within the families there certainly exist situations,

where assets of different kinds play a role in the negotiation of family obligations. However, today we have no data on how common this is.

5.7.5 Carers' or Users' contribution to elderly care costs

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
General practitioner		X				X
Specialist doctor		X				X
Psychologist		X				X
Acute Hospital		X				X
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)		X				X
Day hospital		X				X
Home care for terminal patients	X					X
Rehabilitation at home		X				X
Nursing care at home (Day / Night)		X				X
Laboratory tests or other diagnostic tests at home	X					X
Telemedicine for monitoring	X					X
Other, specify						

b. Social-care services	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Permanent admission into residential care / old people's home		X				X
Temporary admission into residential care / old people's home in order to relieve the family carer		X				X
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)		X				X
Laundry service		X				X
Special transport services		X				X
Hairdresser at home		X				X
Meals at home		X				X
Chiropodist / Podologist		X				X
Telerescue / Tele-alarm (connection with the central first-aid station)		X				X
Care aids		X				X
Home modifications	X					X
Company for the elderly	X					X
Social worker	X					X
Day care (public or private) in community center or old people's home		X				X
Night care (public or private) at home or old people's home		X				X
Private cohabitant assistant („paid carer")		X				X
Daily private home care for hygiene and personal care		X				X
Social home care for help and cleaning services / "Home help"		X				X
Social home care for hygiene and personal care		X				X
Telephone service offered by associations for the elderly (friend-phone, etc.)	X					X
Counselling and advice services for the elderly	X					X
Social recreational centre	X					
Other, specify						

c. Special services for family carers	General access:			Access based on:		
				Means-tested		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Partly reimbursed	wholly reimbursed	Based on severity
Training courses on caring	X					X
Telephone service offered by associations for family members	X					X
Internet Services	?					X
Support or self-help groups for family members	X					X
Counselling services for family carers	X					X
Regular relief home service (supervision of the elderly for a few hours a day during the week)	X	X				X
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)	X	X				X
Assessment of the needs	X					X
Monetary transfers	?					?
Management of crises	X					X
Integrated planning of care for the elderly and families at home or in hospital	X					X
Services for family carers of different ethnic groups	X					X
Other, specify						

6 Current trends and future perspectives

6.1 What are the major policy and practice issues debated on family care of the elderly in your country from the carers' point of view? Are older people and / or carer abuse among these issues?

At present, the issues of financing elderly care and to recruit and retain care personnel, constitute an ever-increasing problem. The issue of financing elder care is actually a kind of ”welfare paradox”, i.e. due to improved general living conditions in Sweden, Swedes are living longer and reaching the age when service and care needs are amounting. This development stresses the tax-based system of financing the welfare of the elderly. Local authorities are requested by the national government to keep their budget in balance, then the ”old-solution” - to raise taxes to finance additional services - is no longer an option. Even if there still some space for rationalisation of the services, the need for a complementary system of financing of the services is growing.

Thorslund and colleagues (1997) have pointed to that Sweden’s welfare state emerged during the prosperous years following the Second World War. The economy was flourishing and the political choices were a matter of which sectors of the society should be supported and expanded. However, today’s political choices consist of allocating resources that seldom suffice to fulfil the needs of the population. Difficult decisions must be made about which service sectors must reduce expenditure and which services must be discontinued. Then, the system of providing care for elderly people cannot be expected to continue unchanged in the face of the numerous changes occurring in society. While the political parties continue to express consensus concerning the basic concepts of the Swedish welfare state, current trends reflect some serious threats to the “Swedish model”.

Then, financing and provision of service and care to future cohorts of elderly is an increasing social-policy issue in a taxed-based system as in Sweden. The debate is focused on whether the public responsibility should be defined more narrow or not and / or whether a greater share of the costs for service and care should be shifted over to the individual user.

Against this background, if and how, support to families should be legislated as an entitlement is growing issue and a target for the Ministry of Social Affairs. In connection to this there are several key policy issues. For example, should support target primarily the elderly person needing care or the family of the elderly too? Second, what are the consequences for the role of women in developing more extensive support opportunities? And third, is there a risk that public support (e.g. cash or payments) could contribute to monetising family

relationships? Finally, the most debated issue: will increase support to family carers lead to a cost explosion?

6.2 Do you expect there to be any changing trends in services to support family carers, e.g. more state or more family support, more services or more cash?

