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PERSONAL ASSISTANCE IN SWEDEN

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1. Introduction

Giving disabled people control over their own lives by providing them the opportunity to steer their own support: that is what direct payment is all about. This implies that disabled people directly receive the budget for their support instead of the government funding the care providers. With this budget, disabled people may engage their own personal assistants. In that way they (or their legal representatives) become budget holders, but also employers. It enables disabled people to shape their own lives in an independent way.

That is the philosophy, which underpins the Personal Assistance Budget as it was implemented by decree in Flanders in 2000. Many years of lobbying had preceded that achievement. The activists of *Independent Living Flanders* have consistently referred to those countries where the system of direct payments was already in use and where it had revealed to be successful.

Ten years later, we now have the *Expertise Centre Independent Living*. We research the functioning of direct payments in Flanders and abroad. We also gather and publish existing information, because knowledge is power. Principles matter of course, but if you are able to underpin principles with facts and figures you stand more firm in the debate.

Take for example figures on the cost of direct financing. Or look at good practices in countries where direct payments are already a well-established system. After having documented the situation in eight different European countries (2008), we decided to concentrate on the Netherlands and Sweden.

The *Independent Living Institute (ILI)* has written this report on the Swedish situation on our demand. We gave ILI a list containing questions and topics on hot issues in Flanders. What is the legal framework? How does the assessment take place? What is the assistant's statute? What are the experiences with private enterprises? In this report, Kenneth Westberg answers these questions. He has written this report under the guidance of PhD. Adolf Ratzka. Suzanne Berg has translated the document into English. Davy Gaeremynck has taken care of the Dutch translation. We thank them for the work and their contribution to the realization of this report.

We hope that this report will incite you to learn even more about this interesting subject, for this is what we plan to work on during the following years.

Elke Decruynaere – Juliska Van Hauwermeiren – Peter Lambreghts,
Collaborators of the Expertise Centre Independent Living



2. General Introduction to the Reform

In 1994, personal assistance became a legalized right in Sweden. Persons with extensive disabilities were granted direct payments. Then onwards, they could purchase personal assistance services through either the municipality or the Social Insurance Agency. The situation of persons in need of personal assistance services before the reform, as well as the events leading up to the legalization, and the role of the Swedish Independent Living movement its origins have been described elsewhere.

The purpose of the reform is to provide assistance during everyday activities, so that individuals with extensive disabilities can live like others in the community. The aim is to enable a “good quality of life” and to cater to the individual’s needs and preferences. The assistance user has the right to choose who is to work as a personal assistant, but s/he may also decide on when, how and where the assistance is provided, and who employs the personal assistants.

Benefits under the legislation are based solely on the individual’s need of personal assistance and are not means-tested, i.e. not dependent on assistance users’ or their families’ income and wealth. Payments do not constitute taxable income.¹

2.1. Who is Eligible to Receive Personal Assistance?

Persons can be eligible for personal assistance, if they belong to one of the three groups specified in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS):

- 1. Persons with an intellectual disability, autism or a condition resembling autism;*
- 1. Persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness;*
- 2. Persons who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service.*

In addition, people have to require assistance with at least one of the following five fundamental needs:

1. Personal hygiene
2. Eating
3. Dressing and undressing
4. Communicating with others
5. Other help, which requires detailed knowledge of the person’s impairment

Persons who need 20 or more hours of assistance per week for these fundamental needs are entitled to personal assistance payments from the Assistance allowance Act (LASS). Payment for personal

¹ SFS 1993:387; SFS 1993:389; Socialstyrelsen (2009a)

assistance from LASS is provided through the Försäkringskassa [Social Insurance Agency]. Persons who need less than 20 hours of assistance per week can apply for personal assistance services or direct payments to purchase services from their local municipality under LSS.

In addition to the assistance hours for the fundamental needs, individuals receive payments for the purchase of additional assistance hours for activities such as assistance for household chores, at work, caring for one's children, during leisure time or when travelling. LASS can be regarded as an appendix to LSS, designed to reduce municipalities' costs. Municipalities, however, are responsible for covering costs for the first 20 hours per week, irrespective of whether an individual has personal assistance under LASS or LSS. This is a pure administrative transfer of costs and does not involve the individual assistance user.

In case a temporary increased assistance need is not covered in the assistance user's original decision, the municipality can grant additional assistance hours. Additional hours can be granted for temporary illness, vacations or tasks at work that require more assistance. Also, assistance users can apply with the municipality for payment of accompanying assistants' entrance tickets to events, meals, accommodations and transportation when travelling. When assistance needs change permanently, individuals can ask for a reassessment.

There is no minimum age for eligibility for personal assistance payments or services but the maximum age for eligibility of assistance payments under LASS is 65. Persons who received LASS payments at a younger age remain entitled after 65. The same applies for personal assistance services or payments for such services provided under LSS from the municipality.²

2.2. How is Personal Assistance Provided?

Users who receive their assistance allowance from LASS can choose to purchase assistance services from their municipality, from private for-profit companies or employ their personal assistants themselves individually or collectively by joining a users' cooperative. Users who receive their assistance allowance from LSS can choose to have their personal assistance provided by the municipality. They can also choose to receive direct payment from the municipality, and purchase assistance services from private for-profit companies or employ their personal assistants themselves individually or collectively, in the same manner as users who receive their assistance allowance from LASS.³

Users who receive their assistance allowance from LASS have a right to receive payment from municipalities covering the costs (i.e. sickness benefits) arising from personal assistants' illnesses. This is viewed as a part of municipalities' fundamental responsibility for assistance, as it is their obligation to provide assistance services for users who do not choose another way of delivery.⁴

² Socialstyrelsen (2010a); Försäkringskassan 2003:6 ver.5

³ Försäkringskassan 2003:6 ver.5

⁴ SKL (2006)

2.3. What is the Size of the Assistance Allowance/Direct Payment for Assistance? What are the Required Accounting Methods?

Assistance allowance is provided according to a flat rate per hour, which is revised yearly. In 2010, the hourly sum provided is SEK 252, approximately € 24.8 (exchange rate according to xe.com at 2010-03-01). The yearly revised rate is set to cover 100% of the costs of the assistance user's assessed number of hours. The flat rate is the same for all recipients throughout the country, regardless which service provider the users choose or if they employ their assistants themselves. When greater expenses can be shown (for example due to many hours or need of specially trained assistants) a flat rate up to 12% higher can be applied for.

Funds are paid in advance. The assessment of assistance hours is based on the needed average per month. However, this decision is based on the sum of hours during a six-month period, after which the recipients are required to account for their use. Recipients of the payments need to show that they actually have used their hours, by supplying time sheets signed by their assistants. Persons, who employ their assistants themselves or who receive higher flat rates, also have to account for the spent funds.

Assistance hours can be used flexible within the six-month period. According to the assistance user's needs and wishes, the sum of used assistance hours can vary monthly, provided that the total amount during the six-month period does not exceed the hours granted. Funds, which are provided for assistance hours and which are not used within the account period, return to the Försäkringskassa [Social Insurance Agency]. Assistance service providers are paid by the user for the number of assistance hours delivered. Any profit is subjected to regular taxes.

While assistance allowance provided under LASS is regulated in detail, direct payment for assistance services from the municipalities under LSS is not. It is not controversial, but the government expects to regulate the work of a government agency, such as the Försäkringskassa [Social Insurance Agency] in quite some detail. The municipalities, however, are local political units with the power to issue local taxes and govern areas of responsibility assigned to them. The municipalities are defined as local self-government in the Swedish Constitution. Of course, their activities are executed under the laws, but for the government to place obligations on municipalities as separate democratic units and to regulate the manner in which they fulfil these obligations, are two separate things.

In principle, there should be no difference for the individual when it comes to receiving payment for personal assistance either from the municipality (LSS) or from the Försäkringskassa [Social Insurance Agency] (LASS). The municipalities should provide payments covering 'reasonable costs'. According to Socialstyrelsen [National Board of Health and Welfare], this should amount to the same sum provided by the assistance allowance under LASS, i.e. app. €24,8 (exchange rate according to xe.com at 2010-03-01).

The Försäkringskassa [Social Insurance Agency] issues guidelines (not binding) for the use of the payments. Assessment of hours by means of a flat rate system was introduced in 1997. The size of the flat rate is decided on recommendation by the Försäkringskassa [Social Insurance Agency] and

Sveriges Kommuner och Landsting, SKL [Swedish Association of Local Government and Regions]. Approximately 87% of the benefit has been dedicated to salaries and employment-related costs. The final 13% of the flat rate is divided into different types of costs that can differ due to the individual assistance users' life. This is based on an average sum to cover costs that arose before the flat rate system. The sums are updated yearly on recommendations from the Försäkringskassa [Social Insurance Agency] and Sveriges Kommuner och Landsting, SKL [Swedish Association of Local Government and Regions], taking into account their experiences of actual costs.

85-87 % is spent on direct and indirect labour costs, including remunerations, employer's social fees and wage taxes, pensions and other costs stipulated by trade union agreements such as workmen's compensation, sick leave and similar insurances and taxable benefits.

5-8 % is spent on administration of personal assistance services, including costs for running and maintaining an office, equipment and material, travel, certified public accountant, company insurances, membership fees in employers' and trade associations, etc.

2-3 % is spent on training for assistance users, personal assistants and office staff such as courses, trainers and the supervision of personal assistants.

1-2 % is spent on measures for safety and work environment, the staff's health and well-being, a staff room, basic equipment, beverages, soap and lotion, etc.

1-2% is spent on the costs of accompanying assistants when outside the user's home, such as entrance tickets, transportation, meals, etc.⁵

Generally, personal assistance can be granted for up to four weeks when users are hospitalized. Longer periods are possible when the nature of one's disability makes the assistance relevant in the hospital, e.g. when a limited number of persons with intimate knowledge of the person's needs is imperative or when the person's ability to communicate depends on a limited number of people who have learned to interpret the person.⁶

2.4. How many Individuals Receive Assistance and which Providers do they Choose?

For October 2009, the Social Insurance Office reports 15,710 persons entitled to the Social Insurance Office's payments for personal assistance under the LASS Act. Of those persons, 48,6% chose the municipality as provider, whereas 37,7% chose private assistance companies, 10,8% opted for a users' cooperative and another 2,8% employed their assistants by themselves. The figures for private firms have risen since 1994 at the expense of the municipal and cooperative providers. The average number of assistance hour used was 110,24 per person and per week. An additional 3,500 persons

⁵ Försäkringskassan 2003:6 ver.5

⁶ SFS 1993:1091; Försäkringskassan 2003:6 ver.5

had personal assistance from municipalities under the LSS Act. No breakdown as to provider category is available for this group.⁷

Approximately 70,000 persons worked as personal assistants in Sweden in October 2007, corresponding to approximately 45,000 full-time positions. The number of assistance users in October 2007 totalled 18,167 under both the LSS and the LASS acts. Also for October 2007, the number of assistance providers (companies and cooperatives) was estimated at 450, which included organizations with 1 and some over 1,000 clients.⁸

2.5. What are the Antecedents to Personal Assistance in Sweden? How was it Introduced?

In an article published 1982 Ratzka, who had direct payments for personal assistance during his university studies in the US, introduced and defined the term “personal assistance”. He argued for direct payments for personal assistance in the form of expanded handikappersättning [disability allowance]. This was an existing benefit by the Försäkringskassa [Social Insurance Agency], and it was intended to compensate individuals for the additional costs of living due to disability. The additional cash payments would replace services in kind delivered by municipalities in the form of cluster housing such as Fokus and municipal home care services. With an amount corresponding to the municipality’s costs for the individual’s current cluster housing or municipal home care services, Ratzka suggested, users would be able to purchase their services from competing service providers. Users who are unable or unwilling to contract service providers or to employ their assistants themselves, should be able to contract municipal services paying with their funds from the Försäkringskassa [Social Insurance Agency]. Among the advantages for assistance users would be freedom of choice, improved service quality as result of competition among service providers, increased self-determination as well as geographical and social mobility.⁹ In 1983, Ratzka organized a conference in Stockholm introducing the philosophy and approach of Independent Living to Sweden. In 1984, he initiated the founding of the first Scandinavian Independent Living organization, STIL (Stockholm Cooperative for Independent Living), and a pilot project with the goal of realizing personal assistance services for STIL members.¹⁰

Situating the concept of personal assistance in a wider context, STIL introduced concepts that were largely new to Swedish disability politics and the Swedish welfare state at the time. These new concepts were self-determination, self-representation through organizations run and controlled by persons with disabilities, de-medicalization, de-professionalization, de-institutionalization and discrimination.¹¹

⁷ Försäkringskassan (2010); Socialstyrelsen (2009c)

⁸ SOU 2008:77 pp.19-22

⁹ Ratzka, A. (1982)

¹⁰ Berg, S. (2008); Ratzka, A. (1986)

¹¹ Ratzka, A. (1989)

After several years of campaigning for personal assistance and tirelessly pointing out the shortcomings of cluster housing and municipal home care services, STIL could start its pilot project in January 1987 with 23 participants. The Ministry of Health and Social Affairs under the leadership of its Social Democratic minister Bengt Lindqvist agreed to finance part of the project's administrative costs, after which the reluctance of the City of Stockholm eased. STIL functioned as a subcontractor to the City of Stockholm, delivering personal assistance services to cooperative members who took part in the pilot project.¹²

STIL, as employer of the assistants, calculated and paid assistants' wages, withheld taxes, paid employment fees and insurances as specified by union agreements. The cooperative also managed contacts with the municipality, the trade union, the media and politicians. Tasks essential for the quality of services, such as recruiting, training, scheduling and supervising assistants, were delegated to the individual member for maximum control and influence over service quality at a minimum of paper work. To prepare members for their supervisory role, STIL offered training and support both individually and in groups based on peer support. The vast majority of the office staff were personal assistance users. Only users were eligible to serve on the cooperative's board. Members' assistance needs were assessed by staff of the municipality's division of home care or cluster housing services, and expressed in a number of hours per month. The number of hours was then multiplied with the flat rate per hour, which the municipality and STIL had negotiated. This amount was paid in advance to STIL on behalf of the member.

