ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives

Sweden

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Pär Schön and Lennarth Johansson
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European Social Policy Network (ESPN)

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The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for the Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

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Summary / Highlights

Policies, legislation and other service measures in Sweden aim to help and support the individual and to promote maximum independence from the family, and not primarily to facilitate the working population remaining in the labour market.

During the most recent years, the fact that families are forced to work fewer hours or leave work due to caring commitments has been highlighted. This new insight has caused discussions about work and care reconciliation to skyrocket. This is despite the fact that Sweden has a comprehensive public long-term care system (LTC), both for younger persons with disabilities and older persons.

In Sweden, caring for children, sick, disabled and older people is a public responsibility. Public policies and programmes providing health care, social services and support, as well as pensions and other forms of social protection are comprehensive. The ambition is for financial security and social rights to be guaranteed for all citizens to the benefits of children, the elderly and people with functional impairments.

The high percentage of women in the labour market necessitates a formal system of care for the elderly, as does the fact that very few older people share their homes with their adult children. The pension system means that few have to abstain from service and care due to economic reasons.

The disability reform was implemented in 1994. Personal assistance for individuals with major functional impairments was an important part of the reform. Both the number of persons eligible for assistance and the average number of hours allowed have increased sharply. Due to the increased cost of personal assistance, the ministers responsible have announced a review of the legislation.

The LTC provision regarding older people has also changed dramatically. During the 2000s, there was a 25% reduction in institutional care. The declining coverage of eldercare has been followed by an increase in care by the family.

The cornerstone for evidence-based policy making is the provision of adequate data, for monitoring and research purposes, of caring and carers. In Sweden, there is an urgent need for better regular and representative statistics, and a robust monitoring or evaluation system, in order to answer questions about targeting, efficiency and quality of the support provided.

Informal care of dependent persons has not been included in Swedish family policy. Support policies for carers can be an integrated part of LTC policy, family policy or an add-on policy. The 2009 legislation (the amendment to the Social Services Act regarding support to informal carers) points towards a break from the traditional Swedish model and a revision of the existing social contract. But it is still an add-on policy, not integrated with other policies, such as pension and employment legislation. Therefore, issues regarding informal caregiving should be fully included in national family policy, i.e. Sweden still lacks a person and family centred caring service – or in other words – a coherent family policy.

1 Description of main features of Work-Life Balance measures for working-age people with dependent relatives

1.1 Overall description of long-term care regime

Sweden has a well-developed welfare system, providing health care, social services as well as pension and social protection to the citizens over the life course. It has been a public responsibility for centuries to care for older and disabled people. The general principle of long-term care (LTC) policy is to provide publicly subsidised, widely available services (in kind) based on the individual's needs, regardless of economic means and family resources, thereby removing the burden of providing services from the family (Sipilä, 1997). A basic idea behind the universalistic feature of the Swedish welfare system is to make the same services affordable for the poor, but still attractive for the wealthier (Szebehely, 2005). Compared to many other countries, Sweden has a comprehensive public LTC system for older and disabled people.

Care of older people is a public responsibility in Sweden, and there are no legal obligations or statutory requirements for children to provide care or economic security for their elderly. However, if a family by its own choice wishes to care for a family member, they should be given recognition and support according to the Social Services Act (SoL) from 1982 and the amendment in SoL from 2009 (see below).

Almost all Swedish welfare state programmes are based upon individual independence. Swedish culture places a high value on individual independence; family bonds should be voluntary and not obligatory. The underlying philosophy has been to promote maximum independence from the family, even if you need support for your daily living. Consequently, issues regarding families as caregivers have not been included in national family policy (Johansson, Long, & Parker, 2011).

Swedish welfare rests on three legislative cornerstones: the National Social Insurance Act (SFS 1999:799), the Social Services Act (SFS 2001:453), and the Act Concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387).

The *Swedish National Social Insurance Act* aims to provide financial security during all stages of life. Everyone who lives or works in Sweden (legal residents) is covered by the national social insurance system, i.e., they are eligible for various types of benefits and allowances. Social insurance is an integral part of most people's lives. It is of great importance, not just for a person's security and well-being, but also for the Swedish economy. Total expenditure on allowance and benefits amounted to around SEK 218 billion in 2014, or just under 6% of Sweden's GDP (Swedish Social Insurance Agency, 2015b).