The “Swedish Model” has been to offer primarily services instead of cash. At present there are no indications of any shift in policy. But in a long-term perspective and related to the issue of funding service and care in the future, new funding models e.g. insurance-based systems has been suggested in the public debate.

6.3 What is the role played by carer groups / organisations, „pressure groups“?

There are three main carers organisations in Sweden. The Dementia Association was founded in 1984 and has now about 12 000 members and some 110 local organisations covering most parts of Sweden. The second organisation; The Alzheimer’s Association Sweden, was founded in 1987, has fewer members, but play and important role. Both organisations are lobbying for expanded housing, service and care, fund research in the field dementia care and also provide help-line, support and information services. The third organisation is the Carers Sweden, founded in 1996 are now gaining more and more importance. The aim of Carers Sweden is to take the role as a national umbrella organisation, and to promote carers´ interest on a broad scale, through advocacy-, information- and awareness raising activities.

The Swedish Red Cross is an very active part in training of, what they call, “professional carers supporters”. From 1999 to 2001, they arranged courses for 900 persons to be trained to run carers support groups all over the country.

6.4 Are there any tensions between carers' interests and those of older people?

No, today there no conflicts between the elderly and their organisations and the carers (and organisations). In fact, several of the pensionist organisations have “improved carers support” on their agenda.

6.5 State of research and future research needs (neglected issues and innovations)

There is a big knowledge-gap that needs to be covered in future, both in terms of basic and applied research.

Among many possible topics, the following are the most urgent:

- Caring and working
- Young carers
- Caring and ethnic groups
- Caring for persons with rare diseases
- Carers support in rural settings
- Outcome of carers support

6.6 New technologies – are there developments, which can help in the care of older people and support family carers?

In 1998, the government established a three-year action plan (1999-2001), with 11 million Euro annual funding, to stimulate local governments to develop an infrastructure of services targeting family caregivers. The plan funded local municipalities to expand services for carers e.g. by setting up caregiver resource centres that offer training, counselling, support groups, respite care, and other information and resources for family caregivers, including day programs for their disabled family members. The experiences and outcome of the Carer-300 project has been systematically followed and evaluated the recent years. A general experience is that is has taken a long time, before local plans have been implemented in to action. However, it is obvious that the number of support programs available has steadily increased. So, the general impression is that the local authorities are responding rapidly, in expanding their supportive services for carers. However, we don't have any data on the quality of the programmes, neither we know how many carers they serve.

The development of carers support has been spurred and the result could be measured in quantative terms and number of programs available. But in a more critical perspective, much of what has been done could not be labelled as innovations, rather "more of the same" of the old well-known programmes. This is understandable, then for a majority of municipalities to offer a systematic and tailored support to carers, is still something new.

Maybe one can say, that the biggest "innovation" is that carers are now being more and more visible and recognised! The carers´ issue have now also found it's natural role and place at the local political agenda, which is a necessity to be able build support for carers.

6.7 Comments and recommendations from the authors

The carers´ issue continues to stay on top of the social policy agenda in Sweden. In 2002, the Parliamentary Standing Committee on Health and Welfare commissioned the Government to analyse the economic consequences of a

new legislation on carer's right to service and support. The question is to analyse the societal costs incurred, if a defined group of carers (of all ages) would be provided with in-home respite services on regularly basis. The result of this work is expected to be presented in 2004.

Irrespective of the outcome of this process, the carers' issue will grow in importance both as a research topic (not only related to care of the elderly) and primarily as a central topic in the public debate.

7 Appendix to the National Background Report for Sweden

7.1 Socio-demographic data

7.1.1 Profile of the elderly population-past trends and future projections

Table 11: The elderly population 1990-2000 and projections for 2010, 2020 and 2030, by age groups

Age	1990	1995	2000	2010	2020	2030
< 65	7 064	7 294	7 359	7 547	7 676	7 824
65-w	1 526	1 543	1 523	1 719	2 043	2 278
80-w	370	415	454	485	519	750
90-w	40	53	63	82	89	103
Total	8 590	8 837	8 882	9 266	9 719	10 102

Source: Statistics Sweden, 2003. Population projections 2003

7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

Table 12: Life expectancy at birth and at age 65 years, by gender (1982, 1992 and 2002)