During the pilot project, STIL developed a system of internal rules and regulations delineating the division of responsibility between cooperative and member, suggesting control mechanisms to the City. Much of this system was taken over by LASS, such as the concept of expressing assistance needs in terms of hours (as opposed to needs categories), time sheets signed by assistants as proof of how funds were used and the ability to save hours and funds over a twelve-month period for maximum flexibility. The pilot project showed the viability of STIL's vision, gained considerable political acceptance and raised interest in other parts of the country as well as abroad, particularly in Norway.

The pilot project was evaluated by external research showing that personal assistants employed by the cooperative experienced half the physical and emotional stress that a comparable group of workers reported in the City's cluster housing facilities. Seventy-five percent of the assistants had interests in common with the person they worked for (as opposed to 25% of the staff in cluster housing); 90% of STIL workers considered it crucial that assistance users are able to choose their assistants (as opposed to 30% of the staff in cluster housing). Eighty percent of the STIL assistants considered STIL to be the best service delivery (as opposed to 30% of the staff in cluster housing).¹³

After two and a half years, STIL asked the City of Stockholm to discontinue the pilot project and instead give all people in need of personal assistance the permanent possibility to join STIL or to form new assistance user cooperatives. The social services administration in the City of Stockholm was sceptical against services shaped and run by STIL. The City suggested compromises that would have entailed more control by the social service administration over STIL's proposed activities. An early

¹² Berg, S. (2008); Ratzka, A. (1990); Ratzka, A. (1993)

¹³ Gough, R. (1994)

response, which also was shared by many people in the disability movement, was to run the project within the City of Stockholm's department of social services, within the existing system. STIL declined and avoided these concessions, afraid to lose control over the project and also refusing compromises on its concept of self-determination.

In July 1989 and with the majority of a single vote, the City adopted a proposal granting inhabitants of Stockholm the right to receive direct payments and organize their own assistance. Other municipalities followed Stockholm's example and several new cooperatives were formed in Stockholm and other parts of the country, many of which copied STIL's approach and received training and financial support from STIL.¹⁴

2.6. What were the Arguments Pro and Contra Personal Assistance?

Privatization leads to bad services and exploitation

In the middle of the 1980's, privatization entered the political agenda. By privatization we mean the rise of private organizations delivering services which traditionally had been provided by public monopolies. Pyslingen, the first private day care centre and day care centres run by parents' cooperatives, fought a long uphill battle before they finally were able to start in 1983. The privatization of service provision was perceived as a threat by the political left, which included the ruling Social Democratic Party. According to these sentiments – which are to some extent still present today - only providers of health and social services owned, run and controlled by government entities are able to guarantee general welfare. Private operators were accused of profiting on vulnerable people's needs at the public's expense.

The labour unions also feared that their members would be exploited. Kommunal [Swedish Municipal Workers' Union] felt threatened by the prospect of disabled people employing their assistants and exploiting them under poor working conditions. In addition, they foresaw difficulties in organizing and protecting union members who were employed by assistance users and worked in their home, instead of in municipal organizations including the semi-institutional cluster housing.

"The disabled will 'eat up' their employees"/---/ They are completely unable to understand that their employees have a private life too."¹⁵

STIL, a not-for-profit membership organization, countered this negative view by pointing out that it was a cooperative and, thus, part of a long and proud tradition of cooperatives started by the labour movement such as cooperative building societies, credit unions, funeral societies or food chains. In negotiating the original contracts with municipalities, STIL received important legal assistance from the Swedish Cooperative Development Agency through a seconded lawyer. The Swedish Folkhem [People's home] harbours two separate trends of providing social security and services: in kind

¹⁴ Ratzka, A. (1993); Berg, S. (2008); Skansgård, B. (2003)

¹⁵ Berg, S. (2008); Nygren, C. (1986)

service provisions regulated and provided by the social services under the municipalities; and direct payment support provided by the government through the Försäkringskassa [Social Insurance Agency]. STIL argued that direct payments were a part of Social democratic ideology, referring to the Social Democratic Minister Gustav Möller, who is credited for introducing the present Swedish social security system in the late 1940's. Möller was known to favour cash payments as part of the social insurance system over services in kind. He propagated welfare benefits in cash, administered by the recipients themselves.

To counter arguments from Kommunal [Swedish Municipal Workers' Union] on the exploitation of personnel, STIL argued that its system relied on assistants' and assistance users' voluntary and mutual consent. In effect, they chose each other, which was in stark contrast to the municipalities' home care services or cluster housing services ran by the principle that "anyone has to work for anyone" and where neither workers nor clients had a choice in this respect.¹⁶

Personal assistance an elitist solution

Another argument against STIL's initiative was the notion that the solution was only for an elite of persons with mainly physical disabilities, since it demanded involvement, time, energy and skills of its members. Several disability organizations as well as civil servants within municipal social service departments voiced their concerns that cash payments for personal assistance might improve services for the strong at the expense of the less assertive assistance users. No evidence was provided for this claim.

Regarding the elitist argument, STIL took the position that, as in all innovations, it takes pioneers to break new ground, test it and lead other people who are ready to follow their example. Thus, pioneers were needed to demonstrate the viability of STIL's vision against resistance from the municipal administration and the disability movement. The subsequent development of LSS and LASS is evidence that direct payment for personal assistance, while pioneered by a few, is a solution for all.

STIL also countered the accusation of being elitist by pointing to its considerable efforts of training and supporting members in their management role, emphasizing the fact that education and self-improvement through mutual efforts had always been one of the cornerstones of the Swedish cooperative movement. According to STIL no service solution should be ruled out because not everybody was willing or able to use it. People, including assistance users, differ from each other in many aspects including family situation, assistance needs, physical and mental capabilities and all should have the right to choose freely their preferred solution as long as their choice did not affect other assistance users negatively.

Foreseeing the elitist argument, STIL had been keen to include children with assistance needs and a young man with Down's syndrome in the pilot group. For these members, STIL developed a solution consisting of either legal guardians or especially trained and supervised personal assistants who complemented the assistance user's abilities and assisted him or her in carrying out the customary

¹⁶ Berg, S. (2008); Ratzka, A. (1990); Ratzka, A. (1993)

tasks of STIL members such as recruiting, scheduling, training and motivating assistants. For the record, in 2009 forty percent of STIL members belonged to this group. Another Swedish cooperative, JAG, based on STIL's model, is fully composed by persons who cannot carry out these functions themselves.¹⁷

Abuse of public funding

There was also initial concern about the risk of misappropriation of public funds or mismanagement by disabled people - sentiments that to some extent still can be sensed in the public discourse.

According to STIL, its model did not involve higher costs of services to the public – most likely considerably lower costs – and it relied on fewer municipal administrators whose functions were now being taken over by STIL members. Thus, more municipal staff resources were made available for municipal clients who needed more help. Once the pilot project after long and careful preparations was running, it became apparent to all persons involved that STIL was capable of handling large funds professionally. In an op-ed article in 1990 in the largest Swedish daily morning paper, STIL provided cost figures to prove this point.¹⁸

2.7. How did the Established Disability Organizations Teact to the Introduction of Personal Assistance?

In defence of boendeservice [cluster housing].

The biggest resistance against personal assistance came from the disability movement, notably from the organizations, among them: DHR – Förbundet för ett samhälle utan rörelsehinder [DHR – the association for a society without disabling mobility – formerly The National Association of the Handicapped]. They had invested energy and prestige in the Boendeservice solution (cluster housing, seen as an improvement over original Swedish Fokus Housing). Boendeservice [cluster housing] combined accessible flats with dedicated home care services. Flats in ordinary residential areas, often within one building or housing complex, were adapted, assigned through the social services and rented out to persons with disabilities who needed personal services. Services were then provided to the tenants by a group of home care workers located in a facility nearby. These were viewed as part of the municipal home care services. Persons with disabilities living in boendeservice [cluster housing] shared a dedicated personnel group.

Cluster housing inmates had complained for years about lack of control over their daily lives; they suffered humiliation because of having to accept assistance – even for the most intimate bodily functions – from literally any male or female worker; and they encountered mobility restrictions, which made assistance possible only in one's home, i.e. "house arrest" as STIL has disrespectfully called it. DHR's answer to these valid complaints was to demand Förstärkt Boendeservice ("reinforced" cluster housing) from the municipality, i.e. "more of the same" in STIL's interpretation.

¹⁷ Berg, S. (2008); Ratzka, A. (1990); Ratzka, A. (1993); JAG (2006)

¹⁸ Ratzka, A. (1990)

While DHR saw the solution in more staff training, STIL demanded power and self-determination for the individual who could be achieved by employing personal assistants, and self-representation for persons with disabilities as a group. STIL also argued that DHR's national chairperson, its director and a large number of board members, were not fit to have any views in the matter since they, as non-disabled persons, had no first-hand experience of living in cluster housing units.¹⁹

Boendeservice [cluster housing], as far as STIL members were concerned, should be seen as institutions according to Independent Living criteria. The most important criteria are bundling housing and attendant services which limit the individual's geographical and social mobility to a restricted number of locations. On top of that, the individual is unable to decide who carries out which tasks, when, where and how. In institutions, inmates do not have the same range of choice as the general population when it comes to the size of the housing unit and its location. They are forced to adapt their lifestyle to the institution's organizational needs.²⁰

Background – boendeservice [cluster housing], a service fitting the Swedish Folkhem [People's home]. DHR's position followed the Swedish welfare state tradition, where stakeholders through negotiations attempt to reach uniform solutions for all individuals; where life is divided into various realms (e.g. education, work and housing); where disabled people's needs are to be integrated and met within each realm; and where the responsibility for meeting one's needs rests with administrative departments of municipal and state government. DHR's underlying vision of society is that of the Folkhem, [the People's Home], a concept which has been instrumental in forming the Swedish welfare state since the 1930's. In the Folkhem [People's Home], all members' needs are met in solidarity, as in a family. The State, similar to a parent, determines nature and amount of compensatory and redistributive interventions. Implementation is delegated to a body of neutral, efficient and well-intentioned civil servants. In this tradition, DHR's members saw themselves entitled to well-functioning home care services or cluster housing services, which did not require any input, time or energy on the part of service recipients.²¹

This approach had led to a patchwork of different services, each under its own administration, regulations, telephone hours and case handling staff. Each service is run by professionals delivering interventions such as pupils' assistance at primary school and high school (elevassistans), attendance at one's work place (arbetsbiträde), night patrol to help people go to bed (nattpatrull), companion services for going out (ledsagarservice), special transportation service (färdtjänst) and visiting nurses (hemsjukvård). Coordinating these services required planning weeks in advance, as well as considerable organizing and diplomatic skills, patience and a high frustration tolerance.

STIL members noted that the Folkhem [People's Home] in its present shape did not give them the same degree of control over their body, their everyday life and life projects, which non-disabled persons take for granted. Dividing their existence into different domains, over which other persons such as professionals and administrators but not the individual had ultimate control, split up their lives and made them feel powerless. The "balkanisation" of one's existence was seen to prevent

¹⁹ Berg, S. (2003); Ratzka, A., (1986)

²⁰ Ratzka, A. (1986); Ratzka, A. (1992)

²¹ Berg, S. (2007); Berg, S. (2008)

people from experiencing themselves as whole persons and caused feelings of inferiority, frustration, and resignation. A solution to the problems caused by cluster housing and home care services, according to STIL's analysis, was to enable individuals with disabilities to see themselves as whole persons again, and to regain power over their lives through the practical means of exercising control over all domains of their everyday life. Personal assistance under the individual user's immediate and full control was this solution.²²

In the beginning of the 1990's, DHR gradually accepted personal assistance as an alternative to cluster housing, after STIL's success had gained massive media support and after more cluster housing residents had climbed to higher positions within the DHR hierarchy.²³

2.8. Which Factors were Decisive for Personal Assistance to Become a Legalized Social Right?

Proof of home care services and cluster housing services bad quality.

In 1988, a Parliamentary Committee was charged with investigating the situation of persons with disabilities in order to suggest solutions. It also considered the living conditions of persons in need of assistance for everyday activities. This Parliamentary Committee confirmed reports, voiced earlier by STIL members and other persons with home care services or cluster housing service, on the low quality of these services. Due to high turn-over rates among the personnel, persons with disabilities were never sure who would enter their doors; 54%, or 400 persons with disabilities receiving home care services or cluster housing services, stated that they had to rely totally or partially on family and friends in order to manage their lives.

"The powerlessness and the disempowerment our interviewees express are all the signs we can expect in a situation such as this: routine limitations of tasks, a work organization built on exchangeable personnel, complaints met with referrals to a system of rules, difficulties to know who decides and to whom you can complain."²⁴

Political support.