All persons in Sweden with care needs, irrespective of age and type of disabilities, are embraced by the *Social Services Act (SoL)*. SoL stipulates that municipalities, of which there are 290, have the ultimate responsibility for ensuring that all residents in the municipality obtain the support and help needed. The municipalities have a special responsibility for people with physical, mental, or intellectual functional impairments to ensure that they are able to live in a way that corresponds to their needs. SoL emphasizes the right of the individual to receive public service and help at all stages of life. Anyone who needs help or support in his or her day-to-day existence has the right to claim assistance if the 'needs cannot be met in any other way'. In 2009 SoL was amended with a paragraph stating that 'social services are obliged to provide support to persons who care for next of kin with chronic illnesses, older people or people with disabilities'. Anyone who identifies themselves as being 'a person who cares for next of kin' may apply, and there are no regulations regarding the amount of help a caregiver must provide to qualify. Also, the law doesn't specify the content or quality of the support that the municipalities are obliged to provide.

Persons with serious functional impairments can also, under certain conditions, be embraced by the *Act Concerning Support and Service for Persons with Certain Functional*

Impairments (LSS); and in certain cases also by the *Assistance Benefit Act (LASS)* (if the requirement for personal assistance for basic needs exceeds 20 hours per week). LSS was a vital part of the Disability Reform that came into force in 1994.

1.2 Description of carers' leaves

Care leave, *Benefit for care of closely related persons (Närståendepenning),* is provided within the framework of the National Social Insurance Act (SFS 1999:799). Those who forgo gainful employment (persons under 67 years of age) to take care of a severely ill, closely related person at home or at a care facility can receive this benefit. Severely ill refers to a life-threatening condition. The benefit is taxable and can generally be paid for up to 100 days for each patient. The maximum amount of this benefit is just below 80% of the sickness benefit qualifying income, based on 7.5 times the price base amount (the price base amount in 2016 is SEK 44,300, ~EUR 4,700) (Swedish Social Insurance Agency, 2015b).

To be able to claim leave from work, a doctor's certificate is needed. The doctor has to verify that the person cared for is terminally ill and that the sick person approves the care leave arrangement. The employer is forced by law to guarantee the employee's position while on leave.

To 'take care' of someone does not literally mean providing necessary care yourself. In other words, there is no presumption that the person receiving the payment should provide direct assistance or support to the terminally ill family member. Furthermore, there is no requirement that the person should be cared for at home. The concept of 'family' here is broadly defined. It also includes neighbours, friends and others who occasionally stand-in for family members.

A further option, which is based on an EU directive (Council Directive 96/34/EC, 1996), is the Act on Employees' Entitlement to Absence from Work for Special Family Reasons. The act states that an employee shall have the right to absence from work where urgent family reasons in cases of sickness or accident make the immediate presence of the employee indispensable. It is not known to which extent this act is used.

1.3 Description of carers' cash benefits

1.3.1 Carers' cash benefits provided by the Swedish Social Insurance Agency (National Social Insurance Act)

Parents can receive *childcare allowance (vårdbidrag)* if their child, up to the age of 19, needs special care or supervision for at least six months. The need for special care or supervision must be caused by the child's illness or by the disability generating additional expenses. Full childcare allowance is 2.5 times the annual price base amount, which in 2014 was SEK 9,250 per month (~EUR 980). Childcare allowance is taxable and accrues pension credits (Swedish Social Insurance Agency, 2015b).

After the age of 19, individuals can become eligible for *disability allowance (handikappersättning).* This allowance is for the person cared for and not for the carer. A person who has been disabled for a considerable time and needs the time-consuming assistance of somebody else in order to manage at home or work, or has other significant additional expenses due to a disability, can receive disability allowance. The allowance can be granted from the age of 19 onwards, as long as the disability occurred before they turned 65. Depending on the assistance needed and expenses incurred, the compensation can be 36%, 53% or 69% of the annual price base amount, which corresponded to SEK 1,335 (~EUR 140), SEK 1,965 (~EUR 210) and SEK 2,559 (~EUR 270) per month in 2014. The level of the monthly disability allowance is reduced if the person has other income, e.g. a pension. Persons with blindness or severe hearing impairment always receive this benefit if the disability occurred before the age of 65. Eligibility is based on a doctor's statement. In 2015, some 64,000 persons received disability allowance (Swedish Social Insurance Agency, 2015b).