	Life expectancy at birth		Life expectancy at 65 years age	
Year	Men	Women	Men	Women
1982	73,4	79,4	14,6	18,3
1992	75,4	80,8	15,6	19,3
2002	77,7	82,1	16,9	20,0

Source: Statistics Sweden,2003

7.1.1.2 % of > 65 year-olds in total population by 5 or 10 year age groups

Table 13: The elderly population in Sweden 2003

Age	No. of persons	Per cent
< 65	7 434 416	82.8
65–79	1 065 316	11.9
80–w	475 938	5.3
65–w	1 541 254	17.2

Source: Statistics Sweden, 2004

7.1.1.3 Marital status

Table 14: Marital status among the elderly, 80 years and older, by gender (%)

	Married	Unmarried	Widow / er	Divorced
Men 80-w	56,0	8,5	29,3	6,2
Women 80-w	18,6	7,3	66,4	7,7

7.1.1.4 Living alone and co-residence

Table 15: Percentage of non-institutionalised elderly, 80 years and older, living alone or co-residing, by gender (1988 / 89 and 2002)

	Living Alone		Co-residing	
Non-institutionalised	1988 / 89	2000	1988 / 89	2000
Men 80-w	38	34	62	66
Women 80-w	71	76	29	24

Source: Own compilations of data from Statistics Sweden

7.1.1.5 Urban / rural distribution by age

Not available.

7.1.1.6 Disability rates amongst > 65 year-olds. Estimates of dependency and needs for care

Table 16: Percentage of of elderly, 65 years and older, needing help with IADL and PADL (1988 / 89 and 2002)

IADL	Total pop 65-w		Non-instutionalised 65-w	
	1988 / 89	2002	1988 / 89	2002
Shopping	22	21	18	16
Cooking	14	14	10	9
Washing up	25	18	20	13
Cleaning	28	22	23	17

PADL	Total pop 65-w		Non-instutionalised 65-w	
	1988 / 89	2002	1988 / 89	2002
Getting up / in to bed	4	5	2	2
Getting dressed / undressed	5	5	2	2
Showering	10	9	6	5

Source: National Board of Health and Welfare, 2004

7.1.1.7 Income distribution for top and bottom deciles aged > 65 years

Table 17: Disposal income per year among elderly, 75 years and older (in 1 000 SEK) in different income groups

Poorest 25 %	Median (50 %)	Top 25 %
97 129	112 610	139 151

Source: Statistics Sweden, 2004

7.1.1.8 % > 65 year-olds in different ethnic groups

Table 18: Percentage elderly born in other countries than Sweden by age (2001)

55-64	65-74	75-84	85-94	95-w	65-w
12.2	12.4	7.9	4.4	5.3	8.0

Source: Statistics Sweden, 2002

7.1.1.9 % Home ownership (urban / rural areas) by age group

Not available.

7.1.1.10 Housing standards / conditions if available by age group e.g. % without indoor plumbing, electricity, TV, telephone, lift (if above ground floor), etc.

Not available.

7.2 Examples of good or innovative practices in support services

Innovative respite programs

Respite services is now available in virtually all of Sweden's 290 municipalities. Especially *in-home respite* care has become a very popular support program. And, an increasing number of municipalities are offering in-home respite, free of charge. There are also interesting trends towards more innovative types of respite services. This involves greater variation and scope of different types of relief services. Here the ultimate goal is to be able to offer carers "24-hours instant relief" or drop-in services. Some municipalities also offer this service without (or with minimal) bureaucracy, in order to maximize access to relief for the carers. Respite could be combined with „weekend-breaks", when carers are offered to stay at spa-hotel, in order to stress-down, take time out, and care for themselves.

Counselling programs

Interesting is also that there has been a substantial growth in counselling and personal support services provided in the municipalities. This has become a vital part of the core package offered the carers. This is at the same time a

good example of collaboration between formal services and the voluntary organisations, as e.g. support groups are often run by voluntary organisations, as well as befriending and sitting services and help-line services, all over the country.

Information and training programs

Another trend is to develop richer opportunities for information – using modern IT-technology-, educational and personal counselling services. And, a training programs, seminars and conferences, addressing both politicians, care personnel, carers and their organisations have been carried out all over the country in recent years. Many local authorities have also developed different types of out-reach strategies. Finally, another popular idea is to appoint a "Carers Consultant", at “Carers Centres”, who function as a two-way co-ordinator of contacts between the formal services and the carers.

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