Strong political support for STIL and its Independent Living principles of self-determination, freedom of choice and personal responsibility, came from the liberal party Folkpartiet, both in Stockholm and nationwide. Under its popular leader Bengt Westerberg, the party became part of the ruling conservative coalition in 1991-1994, with Westerberg as Vice Prime Minister and Minister of Social Affairs. Disability politics were often characterized by political unity, making it in essence apolitical. The issue of personal assistance in Sweden broke the political mould and became a symbolic issue. For Folkpartiet, under Westerberg, personal assistance and Independent Living became a symbol of general politics and ideology. In his capacity as Minister of Social Affairs, Westerberg tabled the propositions for LSS and LASS in Parliament with words permeated by the spirit of Independent Living:

²² Ratzka, A. (1986); Göteborgs Stad (1987)

²³ Ekensteen, V. (1990); Ekensteen, V. (1991)

²⁴ SOU 1990:19 p.371; SOU 1991:46

“The person needing a service must be able to make demands and to shape the service”... Nobody with extensive disabilities and assistance needs will be depending anymore on the municipality’s level of ambition and economy /---/ personal assistance means that the person with a disability has access to his or her own human assistive device which does what the disabled person’s hands, feet, eyes, ears or mind do not manage.”²⁵

In later years, Kommunal [Swedish Municipal Workers’ Union] had changed its position and now agrees that members working as personal assistants enjoy better working conditions than workers in municipal home care services do, the reason being that personal assistants work longer contiguous shifts with one person only compared with many short interventions for home care service clients. Also, personal assistants can choose whom they work for, unlike their colleagues in home care services or cluster housing facilities. In 2009, the union voiced their opposition against a Parliamentary Committee proposal that would replace personal assistance for many users with services similar to home care services. The union argued that the change would worsen the working situation of its members and the quality of life of their users.²⁶

2.9. The Impact of the Enactment of LSS and LASS on Institutionalization

In Sweden, larger residential institutions for citizens with physical disabilities had disappeared before the 1980’s. Residential institutions for persons with cognitive or psychiatric disabilities started to be phased out later and a legal obligation to provide services within the community was enacted in 1985.²⁷ The demand for cluster housing decreased rapidly, with the introduction of LASS and LSS in 1994, when direct payments for personal assistance became available for the inmates. Municipalities, who were responsible for cluster housing, had now economic incentives to close down cluster housing units and to suggest to residents to apply for LASS, as assistance allowance was not granted for services part of cluster housing or group dwellings.²⁸ Group homes, i.e. smaller units with up to five persons, each with their own room and bath, sharing a common staff and common areas in a house or larger apartments, or other specially adapted housing unit are (in 2008) the homes of some 22,300 adult citizens with cognitive disabilities under LSS, which charges municipalities to provide and finance this option.²⁹

Before LSS and LASS provided a legal social right to personal assistance, citizens with extensive assistance needs sometimes had to live in nursing home and similar long-term care facilities, if their municipality did not provide cluster housing. Some persons with disabilities and extensive needs for assistance also lived with their families. As a remuneration for these services, the families received a monthly vårdbidrag [family care allowance] from the Försäkringskassa [Social Insurance Agency]. According to Socialstyrelsen [National Board of Health and Welfare], the introduction of LASS and LSS

²⁵ Lindberg, L. (2008); Westerberg, B.(1993)

²⁶ Kommunal (2008)

²⁷ Ericsson, K. (1985)

²⁸ Berg, S. (2007)

²⁹ Socialstyrelsen (2009c)

led to a decrease in vårdbidrag [family care allowance] of approximately 100 million SEK per year, approximately 10.250.000 € (exchange rate according to xe.com at 2010-03-01).³⁰

Personal assistance has replaced not only care given in institutional form, but has also replaced care provided within the family which enabled family members receiving and providing care. Personal assistance has replaced: personnel within the home care system, family members being compensated for caring, and support personnel within special housing since people do not move into collective dwellings anymore but largely live in their own apartments.³¹

In 1995, the JAG association, whose membership consists of persons with a combination of mobility and extensive intellectual impairments, interviewed 66 members receiving personal assistance within the JAG cooperative. Ten years later, the 55 of them still alive were interviewed again, only four of them had ceased to use personal assistance. The interviews gave the following conclusions in connection to personal assistance:

- In 1993, 20% of the interviewees aged 18 and above lived in housing of their own. In 2005, closer to 60% of the persons interviewed aged 18 and above lived in housing of their own.
- Self-determination in everyday life is enabled through assistance. This, however, puts high demand on adequate supervision.
- Demand for short-term relief residence has decreased sharply since many live in housing of their own.
- Family care allowance, relief service and home care are practically never used by the persons interviewed 2005.
- Demand for health care and number of stays in hospital have decreased during the last ten years. Improved health is reported among the persons interviewed.
- Quicker rehabilitation of persons injured in adult age is due to the possibility of regular training.³²

2.10. Did this Legislation in any Way Influence the Employment Rate of Disabled Persons?

According to research from Statistiska Centralbyrån, SCB [Statistic Sweden], the employment rate among persons defining themselves as disabled (914.000 in 2008) increased from 55% in 1996 to 62% in 2008. However, in the group defining themselves as disabled with reduced work capacity (525.000 in 2008), the employment rate had decreased from 56 to 50%. This research covers a much larger group of people than recipients of assistance (app. 19.000 in 2008), for whom figures are not available. However, the employment rate among family members has undergone a substantial change. Many, who cared for family members at home, have entered the labour market.

The value of receiving assistance for the individual is extremely high. We can show that parents of children with disabilities experience better health because they are able to enter the labour market. Parents of children receiving assistance allowance receive sick pay, unemployment benefit or social

³⁰ Socialstyrelsen (2008); Westberg, K. (2008-07-24)

³¹ Westberg, K. (2008-07-24)

³² JAG (2006)

benefit to a lesser extent than others do. The JAG association confirms this, as more of the members' parents have entered the regular labour market, and in spite of the fact that parents have a possibility to work as assistants for their children, they do this (in 2005) to a lesser extent than in 1995.³³

2.11. What Are the Findings of Research and Evaluation of the Legislation?

Reports of Länsstyrelsernas [County Administrative Board's] show that, in relation to their supervisory role concerning municipal services, local guidelines, which are issued for personal assistance provided by the municipality under LSS, often incorrectly limit the service and the self-determination of the user. In opposition to the legislation, municipalities have limited assistance and ruled out certain tasks, e.g. cleaning of more than two rooms and a kitchen. This has been the object for criticism by the County Administrative Boards.

*"You and I would probably not apply for the same things if we needed assistance. Why should you have to move if you are single and living in a row house or small cottage with three rooms and a kitchen? If you have chosen housing with a living room, a bedroom and a work room you have the right to assistance for cleaning these three rooms."*³⁴

A legal reform enacted in January 2001, extended the right for persons. It extended the right to personal assistance before 65 years of age to the right to retain personal assistance after becoming 65, although limited to the number of hours received before the 65th birthday. If more hours are needed after 65, these can be provided under the Social Care Act (home care). The change was preceded by a survey of the situation:

*"According to the project report, based on 259 persons living in 43 municipalities, it is clear that there exist great variations in support after turning 65. In closer to half of the cases, individuals have received support to a lesser extent after turning 65. Among these were also a handful of persons who did not receive any support at all. In more than 40 percent of the cases the support from the municipality remained at the same level as before measured in hours."*³⁵

In a recent report, Socialstyrelsen [National Board of Health and Welfare] establishes that personal assistance is more cost effective than home care services are. According to this, home care has a 70% higher hourly cost than personal assistance. Good effect on health among assistance users and family members is another find. Home care is over 10% more expensive per paid hour than personal assistance, but on average it is 70% more expensive in actually produced service hour. The difference is caused by the fact that more than half of the working hours are spent on travel-time and other surrounding issues (see chapter 5 for more information).

³³ SCB (2009); Socialstyrelsen (2008); JAG (2006)

³⁴ Länsstyrelserna (2007); Westberg, K. (2009-07-15)

³⁵ Prop. 2000/2001:05

“In this study a nuanced picture of this ‘huge’ cost of more than 21 billion SEK [approximately 2.153.850.000 €, exchange rate according to xe.com at 2010-03-01] for personal assistance under LASS and LSS is presented. The report shows that assistance has replaced a number of services which has to be deducted from this sum since they act as communicating vessels. Care allowance and disability allowance have in total decreased by approximately 100 million SEK [approximately 10.256.000 €, exchange rate according to xe.com at 2010-03-01] that is one part. The big part is of course the home care services which assistance has replaced. It is hard to calculate the exact figure, but the more extensive home care provided to adults have decreased with approximately 60%.”³⁶

³⁶ Socialstyrelsen (2008); Westberg, K. (2008-07-24)

3. Needs assessment

In this chapter, we look at the assessment process, the authorities involved and the methods they use. We discuss the possibility for persons with disabilities, when it comes to influencing the assessment by self-evaluation, and whether the assessment is open and voluntary. We also cover the issue of appeal, whether the applicants live by themselves and their possibilities to receive informal care.

Finally, we look at measures to ensure the quality of the assessment process, and the factors, which influence and decide the actual sum received as assistance allowance.

3.1. Who Carries out the Assessment?

The assessing authorities.

If fundamental needs are estimated 20 hours or more per week, the assessment will be done by the Social Insurance Agency, otherwise by the municipality. Fundamental needs are defined in the legislation as needing help with personal hygiene, eating, dressing and undressing, communicating with others and other help which requires detailed knowledge of the person's impairment. The Försäkringskassa [Social Insurance Agency] issues guidelines for what is counted as fundamental needs, but exactly where the line for such a definition is drawn, is a matter for the Administrative Courts to decide. As the Swedish legislation is more than 15 years old, several precedents exist. A decision by the Försäkringskassa [Social Insurance Agency] should also be communicated to the municipality.³⁷

Independence and neutrality of assessing authorities.

The assessing process within the municipality is financed through the local tax, as happens with other municipal services. The services of The Försäkringskassa [Social Insurance Agency] are financed by a yearly subsidy in the government budget.

As the costs for personal assistance are charged to the budget of the organization responsible for assessment, this is not independent or neutral. However, the assessment is based on a legalized social right, which means that a denial or "cheap" decision can be appealed through the Administrative Court system. A social rights legislation gives persons a right to certain services, provided they need them and they cannot be satisfied otherwise. Decisions made under social rights legislations can be appealed. Non-compliance can be the object for sanctions.

The fact that the officials responsible for the assessments and the budget holders responsible for covering the cost are part of the same organization, i.e. The Försäkringskassa [Social Insurance Agency] or the municipality, has been subject to criticism. The Secretary General for The Swedish Association for Persons with Neurological Disabilities has described the problem in relation to the municipalities:

³⁷ SFS 1993:387; SFS 1993:389; Försäkringskassan 2003:6 ver.5

“The rule of law can be questioned in a situation where the official responsible for LSS-decisions experiences managerial demands for costs restrictions, at the same time as units providing assistance experience economical problems. This could result in disadvantage for the individual.”³⁸

3.2. Which Assessment Tool is used in Sweden? What Methods and Questionnaires are Applied?

The assessment process is done normally through open-ended interviews, where the applicant describes his everyday life including activities one could undertake if provided with assistance. The individual argues for assistance, covering the different aspects of everyday life, and on this basis an assessment of hours required is carried out.³⁹

Recently, a project has been initiated which aims at developing a “neutral” instrument for measuring hours during assessment. The argument behind this project is the existence of local differences in the average assistance hours granted. The Institute for Methodology in Social Work (IMS, department within Socialstyrelsen [National Board of Health and Welfare]), claims that the difference in granted hours between The Försäkringskassas [Social Insurance Agency’s] local offices is due to whether the assessment has taken passive time (between needed actual assistance, e.g. between assisting a person onto the toilet and off) into account:

“Today’s national differences depend on whether only active time measured in minutes per activity is calculated or if passive time between these activities is included.”⁴⁰

The proposed instrument, and in particular the exclusion of so-called passive time, has met a massive opposition from disability organizations, politicians from both left and right as well as persons who sat on the committee responsible for suggesting an instrument in the first place, and municipalities. It is viewed as a threat to the fundamental idea of the assistance reform, a threat to a good working environment and considered a return to the situation before the reform of 1993, where persons with disabilities existed as objects of the welfare state instead as citizens. As Sweden has ratified both the UN Convention on Human Rights for Persons with Disabilities as well as the Optional Protocol, it is assumed that the government has to take action against the implementation of the instrument, as its result will cause a direct breach of article 19 and indirect breaches of articles 23 and 27.

At present time, the instrument as it was designed has not been put into use. Instead, a review and fresh start for cooperation with the disability organizations is planned. A first tentative meeting has taken place.⁴¹

³⁸ Försäkringskassan 2003:6 ver.5; Westberg, K. (2008-02-20)

³⁹ Försäkringskassan 2003:6 ver.5

⁴⁰ Försäkringskassan 2003:6 ver.5; Westberg, K. (2008-11-20)

⁴¹ Westberg, K. (2010-02-09)

3.3. To what Extent is the Assessment Done by Self-evaluation?

The assessment is individual, based on the individual's description of his/her everyday life. The applicant's description is the basis, however the official can have opinions on for example how long it will take to clean two rooms and kitchen. The applicant has a right to be accompanied by a legal assistant or person of his/her choice during appeal.

All regularly occurring activities should be included in the assessment, without exceptions. There are no approved or disapproved activities, no lists. Assistance should be provided for leisure activities, work, parenthood, based on the individual's life. Hours added to the average for regularly occurring periods of ill health or worsening of ground condition could also be included in the assessment.

Vacation or periods when child care, schools and daily occupational activity are closed, as well as summer vacations during higher education and the applicant's own vacation period are viewed as regularly occurring needs and therefore covered by the right to assistance allowance. Extra time, outside activities occurring regularly, is not included. Such hours have to be applied for separately from the municipality. Hours needed for travelling during vacations are not viewed as regular, so they have to be applied for separately from the municipality (LSS) or The Försäkringskassa [Social Insurance Agency] (LASS).