1.3.2 Carers' cash benefits provided by the municipalities (Social Services Act)

Cash payments for informal carers are unusual in Sweden and are not provided by all municipalities. The uptake among carers and dependent people is very low (the last time data was collected in 2006, only 5,300 persons received this benefit). This development is in line with the Swedish principle that services should be offered before cash. There are two types of municipal cash benefits available for family carers in Sweden. In addition to the services provided to the person being cared for, caregivers can receive an *attendance allowance (hemvårdsbidrag)*: this is a net cash payment that is given to the dependent person, to be used to pay the family member for help. The monthly payment is at most about SEK 4,000 per month (~EUR 450). Eligibility is usually based on the assessed level of dependency or amount of caregiving, 'measured' as hours of help needed, or given, per week. Each municipality has the right do decide whether to provide this programme or not, eligibility criteria, level of payment, etc. There is no federal or state regulation.

Another option is the *carers allowance (anhöriganställning)* (actually not an allowance) which means that the municipality employs a family member for the work. Carers allowance provides similar social security protection as for care personnel in the formal services, and is taxed. The salary amounts to the same as a home help employed by the municipality in their own services. This programme is also a matter for the local municipality to decide on, i.e. no national/federal regulation exists. The opportunity to be employed as carer by the municipality is far from a first choicealternative for the municipality. But in certain circumstances, e.g. older persons living in a remote part of the municipality who have a child living nearby this could be a preferable arrangement for all involved. Another situation when carers' allowance is used is to provide services and care to older immigrants, where the municipality does not have care personnel with the necessary language and cultural competence and therefore employs a child, typically the daughter, living nearby. It is not possible to receive a carer's salary for a person in need of care that is 65 years or older. Carers' allowance has been a seldom used benefit, and even more so nowadays.

Since 2006, data on municipal cash benefits is no longer a part of the official statistics of Sweden and consequently is no longer collected at the national level. In 2006, some 5,300 persons received attendance allowance and almost 1,900 persons caring for an older family member received carers' allowance in Sweden. Nowadays, the general understanding is that the number of people receiving attendance allowance is decreasing. This kind of support plays a very residual role nowadays, as services in kind are prioritised over cash benefits.

1.4 Description of carers' benefits in kind

1.4.1 Services provided on the basis of the Social Services Act (SoL)

Based on the Social Services Act (SFS 2001:453), dependent people of all ages and their families are provided with different types of support. From the family's point of view, direct support is service and care targeted to the carer directly (e.g., information and advice, support groups, in-home respite) and indirect support is targeted to the person cared for (e.g., home-help, institutional care, day care, short-term respite care, housing adaptation, safety alarms).

Direct support is offered by most, if not all, municipalities as a general service, and not based on a needs assessment. The intensity, content and quality of the provided support can, however, vary between the municipalities. Indirect support is accessible after a needs assessment. As eligibility criteria used by the municipalities differs, there are substantial variations in the municipal provision of support. Direct and indirect support complement and sometimes overlap each other. It is not unusual for the person cared for to receive both home help and carer respite service at the same time. Day care and short-term institutional respite care are examples of services that are provided to the person cared for, but with obvious benefits for the carer too. Direct and indirect support is of course also provided by the health care services and moreover many carers also receive help from voluntary organisations.

The prime service in the municipality is home help. It includes help with daily activities, e.g. shopping, cooking, cleaning and laundry. It also includes personal care such as help with bathing, going to the toilet, getting dressed and in and out of bed. As well as home help, there is also a comprehensive range of municipal services for elderly people, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, assistive devices, etc.

Table 1. Persons 80 years and older receiving certain LTC-services the 1 of October, 2008-2013. Number and proportion of the population, rounded values.