Personal assistance is not granted during time spent in daily occupational activity, in housing with special services or while in school or childcare, as care is considered part of these and the need for assistance is fulfilled. Exceptions can be made in special cases such as:

“Situations, where the individual's disability cause particular difficulties communicating with others than his/her personal assistant or assistants /.../ when, a presence of a personal assistance is important for the individual's health /.../ in situations, where the form of the disability makes it particularly important that the assistance user has access to a severely limited number of persons /.../ if the disability is such as access to a person with thorough knowledge of the individual and his/her health condition.”⁴²

3.4. Is the Assessment Open and Voluntary? Can a Decision on Personal Assistance be Appealed?

Assessments are always done after a personal application. The assessing officials at the Försäkringskassa [Social Insurance Agency] always discuss their assessment with an official presenting the case. The presenting official is also responsible for the proposed decision, but the assessing official has a right to have a divergent opinion noted in the report and this should also be clear in the final decision. A third official responsible for decision-making then reviews the proposed decision with a report containing the basic data. The applicant has no legal right to comment on the proposal before the decision, but the Försäkringskassa [Social Insurance Agency] regularly tries to

⁴² Försäkringskassan 2003:6 ver.5

provide him/her with such a possibility anyway.⁴³ The municipalities have a similar decision making process where the applicants are allowed to comment on the proposed decision. Decisions on personal assistance are regularly reviewed bi-annually.

Decisions made under social rights legislations can be appealed within the Administrative Court system, the County Administrative Court, the Administrative Court of Appeals and the Supreme Administrative Court. In reality, most appeals go no further than the Administrative Court of Appeals (and sometimes stop after the County Administrative Court's decision) as the higher authority can reject an appeal after initial viewing.

Officials in the Försäkringskassa [Social Insurance Agency] and the municipalities are obliged to provide assistance to applicants wanting to appeal a decision, e.g. actually formulating the appeal. The applicant can also choose to engage a legal representative during the appeal process. Legal representatives can be found through the disability organizations, assistance providers or private law firms. In some instances, where the case is considered too complicated for the individual to plead by him-/herself, so-called legal aid, covering the cost of hiring a lawyer, can be granted by the court but usually the applicant pleads his/her own case. Some assistance providers cover legal fees. This has become a competitive argument for private assistance companies/cooperatives contending for customers.⁴⁴

3.5. Are Living Circumstances and the Possibility of Receiving Informal Care taken into Account?

Personal assistance is provided to cover the full need for such assistance that is not satisfied in any other way. Family members are under no obligation to provide informal care. The Marriage Act declares that spouses shall contribute jointly to the household and each other's personal needs. Assistance can therefore be used to fulfil duties the assistance user has in his role as husband/wife/partner.

"Furthermore, the Supreme Administrative Court stated that spouses have a joint responsibility for the home, and this meant that the husbands could be regarded as responsible for a large part of the tasks relating to this. On the other hand should – considering the aim of the assistance reform that persons with disabilities shall have the possibility to live as others – part of the need relating household chores be covered through the use of personal assistance"

Parents to children needing assistance (up to 12 years of age) are obliged to provide the same level of care parents to non-disabled children are obliged to provide. Assistance is provided for care outside this. Family members can be employed as assistants on the same conditions as other employees. However, if they share a household with the assistance user, they cannot be employed directly by him/her, due to tax regulations. They have to be formally employed by an external

⁴³ Westerberg, K. (2010-02-15)

⁴⁴ Communication with Hanna Eriksson, legal expert, STIL

employer. The assistance user is of course free to start a company or an economic association, which as a legal person can function as employer in these cases.⁴⁵

3.6. How is the Quality of the Assessment Guaranteed?

The structure of the assessment and decision-making processes within the authorities, and the right to appeal any decision in court, can be seen as part of a quality guarantee. Both these are described above.

The officials within the Försäkringskassa [Social Insurance Agency] handling social rights in the disability field have either a Bachelor of Arts in social or behavioural sciences, or are recruited internally and have gained equivalent knowledge through work experience. All officials undergo a one-year long internal training, where three study periods are mixed with two periods of supervised practice. The training contains modules on administrative law, human rights, processes for handling applications, methods for dialogue, knowledge of surrounding situations, formulating decisions and documenting cases, handling threats and violent situations, as well as modules on the specific social rights within the responsibility of the Social Insurance Agency. Persons with disabilities do not take part in the training of the officials.

In the handling of cases officials are guided by 'general advice' and guidelines concerning assistance allowance issued by the Social Insurance Agency, the legislation itself, a continuously updated database with court decisions, and a support function listing questions from local offices and answers to these from the central office. The officials can also ask the medical consultants, i.e. doctors trained in insurance medicine, on how the disability can affect everyday life and possibilities to perform certain activities. Finally, the agency performs random checkups on closed cases. In cases concerning e.g. the right to assistance allowance, it is investigated if all five basic needs have been covered at the assessment.⁴⁶

3.7. How is the Size of the Assistance Allowance/Direct Payment for Personal Assistance Decided?

Budget

The Government sets a standard amount for the assistance allowance each year, for 2010 it is 252 SEK per hour, approximately € 23,8 (exchange rate according to xe.com at 2010-03-01). The Försäkringskassa [Social Insurance Agency], after consulting Sveriges Kommuner och Landsting, [SKL, Swedish Association of Local Authorities and Regions], proposes a standard amount to the Government before 1 March each year. The Government then makes a decision based on this and other economic calculations. Eighty-seven percent of the standard amount is considered to cover costs for salaries, employers' fees etc. This shall at large follow the expected wage development for

⁴⁵ Försäkringskassan 2003:6 ver. 5, quote p.76

⁴⁶ Westberg, K. (2010-02-15)

the coming year. The remaining 13% shall at large follow the raise in the consumer price index. The economic situation in the national budget could also be taken into account.⁴⁷

Minimum wage

Sweden does not regulate minimum wages by law. Like other similar issues regulated in talks between the different partners on the labour market, this system has been in place since 1938. The union agreement covering work as personal assistance puts the minimum wage at 88,95 SEK per hour, approximately € 9,1 (exchange rate according to xe.com at 2010-03-01). This is excluding holiday compensation pay (12%) and working hours supplement, which is provided for work hours during evenings, nights and weekends. For companies, which have not signed a union agreement, minimum wages do not apply.⁴⁸

Raised assistance allowance

Based on special reasons, the Försäkringskassa [Social Insurance Agency] can grant a higher level of assistance allowance. However, the absolute maximum is a raise of the standard amount with 12%, i.e. 282 SEK per hour, approximately € 28,9 (exchange rate according to xe.com at 2010-03-01). Special reasons for raised allowance can be need for assistants with specific training, need for assistant working as a supervisor coordinating the assistance and providing support for the other assistants. Another reason can be a disproportionately large part of assistance hours with working hours supplement. Persons receiving higher level of assistance allowance must account in detail for its use. Persons receiving the standard amount only have to show that it has been paid to the assistance provider. On demand or application, the municipalities can provide extra hours due to increase in the need for assistance in special situations, such as holiday trips. Applications to cover extra costs, e.g. the assistants' travelling and lodging costs, fall under the responsibility of municipalities.⁴⁹

Personal assistance under LSS (from the municipality)

In principle, there is no difference for individuals receiving their allowance either from the municipality (LSS) or from the Försäkringskassa [Social Insurance Agency] (LASS). The municipality should provide allowance for 'reasonable costs' and Socialstyrelsen [National Board of Health and Welfare] is of the opinion that this is the same as costs covered by the Försäkringskassa's [Social Insurance Agency's] assistance allowance, i.e. wage-related costs and certain types of administrative costs. The standard amount per hour decided by the government for the assistance allowance should also be the norm for direct payment from the municipalities. Socialstyrelsen [National Board of Health and Welfare] stated to the Supreme Administrative Court that persons receiving assistance

⁴⁷ Riksförsäkringsverket 2002:6; SFS 1993:1091

⁴⁸ Assistanskoll (2010-01b)

⁴⁹ Försäkringskassan 2003:6 ver.5

under LSS should be provided with equal opportunities as persons receiving assistance allowance under LASS. A satisfying level of direct payment from the municipality is also important to guarantee freedom of choice between assistance providers. Also other costs, as higher allowance and costs for temporary workers during sick leave should be covered. Socialstyrelsen [National Board of Health and Welfare] has no opinion on the period within which assistance hours can be divided, other than there should not be a difference between recipient under LSS and LASS (users receiving the allowance from LASS can flex hours during a six-month period).⁵⁰

According to STIL, users who are provided direct payments from the municipality often can flex their hours over a year. Some municipalities allow flexibility during the whole period covered by the decision, usually two years. However, many of these give notice if the amount of hours used differs more than 10% between months. STIL confirms that municipalities usually provide direct payment according to the standard amount and that recipients can either choose their assistance provider freely or choose to become employers themselves.⁵¹

⁵⁰ Prop. 1992/1993: 159; Communication with official Ulla Clevnert, Socialstyrelsen

⁵¹ Communication with CEO Per-Anders Fröding, STIL

4. Issues and Responsibilities Concerning Employment

In this chapter, we look at issues connected with employment and economy. Different ways of employing assistants are presented: as an individual assistance user, through cooperatives or private companies as well as the possibility to demand that the municipalities provide personal assistance services. You will find information on the employers' responsibilities and information on how different types of employment are regulated through legislation and union agreements in Sweden. The usage of assistance allowance is regulated by an hourly flat rate covering costs as shown here. Assistance providers can and are allowed to make a profit, but are subjected to taxation. We give information about how this can be managed and how assistance users can save and transfer surplus funds over the cut off date or to another provider.

We will also discuss some other aspects, such as the differing ways the system works for assistance users employing their own assistants and providers; how accounting for the usage of assistance allowance to the Försäkringskassa [Social Insurance Agency]; what are the pros and cons of employing your own assistants or employing through a cooperative.

Personal assistance in the original Independent Living concept is connected to the possibility of the assistance user acting as work leader/supervisor of the assistants. We discuss areas of responsibility, from employer responsibility to a user acting as supervisor. Information on how different types of providers manage this, is provided. Finally, we look into possible economic and legal risks of different types of employments, we look at institutions with responsibilities to inspect personal assistant services and report on the legal duties of confidentiality and abuse.

4.1. Who Can Act as Employer for Personal Assistants Provided under LASS and LSS?

Individuals, who are granted personal assistance services or direct payment for such services, can choose to purchase these from municipalities and from private for-profit companies or employ their personal assistants themselves collectively by joining a personal assistance user cooperative. These entities, organized as private companies, corporations or cooperatives, can act as an employer. Assistance can also be purchased from a natural person registered as 'enskild näringsidkare' (sole traders) with Skatteverket [Swedish Tax Authority]. 'Enskild näringsidkare' (sole trades or sole proprietorships) is a business run and represented by one person. If the business loses money, you will have to use your private assets to cover its debt.⁵²

Assistance users cannot register as 'enskilda näringsidkare' (sole traders), as direct payment for assistance is viewed as a benefit and therefore it is not subjected to taxation. However, by simply registering as an employer at Skatteverket [Swedish Tax Authority], they can act as employers themselves. Guardians can be registered as employers and act in this capacity for assistance users

⁵² Bolagsverket 2010-03d

who are minors. In addition, personal assistants who are registered as 'enskild näringsidkare' (sole traders) can sell assistance services directly to the assistance user.

Assistance users can engage several providers of personal assistance services at the same time. They can e.g. employ some assistants themselves and choose the municipality or a company/cooperative as employer for others. This solution can be used when family members, within the same household as the assistance user, work as assistants, for they cannot be employed directly by the assistance user. Users can also partially act as employer and choose another provider for the rest.⁵³

4.2. What Responsibilities are Generally Included in Employership in Sweden?

Salaries and taxes

Employers are responsible for paying salaries to the employees. For employees earning 10.000 SEK, approximately € 1.025 (exchange rate according to xe.com at 2010-03-01), the employer is also responsible for deducting and paying the employee's preliminary income taxes to Skatteverket [Swedish Tax Authority]. For the municipality taxes levels vary. Government taxes are paid on income above 372.100 SEK, approximately € 38.150 (exchange rate according to xe.com at 2010-03-01). Employers also have to pay social security contributions on top of the employee's salary, at present 31,42% of this. Social security contributions consist of old-age pension charge, charge for pension to surviving relatives, health insurance charge, parental insurance charge, work injury charge, labour market charge and general payroll tax.⁵⁴

Legislation and union agreements

The labour market and employer's responsibilities in Sweden are by tradition mainly regulated through union agreements. These are written contracts, between employer organizations and workers unions, regulating employment conditions within a specific sector. There are several employer organizations active within the sector for personal assistance, but only one workers union, Kommunal [Swedish Municipal Workers' Union]. Kommunal [Swedish Municipal Workers' Union] negotiates union agreements with all the employer organizations. There also exists a side-agreement making it possible for employers, who are not members of an employer organization, to sign an agreement.

Sweden does not have regulated minimum wages. Employers, who have not signed the union agreement, can set salary without consideration of any agreement on salary level, payment for unsocial hours or compensation for overtime. Also, they are not obliged to provide the employee with insurance, including occupational pension. However, all employers have a legislated duty to provide vacation pay (12% of hourly wage). All employees are also covered by the statutory social

⁵³ Försäkringskassan 2003:6 ver.5 pp. 126-131

⁵⁴ Skatteverket 2009

insurance managed by the Försäkringskassa [Social Insurance Agency], which is mainly financed through the employment fees.

Statistics, on how many personal assistants are employed outside the union agreements, are not available. However, approximately 30.000 of an estimated 50.000 personal assistants were members of Kommunal [Swedish Municipal Workers' Union] in 2008. Most of them had their work regulated by union agreements. The sharp increase in companies active within the sector in recent years, has resulted also in an increase in employers lacking union agreements. Even though a few of these are larger employers, most of them are small ones.⁵⁵

Even if the labour market in Sweden is mainly regulated through union agreements, several laws regulate specific areas of employment. Laws can be dispositive, i.e. include negotiable demands. This opens up a possibility of compromise, through union agreements, which can provide flexible conditions. In what follows, we will discuss the laws concerning this.

The Employment Protection Act (LAS), which is partly dispositive, regulates notice to terminate employment, dismissals and temporary employment. Notice on termination can be given on objective grounds, i.e. shortage of work, and on personal grounds. Dismissal on objective grounds follows priority rules regulated by law. Dismissal on personal ground is allowed only if other work assignments are not available. Old age and illness is not a ground for dismissal per se. LAS protects mainly regular employment. Temporary or fixed-term employees are exempt from priorities and have shorter periods of notification.⁵⁶

The Work Environment Act (AML) is a frame legislation aiming to prevent work related ill health and injuries, and promoting conditions for a good working environment. The law also focuses on the quality of the work content.⁵⁷ Frame legislation does not contain detailed regulations. For the AML, these are issued by the Arbetsmiljöverket [Swedish Work Environment Authority] in provisions, which are gathered in the Work Environment Authority's Statute Book. E.g. one of these provisions regulates how systematic work environment management shall be done, including risk assessments and preventive measures to achieve a good physical and psychological work environment.⁵⁸

The Working Hours Act (ATL), which is partly dispositive, regulates the maximum amount of working hours, overtime, stipulated rest per workday and week etcetera.⁵⁹ Since 1 January 2007, the European directive on working time is enacted in Sweden, resulting in some parts of ATL being non-dispositive. However, in activities, which cannot be discontinued because of the specific characteristics of the activity concerned like personal assistance, derogations can be made.⁶⁰

⁵⁵ Westberg, K. 2008-03-05

⁵⁶ SFS 1982:80

⁵⁷ SFS 1977:1160

⁵⁸ Arbetsmiljöverket xx; Arbetsmiljöverket, AFS 201:1

⁵⁹ SFS 1982:673

⁶⁰ Official Journal of the European Union 2003

The Employment (Co-Determination in the Workplace) Act (MBL) regulates the relationship between employers and employees. This law includes employee's rights to organize, receive information and negotiate.⁶¹

4.3. What Types of Employment Exist within the Personal Assistance Sector?

According to Kommunal [Swedish Municipal Workers' Union] 999 employers were active within the personal assistance sector in January 2010. Approximately half of them were users employing their own assistants. Of 15.449 individuals granted assistance allowance under LASS (in April 2009), approximately 50% chose a municipality as employer, 36% a private company, 11% a cooperative and 3% chose to employ their own personal assistants. Some 3.300 individuals were granted personal assistance under LSS (in October 2007). Unfortunately, statistics regarding the type of employership for users under LSS are lacking.⁶²

Fixed-term employment, så länge uppdraget varar ["as long as the assignment lasts"] is an exception from the regulations under LAS made in union agreements. The basis for the exception is the self-determination of the assistance user, the right to choose who is going to work as personal assistant. The employment is connected to a certain person, i.e. an assistance user. Possible causes for dismissal are: the user dies or chooses another provider; dismissal based on a specific reason (i.e. the quality of the personal assistance cannot be guaranteed or the relationship between the assistance user and assistant breaks down).

Hourly employment only exists when the assignment is of temporary nature. The personal assistant is then employed for a certain number of hours per occasion due to need of assistance.

Indefinite-term employment where the rules under LAS apply without exception.

Minimum wages were introduced, in the latest union agreements covering the personal assistance sector, varying between agreements but starting from 13.8000 SEK per month, approximately € 1.415 (exchange rate according to xe.com at 2010-03-01). Social insurance contributions for old age pension are regulated in all union agreements to increase from 3,5% to 4,5% up until 2012. A compensation for exceptional working hours is also provided: for evening hours from 18, 30 SEK, approximately € 1,9, for night hours from 36,90 SEK, approximately € 3,8, for weekend work from 45,15 SEK, approximately € 4,6, and holiday work from 90,25 SEK, approximately € 9,3 (exchange rate according to xe.com at 2010-03-01).⁶³ Compensation can also be provided for stand-by hours, when the personal assistant is obliged to be at disposal outside the work place, and on-call hours, when the personal assistant is obliged to be on disposal at the work place. The Försäkringskassa [Social

⁶¹ SFS 1976:580

⁶² Assistanskoll [aggregated data]

⁶³ Assistanskoll 2010-01a

Insurance Agency] is providing assistance allowance at the amount of 1/7 hourly flat rate per stand-by hour, and ¼ hourly flat rate per on-call hour.⁶⁴

4.4. What is the Regulation of Working Hours for the Different Types of Employment?

The rules, stipulated in the European directive on working time, have been subject of negotiations and compromise in several union agreements between employer organizations and Kommunal [Swedish Municipal Workers' Union]. In situations, where special conditions apply, weekly rest of 24 hours and daily rest of 9 hours are allowed instead of 36 and 11 hours respectively. Daily rest can be allowed to fall even lower than 9 hours per day, if the average daily rest during an agreed upon limited period does not fall below 11 hours. The agreed upon period can be as long as twelve months. However, this shall not be compensated in money but in free time for the assistant.⁶⁵

For Arbetsmiljöverket [Swedish Work environment Authority] to investigate if a breach has been made against the Working Hours Act or the exceptions in union agreements, the case has to be reported. The Försäkringskassa [Social Insurance Agency] can report cases where breaches have been made to Arbetsmiljöverket [Swedish Work Environment Authority]. A breach will be visible to the Försäkringskassa [Social Insurance Agency], as assistance users have to send in copies of time sheets signed by themselves as well as the assistant to the Försäkringskassa [Social Insurance Agency]. If the situation is not rectified, a report can be made, taking into account the fact that information on the assistance user cannot be revealed.

Only assistance users who are purchasing personal assistance can be reported. The Working Hours Act is not applicable to users of personal assistance who are employing their assistants themselves. Instead, the Law on Working Time etc. in Household Work covers this type of employment.⁶⁶ In this case, the Försäkringskassa [Social Insurance Agency] can, if a breach is not rectified after it has come to attention, demand repayment of assistance allowance for all working hours outside regulation of working time.⁶⁷

4.5. How Can Providers or Individual Assistance Users Acting as Employers Use Assistance Allowance and Direct Payment for Personal Assistance Services According to Skatteverket [Swedish Tax Authority]?

A legislative reform, enacted 1 July 2008, means that assistance allowance provided under LASS and direct payments for personal assistance provided under LSS, both used to purchase personal assistance, is now being viewed as income in company's/cooperative's business activities. Skatteverket [Swedish Tax Authority] has, therefore started to review business costs to decide which

⁶⁴ Försäkringskassan 2003:6 ver.5 pp. 72-74

⁶⁵ Westberg, K. 2010-02-11

⁶⁶ SFS 1970:943

⁶⁷ Westberg, K. 2009-02-10a

are tax-deductible. Costs are considered deductible if they originate from the provision of assistance. For example, costs relating to furniture can be considered deductible if the personal assistants are using them at work and causing wear.⁶⁸

If a provider has saved funds for a customer (assistance user) at the turn of the year, these will be treated as profit and, thus, subject for taxation. However, it is possible to reserve funds, for customers'/members' (assistance users) assistance costs without having to pay taxes providing that the total sum and use of funds are specified, i.e. what the funds are going to be used for, when and how much is required. Skatteverket [Swedish Tax Authority] puts high demands on specification due to this being an exception from the rule. There is no limit to how much can be set aside. It is not possible, however, to put aside funds for unexpected costs for example for occupational injuries, payment and benefits in connection with termination of employment or unplanned travelling.

Family members, employed as personal assistants and sharing household with the assistance user, also have to pay tax for travels, if they are considered as travelling both in the capacity of personal assistant and family member. In that case, the trip is considered a taxable benefit. This does not apply, if for example the family member is working as personal assistant for an assistance user, who is travelling in a work related capacity.⁶⁹

4.6. How do Providers/Individual Assistance Users Acting as Employers have to Account for Assistance Allowance and Direct Payment for Personal Assistance Services?

Accounting the use of assistance allowance is done separately from regular bookkeeping. Accounting the allowance usage to the Försäkringskassa [Social Insurance Agency] does not exclude providers and assistance users employing their own assistants from the obligation of bookkeeping and declaration of profit and paid salaries. These are part of the general business and employment legislation in Sweden and do not differ from employment obligations within other sectors.

Individuals granted assistance allowance are responsible for accounting to the Försäkringskassa [Social Insurance Agency]. However, the employer of the personal assistants can provide administrative services, such as preparing monthly timesheets for the assistants and drawing up monthly reports of the amount of assistance hours used. The assistance user then signs these papers. Extended accounting, due no later than two months after the end of the accounting period, is done every sixth month. The six-month report gives an account of the amount of hours of personal assistance purchased and the providers they were purchased from. Allowance for non-used hours must be repaid.

Users who employ their own assistants, as well as users who are granted assistance allowance at a higher level (possible up to 12%), also have to account for the average hourly costs:

⁶⁸ Westberg, K. 2009-04-27

⁶⁹ Westberg, K. 2008-12-15

- for salaries (excluding compensation for unsocial hours) and employment fees,
- of compensation for working hours (at night, during weekends, ...),
- directly connected to assistance such as working clothes and entrance fees etc. for assistants,
- for training and mentoring assistants,
- related to work environment measures,
- connected to staff such as health care, provisions aimed at well-being,
- for administration.

Normally, a summary account is enough. However, if the Försäkringskassa [Social Insurance Agency] thinks there is reason to account records shall be shown.

Users who employ their own assistants have to repay any remaining funds to the Försäkringskassa [Social Insurance Agency]. Assistance users granted assistance allowance at a higher level have to repay the extra funds not used.⁷⁰

4.7. What are the Rules for Users Employing their Own Personal Assistants?

If assistance users employ their own personal assistants and the employer has not signed a union agreement, the Law on Working Time etc. in Household Work is applied, since the assistants are working in their employer's household. This legislation replaces both the Employment Protection Act and the Working Hours Act, and allows employers to terminate contracts without providing any reason. Its rules regarding working hours are different. E.g. it does not stipulate a minimum required amount of rest per day, but has an absolute requirement of 36 hours weekly rest. The Work Environment Act is also applicable.⁷¹

Since the assistance allowance is not taxable, users employing their own assistants cannot use assistance allowance to compensate themselves for work with administration or supervision. Instead, they can choose to manage administrative work without extra compensation and use more of the allowance for higher salaries or costs connected to assistance. Alternatively, the allowance can be used to buy administrative services from an external company or 'enskild näringsidkare' (sole traders).⁷² It is also possible to employ a person specifically to manage the administration, if the person is not a family member in the same household (same rules apply as for employment of family members as assistants).⁷³

Note that companies providing bookkeeping, administration of salaries, substitution services, education and training of personal assistants, recruitment, legal advice etcetera exist. Some of these companies demand that the user, acting as employer, agrees on following a specific union agreement. However, these companies are providing services to an extent that they resemble assistance providers, even if the user still has the role of employer.

⁷⁰ Försäkringskassan 2003:6 vers.5 pp.136-150

⁷¹ SFS 1970:943;

⁷² Försäkringskassan 2003:6 ver. 5 p.130

⁷³ Westberg, K. 2009-02-10b

4.8. What are the Pros and Cons of Employing your Own Assistants?

Assistance users, who employ their own assistants, can decide which tasks they perform themselves and which tasks they have executed. The Försäkringskassa [Social Insurance Agency] also grants them assistance allowance for “time which can be compared with assistance”, which includes the right to retain assistance allowance during stays in hospital (up to four weeks), pay salaries during periods of termination if the assistance user dies, and compensation for costs of providing a substitute worker when the ordinary assistant is ill. Note: covering this cost is in fact a municipal responsibility, but using assistance allowance means less administration and possible conflict over payment.⁷⁴

Personal assistance, performed by assistants employed by the user, is regulated under the Law on Working Time etc. in Household Work. The regulation of working time is slightly less strict under this legislation, though exceptions in union agreements are not allowed. However, the Independent employers' organization for co-operative business (KFO) demands that assistance users acting as employers follow the Working Hours Act, if they want to become members of the organization.⁷⁵

One disadvantage for users acting as employers, is the inability to employ a family member of the same household. More of a detriment are also the rules enacted 1 July 2008 demanding that they account for the allowance use by submitting every receipt. The users also have to repay unused funds every six months, which means a buffer to cover unexpected costs is thus eliminated.⁷⁶

4.9. What are the Rules for Cooperatives Acting as Employers?

The legal requirements and demands are the same for cooperatives and companies. In both cases, all of the assistance allowance must be used to purchase assistance from the company/cooperative, since assistance allowance must be repaid to the Försäkringskassa [Social Insurance Agency] if not used. If assistance is purchased from a provider, the assistance user can authorize that the funds are paid directly to the provider.⁷⁷

4.10. What are the Responsibilities of a Supervisor/Work Leader? What Types of Support can be Available for Assistance Users Acting as Supervisors?

The legislation does not regulate employer responsibility, except for the area of work environment (see below).

⁷⁴ Westberg, K. 2008-07-10

⁷⁵ Arbetsgivarförbundet KFO 2007

⁷⁶ Westberg, K. 2008-05-05; Westberg, K. 2008-05-15

⁷⁷ Försäkringskassan 2003:6 ver.5 p.124

Depending on the provider, assistance users can choose to act as a supervisor for their assistants. As supervisors, they can be in charge of recruiting, scheduling, assigning and reassigning tasks, training and introducing newly employed assistants, scheduling vacations, managing substitute workers or their own substitute pool. How much responsibility the individual users are allowed, varies sharply between providers. E.g. 119 providers, out of 171 registered on the web based service portal Assistanskoll, stated they provided a pool of substitute assistants for their members/customers.⁷⁸

Training and peer support, for assistance users acting as supervisors, is provided by cooperatives and a minority of companies. It is also possible to purchase courses and training from private companies or e.g. from such agents as the Interest Group for Persons granted Assistance (IfA).

Personal assistance is a service developed and defined within the philosophy of Independent Living (see DPI – tools for power).⁷⁹ It has a dual aim of providing means for living a self-determined life, as well as promoting individual growth through the process of taking control over the assistance necessary to achieve this. Cooperatives providing training and peer support for the users stick to these principles, even if the practical organization of it can differ.