Year*	Population 80+	With:							
		home-help in ordinary living		institutional care (permanent)		short-term institutional care		day care	
	Number	Number	%	Number	%	Number	%	Number	%
2008	493,113	113,571	23.0	76,971	15.6	8,086	1.6	7,704	1.6
2010	496,904	116,000	23.3	73,740	14.8	8,063	1.6	7,562	1.5
2011	498,218	118,852	23.9	72,941	14.6	7,800	1.5	7,537	1.5
2012	498,148	118,823	23.9	70,410	14.1	7,171	1.4	7,234	1.5
2013	497,717	115,235	23.2	64,301	12.9	5,932	1.2	6,481	1.3
2014	499,408	115,460	23.1	65,056	13.0	6,685	1.3	6,995	1.4

* *Individual-based statistics not available for 2009.*

Source: Social Services Registry (National Board of Health and Welfare) and population statistics (Statistics Sweden) (National Board of Health and Welfare, 2015).

Since the Community Care reform 1992, municipalities are responsible for all types of institutional care (or LTC institutions according to the OECD terminology). This covers nursing homes, residential care facilities such as old age homes, service houses, group homes for persons with dementia etc. These municipal services are available and accessible for people of all ages, but overwhelmingly used by older people.

1.4.2 Services provided by the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS)

LSS (SFS 1993:387) is a law that sets out rights for persons with considerable and permanent functional impairments. Its ten measures for individualised special support and services are to provide such persons with good living conditions in the community, rather than institutional care (Clevnert & Johansson, 2007; National Board of Health and Welfare, 2009). Those covered by LSS are persons with:

- Intellectual impairments, autism or conditions similar to autism.
- Significant and permanent intellectual disabilities following brain damage in adulthood. The injury has to have occurred through physical violence or physical illness.
- Other permanent physical or mental disabilities that are not due to normal ageing. The disabilities have to be so severe that they cause significant difficulties with daily living activities.

The measures available are:

- Counselling and other personal expert support.
- Personal assistance.
- Companion service.
- Contact person.
- Relief service in the home.
- Short-term stays away from home.
- Short period of supervision for schoolchildren over 12 years of age.
- Foster homes and special housing for children and young people.
- Residential arrangements with special service for adults or other specially-adapted residential arrangements.
- Daily activities.

A central tenet of the LSS is that persons with major functional impairments and an extensive need for support in their daily lives may be entitled to personal assistance. The municipality is financially responsible for those who need assistance for less than 20 hours a week. A person who needs assistance for more than 20 hours a week may be entitled to assistance benefit. The right to this benefit is set out in the *Assistance Benefit Act (LASS)* (1993:389). The Social Insurance Administration takes decisions regarding LASS. The municipality is financially liable for the first 20 hours in such cases as well. Personal assistance has to have been granted before the person reaches the age of 65, and the number of hours of assistance cannot be increased after the person's 65th birthday. The measures in LSS are in principle free of charge to the user, with a few exceptions, e.g., a person who lives in housing with special services has to pay rent for the flat and costs for food and other personal expenses, but the individual will not be paying for service and support from staff. Only 'reasonable' fees are charged (National Board of Health and Welfare, 2009).

A person needing help could 'employ' a family member to provide the help needed. This is not a cash benefit that goes to the parent. The family member is employed by the municipality and paid on the basis of the number of hours of help the disabled person needs, according to a needs assessment. The income is taxed. In all, there were some 19,800 persons eligible for assistance allowances in 2014. The percentage of those eligible for assistance allowance and being cared for by a family member is not known.

2 Analysis of the effectiveness of work-life balance measures for working-age people with dependent relatives

2.1 Assessment of individual measures

Due to lack of data and evaluations regarding carers' leaves and carers' cash benefits, we are not in a position to do a comprehensive assessment of the employment effect of carers and of the wellbeing effect on the carer and person being cared for.

2.1.1 Carers' leaves

The number of recipients of Benefit for care of closely related persons has increased since 2000. Since 2008, the number of recipients has increased by 60%. In 2015, some 15,700 persons used the care leave, which could be compared with some 90,000 deaths in Sweden annually (Swedish Social Insurance Agency, 2015b). This benefit is mainly used for care of older persons. The 'next of kin regulation', which was amended in the SoL legislation in 2009, is most likely a contributing factor to this increase. The amendment of the SoL increased the focus on relatives' legal rights.

Despite this increase, the Benefit for care of closely related persons is a relatively small benefit, in 2013 SEK 153 million (~EUR 16.5 million) was paid out. Given the fact that around 90,000 persons die annually, there should be room for a larger uptake, i.e., an indication that this benefit is underused.