STIL (founders of Independent Living in Sweden) demands that prospective assistance users within the cooperative partake in an introductory training. They start with a three-day course in guiding and supervising assistants, legislation and agreements regulating the sector, developing leadership and recruitment. This is followed by two additional courses in systematic work environment management as well as dialogue and conflict management. STIL also offers half-day courses, in recruiting assistants, termination of contracts, promoting dialogue with assistants, vacation planning, as well as peer support meetings a couple of times per month. Peer support meetings are always led by an assistance user. The cooperative provides administrative services such as the web-based scheduling and reporting system Aiai.⁸⁰

4.11. Can Assistance Users Act as Supervisors of their Assistants within Municipalities and Private Companies?

It is possible for the assistance users to supervise and manage their own assistance, also when the municipalities or private companies provide this. However, the municipalities usually manage most of the supervision.

The most recent parliamentary enquiry into the issue of personal assistance under LSS (also includes assistance provided through assistance allowance under LASS) concluded that there are differences in possibilities, for the assistance users to exercise freedom of choice and self-determination, depending on the type of provider. In general, users have less control over assistance received from municipalities, while assistance through cooperatives resulted in the highest degree of self-

⁷⁸ Assistanskoll 2010-02-26

⁷⁹ DPI 1992

⁸⁰ STIL 2009

determination. Private companies provided their customers with more control over the assistance than municipalities did, but less than users' cooperatives.⁸¹

According to the former chairperson of the Parliamentary Committee, assistance through membership in a cooperative meant having the greatest possibility of control over, e.g. choice of assistants, decision to change assistant or terminate contract, when assistance services are provided, and what tasks to perform when. Approximately 70% of the users receiving assistance through a cooperative or a private company, answered *YES* when questioned if the provider was able to offer the assistance asked for. The users receiving assistance from municipalities, answered less than 50% positively.⁸²

Cooperatives and certain private companies prefer that all users, who are able to act as supervisors, do so. E.g. the chief executive of the private company Särnmark states that, even in cases where a vice supervisor has the responsibility over systematic work environment management, the user is normally supervising the daily work. For Särnmark, this is a very important point and a necessary criterion of protecting the integrity of assistance users. There is no other person truly capable of knowing how an individual wants his/her daily life to be. If someone other than the user is supervising the assistants, there is a large risk that all the "variables that make up self-determination and the opportunity to be respected are moved outside the individuals reach and control". There is a panoply of examples of how users turn passive when responsibility and real influence are taken away.⁸³

4.12. What Specific Responsibilities can Pose a Problem when Delegating Supervision/Work Leadership from Employer to Supervisor?

According to Arbetsmiljöverket [Swedish Work Environment Authority], responsibility for the work environment has to rest with one of the assistance provider's employees. It cannot be transferred to e.g. members of a cooperative or users who are customers of a private company. Assistance users, in the view of Arbetsmiljöverket [Swedish Work Environment Authority], do not form a part of the employer's activities in a manner that is required to follow the authority's statutory guidelines. Assistance users can only act as supervisors to assistants they employ themselves.⁸⁴

STIL thinks that the assistance user, who is a member of the cooperative and thus has received training, should also supervise questions regarding work environment, since this concerns the design of the home and the life the individual leads. To presume that the members are unable to take this responsibility is to distrust disabled people and their capacities. STIL is at present preparing to have the cooperative's opinion tested in court.⁸⁵ After discussions with Arbetsmiljöverket [Swedish Work Environment Authority], the private company Särnmark has chosen to split the responsibility for systematic work environment management and delegated parts to an employed vice supervisor.

⁸¹ SOU 2008:77 pp.482-483

⁸² Dagens Nyheter (2005-07-18)

⁸³ Westberg, K. 2009-08-04

⁸⁴ Arbetsmiljöverket (2004)

⁸⁵ Communication with Suzanne Elmqvist, head of RESURS-department at STIL 2010-03-03

Following the opinion of Arbetsmiljöverket [Swedish Work Environment Authority], the assistance user plays two roles. Therefore, he cannot bear responsibility for the work environment. According to Särnmark's chief executive, however, the question is more complex and it should not be assumed that a provider or assistant has a preferential right to interpret a situation from an individual's private life.⁸⁶

4.13. What Types of Costs are Included in Assistance Allowance and Direct Payment for Personal Assistance Services?

The Försäkringskassa's [Social Insurance Agency's] guidelines include recommendations on what type of costs are included in the assistance allowance – hourly flat rate of 252 SEK, approximately € 25,8 (exchange rate according to xe.com at 2010-03-01). The guidelines also recommend the percentage of the assistance allowance, which is to be addressed for each type of cost. The percentages are mere recommendations and can differ from the real situation, depending on the life and needs of the user.

Direct payment for personal assistance from the municipalities is not regulated by the Försäkringskassa [Social Insurance Agency]. The municipality decides the exact sum provided. As stated above, direct payment from the municipality should cover reasonable costs and, therefore correspond to the levels recommended by the Försäkringskassa [Social Insurance Agency]. The municipality is also responsible for covering extraordinary costs as well as covering the need for temporarily increased numbers of assistance hours. Because of this, the municipality should provide direct payment above the recommended norm, if the situation demands so.

Salaries, employment fees etc. recommended at 87% or 219 SEK per hour, approximately € 22,5 (exchange rate according to xe.com at 2010-03-01):

Salaries and remunerations for costs for employees, stipulated social fees, special income tax, insurance premiums, taxable benefits and other similar remunerations and costs.

Administrative costs recommended at 5-8% or 13-20 SEK per hour, approximately € 1,2 (exchange rate according to xe.com at 2010-03-01):

Costs originating from the administration of assistance, for example, purchasing administrative services, chattels, auditing, company insurances, fees to employer and branch organizations.

Training costs recommended at 2-3% or 5-8 SEK per hour, approximately € 0,5-0,8 (exchange rate according to xe.com at 2010-03-01):

Costs for courses, teachers and lecturers, premises for education and training of assistants and assistance users, costs for instructing and supervision of assistants (their salaries not included).

Assistance expenses recommended at 1-2% or 3-5 SEK per hour, approximately € 0,3-0,5 (exchange rate according to xe.com at 2010-03-01):

⁸⁶ Westberg, K. 2009-08-04

Costs the user has for his assistants in joint activities outside the home, e.g. travel expenses, entrance fees and similar costs for assistants participating in activities together with the assistance user. Note: only costs for assistants are included.

Expenses for work environment measures and staff recommended at 1-2% or 3-5 SEK per hour, approximately € 0,3-0,5 (exchange rate according to xe.com at 2010-03-01):

Costs for measures improving the assistants' work environment, for example, simpler technical aids or solutions to problems, measures to enable good staff hygiene, providing a room for assistants working stand-by and simpler aids such as plastic gloves and aprons.

Staff costs such as employee health care benefits, activities to promote health maintenance, coffee, hand crème, soap etc. for the assistants, as well as personnel activities, days and similar arrangements.⁸⁷

Statistics from comparison between 73 providers by Assistanskoll

- Salaries, employment fees etc. varies between 168-227 SEK, approximately € 17,2-23,3. On average, an assistant is paid 207 SEK per hour, approximately € 21,2 (exchange rate according to xe.com at 2010-03-01).
- Administrative costs vary between 3-50 SEK, approximately € 0,3-5,1, and amount to an average 21 SEK per hour, approximately € 2,1 (exchange rate according to xe.com at 2010-03-01). Any profit made by the provider is included in administrative costs.
- Training costs vary between 3-50 SEK, approximately 0,3-5,1 €, and amount to an average 10 SEK per hour, approximately € 1 (exchange rate according to xe.com at 2010-03-01).
- Assistance expenses vary between 3-50 SEK, approximately 0,3-5,1 €, and amount to an average 10 SEK per hour, approximately € 1 (exchange rate according to xe.com at 2010-03-01).
- Expenses for work environment measures and staff vary between 3-25 SEK, approximately € 0,3-2,6, and amount to an average 7 SEK per hour, approximately € 0,7 (exchange rate according to xe.com at 2010-03-01).⁸⁸

4.14. Can Surplus Funds be Saved or Transferred?

The enactment of new legislation included in LSS 1 July 2008 means that all funds paid out to the assistance provider are viewed as revenue. As a consequence, the provider has to declare the use of the funds to Skatteverket [Swedish Tax Authority]. Assistance users can no longer dispose freely of

⁸⁷ Försäkringskassan 2003:6 ver.5 pp.111-115

⁸⁸ Assistanskoll 2010-01b

remaining funds. Saved funds cannot be transferred from one provider to another if the assistance user chooses to change provider. When changing provider, the old provider can still pay for the expenses from former customers using their saved funds. If the former provider pays for expenses, after the assistance user has changed to another provider, a deduction for these expenses will be accepted by Skatteverket [Swedish Tax Authority] when declaring profit for taxation.

Remaining funds can also be used to cover costs for the salaries and allowances for expenses for a former customer's assistants. In this case, the former provider can temporarily hire an assistant, e.g. during a trip and then cover all costs for salaries, employment fees and assistance expenses using the saved funds.⁸⁹ However, the providers themselves decide if this is possible and if they are willing to do it. When comparing different providers using Assistanskoll, 35 (mostly smaller assistance companies and cooperatives) out of 158 providers reported that saved funds can be used after changing to another provider.⁹⁰

4.15. How is this Managed within Private Companies?

Accounting and administrative costs:

Providers differ when it comes to accounting payment for personal assistance. This difference lies in how much the provider charges for administrative services, and if the provider saves the results in individual assistance user's 'projects'. When comparing different providers, 44 out of 158 report that they charge a fixed administrative fee and make a budget for the customer. Administrative fees vary between 6-28 SEK, approximately € 0,6-2,8, and amount to an average 20 SEK per hours, approximately € 2 (exchange rate according to xe.com at 2010-03-01).⁹¹

IGS assistans, a private company with 29 customers, reports that the administrative fee is set to cover the company's cost and that the customer can influence its size. Every customer has an individual budget that is reviewed when needed. In this individual budget, the funds are divided into salaries and employer fees, assistance expenses, training, administration and saved funds, e.g. for future travels. The administrative fee can be lowered if assistance users recruit their own assistants and substitute assistants.

"Some customers reserve more [of their budget] for salaries or training of the assistants while customers who travel more and lead an active life reserve more for assistance expenses. /---/ Salaries can vary, but only to a certain degree, at least 85% of the assistance allowance has to go to costs for salaries, that is the restriction we have."⁹²

Other providers do not account for the use of funds at all. The private company Olivia assistans does not have a fixed administrative fee for their services, but retains the surplus after salaries, employer fees and assistance expenses are paid. The company's profit at the time of interview (2008) was around 4-5% of its turnover.

⁸⁹ Westberg, K. 2009-05-14

⁹⁰ Assistanskoll 2010-01c

⁹¹ Communication with Philip Day, Independent Living Institute

⁹² Westberg, K. 2007-11-08

“This means that the fee to Olivia varies from customer to customer. On some customers, we take a loss because they have large assistance expenses or need much instruction, while others are very profitable as the work flows without problems. /---/ [The customers cannot take saved funds with them when leaving the company] since we view these as the company’s money. The customers do not have a large amount of influence over the company’s economy, the essential issue is that the customer during his time with us receives personal assistance of high quality and that the assistants receive good instructions and support from their supervisor.”⁹³

The JAG Cooperative is owned by JAG Association, a non-profit organization, which means that the cooperative’s assets cannot be distributed or used for anything but the aim of the association. The JAG Association is part of the Independent Living Movement in Sweden and organizes persons with multiple extensive disabilities, one of these being an intellectual disability. All of the members in the cooperative make a budget for their costs, but the cooperative has a collective responsibility for the business costs. If something unexpected happens in the assistance situation, the member need never be without resources. That is also why members cannot take saved funds with them, when they leave the cooperative.

“Since it is a joint economy, as a new member you arrive at a set table. This you also have to leave behind when you change your assistance provider, on the other hand, you have power to influence how JAG is run since you are a member. Fourteen of the members also have their occupational activities at the office, which explains why we have such a large administrative workforce. Members can also participate in different activities as member trips, member meetings and soon everyone will get their own member computer to manage their part of the administration.”

Salaries and employment fees generally take 90% of the assistance allowance. In this percentage, the fee to the deputy supervisor (service guarantor), a maximum of 6 SEK per hour, approximately € 0,6 (exchange rate according to xe.com at 2010-03-01), which is a compensation for supervision, scheduling and staffing. The deputy supervisor is obliged to work as assistant if nobody else is available. There is no substitute pool.

“Our members normally have so extensive and complicated needs that a long introduction is needed for assistants. That is why we cannot use personnel that is not trained [in working] for that member. Instead, the deputy supervisor has the final responsibility that members get their assistance.”

JAG has monthly three-day courses where both members and assistants are offered parallel lectures on, e.g. mobility training, alternative communication, epilepsy or autism.

⁹³ Westberg, K. 2007-12-05

“Members have extensive and multiple disabilities and many have additional medical complications, so we try to get the best experts in the country. We also have two-day courses with training for the service guarantors in e.g. supervision.”⁹⁴

4.16. How is this Managed within Municipalities?

Municipalities normally do not have a separate budget for an assistance user’s assistance expenses. Smaller expenses are handled by the municipality reimbursing assistants at the presentation of receipts. In order to have larger sums covered, e.g. for travel costs for accompanying assistants, the assistance user generally has to apply in advance for financial support from the municipal department for social services. In Stockholm, for example in the district of Södermalm, assistance is handled by two units, which also administer any complementary support the users might need.

Stockholm municipality administer some 26.000 assistance hours, purchased with assistance allowance from the Försäkringskassa [Social Insurance Agency]. The budget for this is around 90.000.000 SEK, approximately € 9.231.000, which is 7.000.000 SEK, approximately € 718.000 more than the assistance allowance received from the Försäkringskassa [Social Insurance Agency] under LASS (exchange rate according to xe.com at 2010-03-01).

“The provision of personal assistance has generated a budgetary deficit every year, it is slightly higher at the present time since the number of assistance users [choosing to purchase assistance services from Stockholm municipality] recently went down, which leads to a surplus of personnel. /---/ another reason could be that our overhead costs are higher due to costs for premises that private providers might not have.”⁹⁵

There are several reasons for municipalities’ higher costs for providing personal assistance, according to the Swedish Association of Local Authorities and Regions.

“Above all, it is due to an obligation to cover costs for assistants’ sick pay, which private providers do not have to do, as the municipalities have to cover costs for sick pay both within their own activity and within private providers’ activities [for assistance users who are inhabitant of the municipality]. This is not compensated through the hourly flat rate, which is something we have tried to point out every time this is reviewed. /---/ [Also,] municipalities get stuck with providing assistance during extra working hours, while private providers get to administer the ordinary working hours. We do not know how common it is [that assistance users are purchasing assistance during extra working hours from the municipality and from a company or cooperative during ordinary working hours] but it causes irritation when it happens.

Personnel costs can be higher, partly because some private providers do not have union agreements, but also because the regulations in the municipalities’ union agreements differ

⁹⁴ Westberg, K. 2007-11-03

⁹⁵ Westberg, K. 2009-11-22

from regulations in private provider's union agreements. This applies, for example, in regards to remuneration for on-call hours and salaries during periods of notice of termination, as the majority of employees in the municipalities are employed for indeterminate time with at least one months notice period. /---/ Certain cases [which are turned down by private providers] can demand that the municipalities provide doubled assistance [i.e. two assistants working at the same time instead of just one] due to work environment reasons, which is not covered by the Försäkringskassa [Social Insurance Agency].”⁹⁶

4.17. Do Employers within the Sector of Personal Assistance Run any Legal and Economic Risks?

Costs due to unexpected crisis or many assistants leaving simultaneously:

The private company Särnmark Assistans underlines that the possibility to save assistance allowance and direct payment for personal assistance services, is a prerequisite for managing employership well in unexpected situations.

“Problems can rise quickly in the work place, which can demand crisis management in form of instructions and closely occurring personnel meetings. The same applies if one or more assistants resign at the same time, causing unfunded costs for recruitment and introduction of new assistants. According to the guidelines, costs like these shall be covered by the hourly flat rate.”⁹⁷

Costs due to provision of personal assistance during stays in hospital and salaries etc. during termination periods for assistants when assistance users die.

11 June 2008, the Försäkringskassa [Social Insurance Agency] introduced a new interpretation of the regulation concerning “certain time placed on level with provided assistance” in §6 of the Assistance Allowance Ordinance.⁹⁸ The possibility of being granted assistance allowance for assistance needed during hospital stays, is now limited to users employing their own assistants. The same applies to costs for salaries etc. during periods of termination for assistants of users who die.⁹⁹

STIL, the Independent Living cooperative in Stockholm, thinks an economic buffer is necessary in a situation where the assistance user dies and where the assistants are left without a job. A possibility to put aside funds for a situation like this, should exist or, ideally, the Försäkringskassa [Social Insurance Agency] should pay salaries etc., during the period of termination according to current union agreements.

“If a member of STIL dies, the union agreement demands that salaries during termination of contract period are paid to all the assistants. It can cover salaries for two weeks, a month, or even more if the assistant had been employed a long time. It can also cover termination

⁹⁶ Westberg, K. 2008-10-25

⁹⁷ Westberg, K. 2008-01-13

⁹⁸ SFS 1993:1091

⁹⁹ Försäkringskassan 2003:6 ver. 5 pp.133-134

salaries for up to 20 assistants. Today there is no part of the assistance allowance that covers this.”¹⁰⁰

The employer should also be able to save funds to compensate assistants for loss of income, according to Särnmark Assistans. In this case, the Försäkringskassa [Social Insurance Agency] withdraws the right to assistance allowance.

*“This is important, to provide security both for the assistance user and the assistants, and so be able to keep assistants that have been working a long time. The possibility of providing compensation in these cases can easily be measured against costs connected to introduction of new assistants.”*¹⁰¹

From the perspective of interest politics, representatives for the Swedish Association for Persons with Neurological Disabilities (NHR) state that this affects fair competition, as it will get increasingly harder for small companies to act and fulfil their duties. Big companies and municipal providers will be advantaged in a competitive sector.

*“An assistant, who is informed about this, will probably choose to take a job with an assistance user acting as employer, a big company or a municipality rather than a smaller assistance company, which then gets a worse starting point.”*¹⁰²

Rehabilitation responsibility

Employership entails a responsibility for rehabilitation, when an injury is deemed as having a direct connection to the work, which can result in costs. An employer might also have to cover costs for rehabilitation during a long-term sick leave. Stefan Pelc, assistance user employing his own assistants, thinks a reasonable buffer in his case, would be SEK 50.000-100.000, approximately € 4.900-9.800 (exchange rate at end of February 2010). This buffer, separated from everyday economic activities, would be a special account only to use for unexpected expenses.

*“The rehabilitation assessment is paid by the Försäkringskassa [Social Insurance Agency] but if I want to keep an assistant, it can involve covering costs of all types from treatment for back injuries to alcohol abuse. I do not have the possibility to offer my assistants this, if I do not have an economic buffer.”*¹⁰³

¹⁰⁰ Westberg, K. 2008-01-13

¹⁰¹ Westberg, K. 2008-01-13

¹⁰² Westberg, K. 2008-08-02

¹⁰³ Westberg, K. 2008-01-13

Problems to get money from municipalities for assistants' sick pay

According to STIL (the Independent Living cooperative in Stockholm), before 2006, it was common that municipalities and assistance providers signed agreements on how assistants' sick pay should be reimbursed. However, Sveriges Kommuner och Landsting [Swedish Association of Local Authorities and Regions] noted that this procedure was wrong and issued new guidelines. These stipulated that the issue of sick pay should be handled according to the Administrative Procedure Act with application, investigation and decision.¹⁰⁴

The Supreme Administrative Court ruled the issue of what should be seen as an increased cost and decided that the municipality should reimburse the costs of the sick pay. However, there has been a problem with the issue of sick pay since then, as certain municipalities maintain that they have not received enough basic data to calculate the increased costs. There are also different interpretations on how to calculate the increase cost.¹⁰⁵

Conflicts with employees

According to the employer organization KFO, almost all conflicts summoned to the arbitration tribunal deal with termination of contracts. When the employee is a member of a workers union, negotiations take two steps, i.e. local and central negotiation. After this, a negotiating committee with representatives from workers unions and employer organizations handle the conflict. If no agreement can be reached, on demand of either party the conflict can be handed over to an arbitration tribunal, consisting of representatives from workers unions and employer organizations. If the personal assistant is not a union member, as is the case with many of them, preliminary negotiations do not always take place. This sometimes increases the number of cases.

“Then the conflict can go straight to the negotiating committee and arbitrary tribunal, it is usually regulated in employment contracts that all conflicts shall be treated by an arbitrary tribunal, even when the assistant is not a union member.

At the same time, it is unusual that a conflict goes as far as the arbitration tribunal.

“More than 90% of all conflicts are solved through conciliation and most of the cases, which go as far as being summoned, reach a settlement during the time the case is considered by the arbitration tribunal. /---/ The damages [if you lose a case] vary, but sums around 100.000 SEK are not unusual [approximately € 10.250, (exchange rate according to xe.com at 2010-03-01)]. Losing a case in court means you have to pay the opponent's legal fees as well, which can be a question of remunerated work for at least 50 hours at a cost of 1.500-2.500 SEK per hour [approximately € 154-256 (exchange rate according to xe.com at 2010-03-01)]./---/ [Costs of a conciliation] vary extremely much, anything from 5.000 to 100.000 SEK exist [approximately € 510 to 10.250 (exchange rate according to xe.com at 2010-03-01)]. You should not need saved funds to cover the worst case scenario since this is so unusual, but you

¹⁰⁴ SKL 2006:39; SFS 1986:223

¹⁰⁵ Westberg, K. 2009-11-23

should have around 25.000 SEK [approximately € 2.565 (exchange rate according to xe.com at 2010-03-01)] in readiness.”¹⁰⁶

At Persona Assistans, the opinion is that an economic buffer around 100.000 SEK, approximately € 10.250 (exchange rate according to xe.com at 2010-03-01), is a safeguard against costs for conciliations and damages.

“First of all, everyone can get costs for a month’s termination pay if you have to give an assistant notice. At our company, the customer can refuse to let the assistant continue working. We try to transfer the assistant, but sometimes there is no new workplace and then he/she has to be given notice. The same applies to administrative personnel at the office, who for some reason cannot continue working. Furthermore, everyone can, even if this is unusual, end up with a conflict resulting in conciliation costs and in worst case scenario damages.”¹⁰⁷

4.18. Are Assistance Providers Allowed to Make Profit?

Owners of assistance providers can make profit, which is then subjected to taxation.

Aktiebolag (a limited company) is a legal entity. It is represented by a board of directors and in certain cases by a managing director. The owners are not personally responsible for debts in a limited company.¹⁰⁸

In a limited company, 26,3% of the profit is claimed as tax, also any dividend taken by the owners is subject to tax in their income declaration. Normally, tax rate for dividends is 30%, but it can be lowered to 20% in companies with four or less owners and for dividends up to 84.400 SEK (present rate), approximately € 8.650 (exchange rate according to xe.com at 2010-03-01).¹⁰⁹

Handelsbolag (trading partnerships) is owned by two or more persons. It is a legal entity but the partners remain personally and jointly responsible for the company’s debt.¹¹⁰

Profit in partnership companies are not subject to tax. Instead, each partner claims tax for their share of the profit. As partial owner, you can withdraw money from the company during the year. In partnership companies, every owner is subjected to marginal tax for social security payments of 29,71% and also his regular income tax.¹¹¹

Ekonomisk förening (an economic association) is a legal entity set up by at least three natural or legal persons. Members are not responsible for the association’s debts outside the membership fee.¹¹²

¹⁰⁶ Westberg, K. 2007-12-14

¹⁰⁷ Westberg, K. 2007-12-14

¹⁰⁸ Bolagsverket 2010-03a

¹⁰⁹ Tillväxtverket 2010-03a

¹¹⁰ Bolagsverket 2010-03b

¹¹¹ Tillväxtverket 2010-03b

¹¹² Bolagsverket 2010-03c

Profit in an economic association is subjected to state tax of 26,3%. Dividend can be paid to the members. Payments to members, which are not compensations for work or as a quid pro quo, are viewed as dividends. Dividends may only be taken from existing surplus; they are not tax deductible but subject for taxation as financial income for the members.¹¹³

Enskild näringsidkare (sole trader or sole proprietorships) is a business run and represented by one person. There is no legal division between the owner's private economy and the company's. The owner is subjected to marginal tax for social security payments of 29,71% and also his regular income tax.¹¹⁴

Five largest assistance providers report following profit margins 2008

- Assistansia AB: 8,0 %
- Frösunda LSS AB: 0,0 %
- Olivia Assistans: 8,5 %
- VH Assistans: 7,3 %
- Nordström assistans: 1,8 %

Smaller assistance providers with larger profit margins 2008

- Marcus Assistans: 27,1 %
- Charkas Assistans: 28,3 %¹¹⁵

4.19. What does the Duty of Confidentiality Mean?

The employer explains the content and requirement of the duty of confidentiality to the employee, who generally engages to respect this by signing a written agreement.

“He, who is or has been active within a professionally managed private enterprise, which concerns measures according to this legislation, may not reveal unauthorized what he learned about an individual's personal circumstances.”¹¹⁶

A duty of confidentiality means that the employee is prevented from revealing information about an individual's personal circumstances to unauthorized persons or to authorities. Personal circumstances are e.g. the individual's health, family situation, education, professional activities, economy and social situation. Addresses, telephone numbers, computer lists, audio and video tapes as well as images, are also included.

¹¹³ Tillväxtverket 2010c

¹¹⁴ Bolagsverket 2010-03d

¹¹⁵ Ratsit

¹¹⁶ SFS 1993:387 §29

If the concerned individual directly or indirectly agreed that information can be revealed, the employee may do so only if the information does not harm any related individuals, who have not agreed. The concerned individual's perception determines what is harmful, not the employee. Information covered by a duty of confidentiality may be revealed to an authority, if there is a legal obligation to do so. Individuals, demanding information covered by duty of confidentiality, must be able to prove their right to gain such information by referring to legislation.¹¹⁷

4.20. What Institutions are Responsible for Inspection of Assistance Providers?

Socialstyrelsen [National Board of Health and Welfare] is the authority responsible for central supervision of activities under LSS. As such, Socialstyrelsen [National Board of Health and Welfare] has to provide advice and guidance, control that failings and irregularities are attended to, provide knowledge and experience gained through the supervision, as well as provide advice and information to the public.

There is no demand of permit to provide personal assistance. The supervision is therefore slightly different, regarding personal assistance compared to e.g. housing with special services or occupational activity, provided under LSS and for which a permit is required.

“With personal assistance, it is the individual who chooses the provider and, thereby, him/herself assesses whether the provider fulfils the demands. If the individual is dissatisfied, he/she can change provider.”¹¹⁸

However, the recently closed parliamentary committee reviewing LSS, delivered a proposal of strengthened supervision and control. At present the Ministry of Health and Welfare is preparing a Government Proposition (proposal of reform directed to the Swedish Parliament) which includes regulation of supervision. According to the Ministry of Health and Welfare, the proposal will demand a permit for all private assistance providers.

Nevertheless, assistance users employing their own assistants will not be required to have permits as their activities are not viewed as managed on professional basis and, therefore, there is not the same need of supervision in advance. Instead, they will only have to report their activities to Socialstyrelsen [National Board of Health and Welfare].