2.1.2 Carers' cash benefits

The number of parents receiving childcare allowance rose by more than 70% since 2000. Children with psychological conditions accounted for the greatest increase. In 2003, the age limit for childcare allowance was raised from 16 to 19 years, causing an increase in the number of childcare allowance recipients from that year. In 2015 there were some 55,000 persons receiving care allowances in Sweden (Swedish Social Insurance Agency, 2015b).

The number of people receiving disability allowance rose slightly in the early 2000s and then levelled off. The minimum age for receiving disability allowance was raised from 16 to 19 in 2003. More women than men receive disability allowance (53% women and 47% men in 2014). The proportion of people receiving disability allowance is largest in the 60-69 age group. Just under 64,000 persons received this benefit in 2014.

2.1.3 Carers' benefits in kind

There has been a dramatic increase in the costs for personal assistance according to LSS and LASS. Therefore, the Social Insurance Agency (*Försäkringskassan*) was commissioned by the government to analyse and report on the development of the assistance allowance. The results were presented in December 2015. In 1994, when Sweden implemented the LSS reform, the introduction of attendance allowance (to cover personal assistance) was an integral part of the reform. The number of people who qualify for the allowance has increased from 6,100 when it was introduced in 1994 to 16,400 in 2014. During the same period, the average number of hours per week and recipient has risen from 67 to 124. As a result, the total number of hours has increased from 21 to 100 million hours in 20 years (Swedish Social Insurance Agency, 2015a). The increase can largely be explained by amendments in the law, legal usage and standardisations. On a more general level, the increases that have occurred can also be attributed to the absence of limits in the law regulating people's rights to this benefit. Both the minister for finance and the minister for health and social affairs have pointed out that a review of the LSS-legislation is needed due to the marked increasing costs for this programme.

The LTC provision regarding older people has also changed dramatically during recent decades, for example in the coverage ratio of persons receiving services; the amount and type of help provided; as well as the numbers of people receiving home-based or institutional care respectively. For decades, Swedish policy and practice regarding the care of older people has been guided by the 'ageing-in-place-policy'; that is, in their own homes rather than in institutions. This policy has led to a gradual downsizing of institutional resources. During the 2000s, there was a 25% reduction in institutional care. Accordingly, an increasing proportion and number of frail older people are now dependent on help in their own homes – both on formal home-help, and on informal help provided by their families and relatives. Approximately two thirds of all care for community-living older people is provided by informal caregivers, and the proportion of older people relying on family for care has increased over the years (National Board of Health and Welfare, 2015).

Taken together, the development of services under LSS/LASS and LTC for older people under SoL (as shown in Table 1) point in different directions. The number of LSS recipients has increased, a development that has been positive for persons with functional impairments, but also most likely has had beneficial employment and wellbeing effects for carers.

With regards to LTC for older people under SoL, the development has gone in the opposite direction; fewer people are provided with services and care in 2014, compared to 2008. This points to negative consequences for older persons and on the family carer's potential to work. The reductions in formal LTC for older people have been accompanied by a re-familialisation of care. Although formal care is still extensive in Sweden, the contribution of informal carers is substantial (see next section). The proportion of older people relying on family for care has increased over the years.

2.1.4 Informal caregiving in Sweden – figures and consequences

During the most recent years, the fact that families are forced to work fewer hours or leave work due to caring obligations has been highlighted. This new insight has led to an increased interest in informal care giving and work and care reconciliation.

Until recently, population based data on informal caregiving has not been available. In 2011, the National Board of Health and Welfare was commissioned by the government to carry out a study of informal caregiving of persons with disabilities and older people, covering the whole country and the adult population.

Table 2: Caregiving in the Swedish population (18 years and older) in relation to intensity of care provided 2012.

	Estimated number of the total population	Estimated percentage in the total population (%)
Provide no care	6,232,000	82
Provide care daily	419,000	6
Provide care least once a week	619,000	8
Provide care least once a month	300,000	4
Total number of persons in the population (18+)	7,570,000	100

Source: National Board of Health and Welfare, 2012.

As seen in Table 2 above, 18% of the population 18 years and older provides help, support and care on a regular basis. This corresponds to over 1.3 million persons in the population. Given the intensity in caregiving, more than 400,000 persons (6%) provide help on a daily basis, more than 600,000 (8%) weekly, and some 300,000 persons (4%) provide help at least once a month.

Table 3 shows caregiving related to gender and age. Women help more often than men in general, but spouses/partners help equally often (not shown here).

Table 3: Caregiving in the Swedish population (18 years and older) in relation to gender and age

	Yes (%)	No (%)	Total (%)	N
TOTAL	18	82	100	8,202
Gender				
Women	20	80	100	4,382
Men	16	84	100	3,820
Age				
18–29 yrs	12	88	100	902
30–44 yrs	13	87	100	1,655
45–64 yrs	24	76	100	2,926
65–80 yrs	19	81	100	2,125
81+ yrs	15	85	100	594

Source: National Board of Health and Welfare, 2012.

Approximately 900,000 persons (70%) of the caregivers are of working age. As shown in Table 3, caregiving peaks in the 45 to 64 age group. 24% of those aged 45-64 identified themselves as caregivers (corresponds to more than 580,000 in the population). Older people (65+) are also frequent caregivers, just over 325,000 in the population identified themselves as caregivers (author's own calculations based on data from National Board of Health and Welfare, 2012). Older caregivers give more intensive help than younger caregivers.

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

In a recent dissertation, Ulmanen (2015) examined the extent of family care for older people and the negative effects of caregiving on the caregivers' working life. A conclusion regarding policy was that the expansion of Swedish eldercare has been driven solely by the needs of older persons; working daughters' needs with respect to eldercare have been a 'blind spot in Swedish eldercare policy'. The downsizing of institutional care has not been fully compensated by the increase in homecare services, resulting in a significant increase in informal care in all social groups, and among both adult sons and daughters. Daughters with less education were the primary providers of informal care. Both caregiving daughters and sons suffered negative consequences of caregiving to the same extent; for example difficulties in managing to accomplish their work tasks and taking part in meetings, courses and travel. They were also equally likely to reduce their working hours and quit their jobs. It was, however, considerably more common for daughters to experience mental and physical strain, difficulties in finding time for leisure and reduced ability to focus on their job.

The wellbeing of carers and the person they care for is very dependent on the availability, affordability, quality and accessibility of public services. Recent development in the caring services tends to go in the opposite direction, i.e. services are becoming increasingly rationed, which probably has repercussions on the carers and those cared for. As mentioned above, the fact that people have to reduce working hours and ultimately have to leave work is an evident symptom of growing problems. Unfortunately, no further data is available.

International comparative studies show that countries with high numbers of paid care workers, also tend to be countries spending the highest proportions of GDP on LTC (typically the Nordic countries). A report from the Social Protection Committee Working Group on Ageing (2014) showed that the lowest percentage of informal carers is found in Denmark and Sweden, which are also the countries with the most paid carers. Compared to many other countries, more caring is done by paid LTC workers in Sweden, and the proportion of informal carers providing daily care is much lower.

According to data from the Labour Force Survey (LFS) on reconciliation of work and family life from 2010 (see Statistical Annex in Synthesis report on Work-life balance measures for persons of working age with dependent relatives), the proportion of persons in Sweden who '*regularly take care of other children up to 14 years of age (other than own/spouse's children living in the household) or of ill, disabled, elderly relatives/friends aged 15 or more in need of care*' is much lower than the EU-average, whereas the gender distribution of those doing the caring – 60.5% women, 39.5% men - was identical with the EU-average. The LFS data shows that Sweden has one of the highest percentages of women in the labour market in Europe (77.6% against 63.4% in the EU-28, 2014). The LFS indicator '*inactive population – looking after children or incapacitated adults as the main reason for not seeking employment*', applies to 4.3% of the Swedish population in the age group 15 to 64 (7.5% among women and 0.4% among men). These numbers are substantially lower than the EU average (total: 9.6%; women: 15.0%; men: 1.2%).

Szebehely (2010) has studied the association between middle-aged women's participation in paid work and the magnitude of LTC in different countries. The association is weak among most countries, but the Nordic countries (Sweden, Finland and Denmark) show both high participation in the work force and more public resources for LTC. Therefore it could be argued that public LTC for older people is not only a cost, it is also a precondition for women's labour force participation, and thereby a precondition of a broader tax base to finance public welfare services.

2.2 Assessment of overall package of measures and interactions between measures

The measures described in Part 1 are not, mainly, designed to address issues regarding work-life balance. Policies, legislation and other service measures in Sweden aim to help and support the individual and to promote maximum independence from the family and not primarily to facilitate the working population staying in the labour market. The high percentage of women in the labour force (80%) is evidently an effect of extended public welfare programmes. Obviously, the legislative measures in SoL and LSS have been effective in unburdening families and carers of older and disabled persons. LSS has also provided the opportunity for many severely disabled persons to live an independent life. Before LSS came into force, these persons were doomed to a life in institutions or to a life dependent on their families.

As mentioned earlier, increasing LSS costs have been a great challenge for the municipalities and the government during the last decade. An unexpected 'side effect' of the increasing LSS costs is that care provided by families has become visible. Those covered by LSS are, since the introduction of LSS in 1994, entitled to special support and services that earlier were provided by the families to a large extent.

The paragraph added to SoL in 2009, stating that social services are obliged to provide support to persons who care for next of kin, has contributed to a rather rapid development of supportive services, especially support for carers of older people. Municipalities all over Sweden have expanded the availability, access and diversity of support.

However, carers' organisations have raised critical voices. They point to lack of tailoring, quality and timing of support. They complain about training and professional skills among care workers in the municipalities, and them not being able to understand the diversity of caring needed and the situation of carers. From a carers perspective, the results are even more ambiguous and contradictory. The outcome in terms of support to individual carers and families is difficult or impossible to show, as no system for documentation or statistics over support to carers exists.

With regards to interaction between programmes, we are nowadays witnessing a negative interaction between less generous services for families with disabled persons and reduced working hours due to caring responsibilities. The driving force behind this development in old age care has been the rapid reduction of institutions for older people (as well as hospital beds), which evidently has had negative repercussions on their adult children's ability to work to the extent that they would prefer. The declining coverage of eldercare services has been followed by an increase of family care, affecting mainly older people with lower education while those with higher education and more financial resources are instead increasingly purchasing private services (in recent years subsidised by a tax reduction for domestic help and care) (Rostgaard & Szebehely, 2012; Szebehely & Trydegård, 2012).

The growing work-life balance problem is a relatively new insight in Sweden. It was not until 2014 that this work-life balance issue was recognised in the political discourse, when the left parties pointed out that around '140,000 persons have quit their jobs or reduced their working hours to care for their old parents'.

2.3 Policy recommendations

The Nordic welfare model, where care for disabled and older people is a public responsibility, has been shown to be an effective way to relieve the care burden of families. Despite cutbacks in the public care system, Sweden still has a generous public care system compared to many other countries. But it is clear that if the welfare system is dismantled, the care burden of families will increase.

The high percentage of women in the labour market (77.6% in 2014) necessitates a public welfare system to care for disabled and older people, as does the fact that very few older people (less than 3%) share their homes with their adult children.

If the Swedish model with a public responsibility for the care of children, the disabled and older people is to prevail, one of the major challenges will be to secure financial sustainability.

According to the Swedish model and context, the best support for relatives should be good public care and services for those in need, for example institutional care, home-help, personal assistance and hospital beds, as well as personnel with adequate education and competencies.

In a long term perspective, there is a need to develop a system for identification and needs assessment, as a base for tailoring support, which must capture the dynamic, diversity and the ways in which caring demands change over time. Risk assessment for carers should be part of the normal assessment procedures and monitoring of persons in need of care.

The cornerstone for evidence-based policy making regarding caring and carers is the provision of adequate data for monitoring and research purposes. In Sweden, there is an urgent need for better regular and representative statistics and a robust monitoring or evaluation system in order to answer questions about targeting, efficiency and quality of the support provided.

Informal care of dependent persons has not been included in Swedish family policy. Support policies for carers can be an integrated part of LTC policy, family policy or an add-on policy. The 2009 legislation (the SoL amendment regarding support to informal carers) points towards a break from the traditional Swedish model and a revision of the existing social contract. But it is still an add-on policy, not integrated with other policies, such as pension and employment legislation. Therefore, issues regarding informal caregiving must be fully included in national family policy, i.e. Sweden still lacks a person and family centred caring service – or in other words – a coherent family policy.

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