“[R]equirements for permit concern skill development, knowledge about legislations regulating the activity and about approach, treatment and economy etc. For providers of assistance to children and youngsters, it is important that the description of the skill of the personnel includes factors that are important to provide children with good quality personal assistance. /---/ All private assistance providers, which have received permits, and assistance

¹¹⁷ Arbetsgivarförbundet KFO 2008

¹¹⁸ Westberg, K. 2010-01-28

users, who employ their own assistants and report their activities, will be known by the National Board of Health and Welfare in this system.”

“The proposal can result in a slight limitation of the number of private assistance providers [if they will not get permits]. However, the Government states this will be compensated by the protection for assistance users, which can provide a demand for permits. The intention is that personal assistance provided by private companies shall become even more competitive.”¹¹⁹

4.21. What does Reporting under Lex Sarah Mean?

Social Service Act chapter 14 (section 2), is commonly known as Lex Sarah, after the Swedish paramedic Sarah Wägner, who disclosed terrible conditions in a nursing home for the elderly in 1997. Lex Sarah puts a duty on everyone active within care, both for the elderly and for persons with disabilities, to verify that the persons receive “good care” and have “secure living conditions”. Individuals have a duty to report “serious abuse” to the municipality social welfare committee, if the situation is not immediately rectified, the social welfare committee shall report the case to Socialstyrelsen [National Board of Health and Welfare].¹²⁰ All personnel in services regulated under LSS, as e.g. personal assistance, have a duty to report serious failings affecting users of the services according to Lex Sarah.

“Employees in municipalities shall report directly to the municipality’s social service committee, employees in private enterprises, i.e. companies, cooperatives and assistance users acting as employers, shall report to the responsible personnel of the provider and send a copy of the report to the municipality social service committee at the same time. /---/ a report shall be made to the municipality of domicile, even if the Försäkringskassa [Social Insurance Agency] made the decision on personal assistance”.

Everyone, who is working in the activity, is bound by the duty to verify its quality, assistants, administrative personnel and assessing and deciding officials. Family members, however, cannot report a situation under Lex Sarah.

“On the other hand, family members can report failings and irregularities directly to the municipality’s social service committee or its personnel, to the provider or to one of its employees. Family members can also report failing directly to the National Board of Health and Welfare”.¹²¹

All providers shall have routines on how to do a Lex Sarah-report and whom to turn to. Reports focus on a situation instead of on an individual, and they shall include what has happened, when it happened and whom it has affected. The reports shall be investigated as soon as possible, preferably

¹¹⁹ Westberg, K. 2010-02-18

¹²⁰ SFS 2001:453 kap.14 §2

¹²¹ Westberg, K. 2010-01-28; Försäkringskassan 2003:6 ver.5 p pp.23-25

not by personnel in supervision positions connected to the reported activity due to a risk of exclusion and objection. The investigation shall be filed for at least two years.

Socialstyrelsen [National Board of Health and Welfare] issues guidelines on what are considered severe failings and irregularities:

- Treatment, that clearly deviates from fundamental demands of respect for self-determination, integrity, security and dignity.
- Physical abuse, such as hitting, pinching and rough handling.
- Psychological abuse, such as threats, punishment, harassment, intimidation and violation.
- Economic abuse, such as theft, extortion and embezzlement.
- Sexual abuse, such as unwelcome advances and harassment.
- Deficiencies in the activity that affects personal hygiene and diet.
- Deficiencies in supervision.

A duty of confidentiality does not prevent that information is presented to another authority, if demanded by legislation or ordinance. If the prerequisites for reporting are fulfilled, i.e. severe failings or irregularities have been noted, information will be forwarded to the responsible committee, irrespective of secrecy.¹²²

4.22. What does Reporting According the Social Service Act for Protection of Children Mean?

Where children may be at risk, it is a duty to report those situations to the municipality social service committee, as regulated in the Social Service Act chapter 14 §1. This also applies to activities under LSS and, in this case, includes all employees in the municipality and all employees in professional private activities.

For employees, it concerns information they received at work. They cannot report anonymously. The duty to report and disclose information overrides the legal obligation of secrecy. The protection of integrity, found at the centre of legalized duties of secrecy, give way for children's need for protection.¹²³

¹²² Försäkringskassan 2003:6 ver.5 pp.23-25; SOSFS 2008:10

¹²³ SFS 2001:453 chap.14 §1; Försäkringskassan 2003:6 ver. 5 p.26

5. Personal Assistants

In this chapter we focus on personal assistants: the requirements to work as an assistant; the specific characteristics defining them as a group; the organization representing them. We also report whether personal assistant is an accepted profession and look into the status, qualifications, payments and seniority conditions.

Personal assistance aims to provide the assistance user with self-determination, but this is dependent on the personal assistant performing the necessary tasks. This chapter also covers which tasks are included within personal assistance and if there are any restrictions as to what an assistant is allowed to do. Is self-care allowed, and can this be delegated to a personal assistant? Finally, we address the use of service guarantors and vice supervisors for assistance users incapable of supervising.

5.1. Who can Work as a Personal Assistant?

The Government proposition of the LSS/LASS acts states that the “individual should have a decisive or very big influence on who is employed as personal assistant”.¹²⁴ Therefore, anyone, whom the assistance user chooses, can work as a personal assistant. Within the municipalities, two different union agreements are used: one for personal assistants employed only for a certain assistance user, and another for personal assistants employed to assist several users.

In the first situation, the personal assistant is neither required to have care qualification nor to be available for other assistance users. In the second situation *“the user relinquishes some of the influence over who will be employed since the employee must have care qualifications and be available for other work assignments, despite this the user shall be provided with as much influence over who gets employed as possible.”*¹²⁵

5.2. Who Works as a Personal Assistant? How many Assistants are There?

According to Socialstyrelsen [National Board of Health and Welfare] some 50.000 persons were working as personal assistants in 2004, a majority of these (77%) were women. The number was estimated to rise to 60.000 by 2010. The exact number is hard to pinpoint as persons employed as personal assistant are regularly mixed with persons employed in home care services. The number of men employed as personal assistants is higher than for other types of care activities. Studies show that women to a higher degree want to receive assistance from other women while men accept both women and men as personal assistants. Women felt more embarrassed and exposed when men were assisting them with intimate tasks. They were also more sensitive to how the environment, both family and neighbours, perceived the fact that they received male assistance for intimate

¹²⁴ Prop. 1992/93:159 p.174

¹²⁵ Westberg, K 2008-10-25

tasks. The more positive attitude of men, to allow more female personal assistants, might very well be characterized by the long-standing tradition of women fulfilling the caring role.¹²⁶

According to Kommunal [Swedish Municipal Workers' Union]:

- four out of five personal assistants are women,
- most personal assistants are between 25 and 44 years old,
- every third assistant is of foreign origin - Finnish, Iraqi, Norwegian and Bosnian origin is most common,
- two out of three have worked more than three years as assistants,
- one out of four work full time,
- eight out of ten are employed by municipalities.¹²⁷

Research, on personal assistance in Sweden, shows that the assistants' educational background varies from ground school up to higher education. The surprisingly large part of assistants with higher education and the high turnover of employees within the profession, indicate that personal assistance often is viewed as a temporary job. Although one out of five assistants does not have any care qualifications or experience of care work, studies have shown that a majority (58%) of personal assistants do. As persons with disabilities exchange care provisions for personal assistance, employees can also transfer to the new provider at the user's request. It is quite common for users to require and/or seek assistants with care qualifications and experience though others are unwilling to employ assistants with such qualification or experience.¹²⁸

The importance of language is reflected in how often fluent Swedish is demanded in advertisements for assistants. If the linguistic communication between assistant and user is not sufficient, e.g. speaking and understanding each other, this will cause problems and probably impair the quality of assistance. However, this also counts for persons with disabilities of foreign background needing assistance. Research shows that almost 19% of persons working as personal assistants are born outside Sweden.¹²⁹

5.3. Are Personal Assistants' Interests Protected by Organizations or Union Agreements?

Kommunal [Swedish Municipal Workers Union] is the organization responsible for negotiating union agreements within the area of personal assistance. Their negotiating partners among the employers' organizations are Arbetsgivarföreningen KFO [Independent employers' organization for co-operative business], Kommunala Företagens Samorganisation [KFS, Swedish Organization for Local Enterprises], Vårdföretagarna [Association of Private Care Providers] and Arbetsgivaralliansen [Employers' Alliance]. They also negotiate union agreements within personal assistance with Sveriges Kommuner

¹²⁶ Socialstyrelsen 2007

¹²⁷ Kommunal (2004) p.16

¹²⁸ Socialstyrelsen 2007 pp.28-29; Kommunal 2004 p.16

¹²⁹ Socialstyrelsen 2007 p.29

och Landsting [Swedish Association of Local Authorities and Regions] as well as provide a union agreement for unorganized employers.¹³⁰

5.4. Is Personal Assistant Viewed as a Profession? What is the Salary Level Compared to other Professions?

Personal assistant is a well-established profession. Employment contracts with the employee status as personal assistant, are used throughout the country since the enactment of LSS/LASS (1994). However, these contracts existed in certain parts of the country before 1994. Employees joining Kommunal [Swedish Municipal Workers' Union] do so in the section for 'personal assistants' and Arbetsförmedlingen [Swedish Public Employment Service] publishes available positions under the title of 'personal assistant jobs'.¹³¹

Salary levels are commonly compared with salaries of nurse/care assistants within health care. Personal assistants' salaries are limited by the level of the assistance allowance, which covers all expenses for personal assistance. The yearly flat rate can only be extended with a maximum of 12%, so the individual competence of the employee and special need of the user influence salary levels to a limited extent. However, the yearly flat rate is mainly the result of labour market negotiations between employers' organizations and unions. According to Riksrevisionen [Swedish National Audit Office] the flat rate for assistance allowance is calculated on the basis of salary levels for nurse/care assistants.¹³²

Kommunal [Swedish Municipal Workers' Union] reported that in November 2008 the average monthly salary for personal assistants, employed by the municipalities, was 19.300.-SEK, approximately € 1.980 (exchange rate according to xe.com at 2010-03-01), a level equalled in Assistanskoll's statistics. This is a fraction higher than the average monthly salary of care assistants within municipal care services.¹³³

5.5. How Long do Employments Usually Last? Do Assistants Work Full-time?

Staff turnover within personal assistance is high, with an average estimated at 40% per year. The profession is viewed both as a profession with a shortage of skilled workers and as a temporary occupation. According to Kommunal [Swedish Municipal Workers' Union], it is viewed as a good and developing employment for a couple of years, but also one that can cause social instability in the long run due to insecure employment and flexible hours. Other type of jobs and educations are more attractive. Every other personal assistant in the age group 24 – 34 years is actively looking for a job or education outside the field.¹³⁴ A large part of personal assistants work part-time or less than full-time

¹³⁰ Kommunal 2007 p.223

¹³¹ Socialstyrelsen 2007 p.12

¹³² Socialstyrelsen 2007 p.27; Riksrevisionsverket 2004 p.141

¹³³ Kommunal (data file); Communication with Philip Day, Independent Living Institute

¹³⁴ Socialstyrelsen 2007 p.13; Kommunal 2004 p.7

as work hours have to be adapted according to the user's need. Part-time is also traditionally common within jobs dominated by female employees, particularly within care work. Average employment time among personal assistants within municipalities was 79% in November 2008.¹³⁵

5.6. What Qualification is Required to Work as Personal Assistant?

According to LSS, no qualification is needed and the user can choose freely whom to employ. Often personal characteristics and references are viewed as more important than formal qualifications. Arbetsförmedlingen [Swedish Public Employment Service] states that suitable education the upper secondary school's care program or similar educations provided by folk high schools or higher vocational education courses.¹³⁶ Kommunal [Swedish Municipal Workers' Union] has commented on available education for personal assistants and claims that education has to provide basic competence in e.g. ergonomics, LSS, ethics and duty of confidentiality.¹³⁷

Demand for specific qualifications for personal assistants is an ideological issue for many assistance users and their representative organizations. Many users, with experience of receiving care in the former system, think differently about competences when recruiting personal assistants. They view experience from care work as detrimental for the user's self-determination, and consider it a risk of restricting the assistance user's supervising function – at the core of LSS.¹³⁸

“When they come from the long-term elderly care they see me as if I was senile. Experts, that is what they are and they know. When I was instructing a girl, she said that she knows so there is no need for me to speak. She had work at /.../ and knows what to do. It is actually a bit individual, I said, but she knew.”¹³⁹

Competence sought in advertised positions varies highly. Some users want assistants, free from perspectives existing in care qualifications, or look for individuals with experience from the service sector. Others have specific needs and want individuals with care or health care qualifications. Qualifications in sign language or BLISS for communication, physical strength to handle heavy transfers or a driving license, are also commonly asked for. Assistance users can seek individuals tolerant of different domestic animals or smoking; or if users are allergic, they can demand assistants without contact with animals, who do not smoke or use scented products. It is also common for the user to seek individuals interested in e.g. music or sport or with computer skills.¹⁴⁰

¹³⁵ Socialstyrelsen 2007 p.25; Kommunal (data file)

¹³⁶ SFS 1993:387; Arbetsförmedlingen (data file)

¹³⁷ Kommunal 2007 p.42

¹³⁸ Socialstyrelsen 2007 p.19

¹³⁹ Gough R. 1994 p.181

¹⁴⁰ Socialstyrelsen 2007 p.19

5.7. Are there Conditions of Seniority for Personal Assistants?

For personal assistants employed on indeterminate time contracts, seniority affects the period of notification of termination as follows:

- employment less than 2 years – 1 month notice period,
- employment between 2 and 4 years – 2 month notice period,
- employment between 4 and 6 years – 3 month notice period,
- employment between 6 and 8 years – 4 month notice period,
- employment between 8 and 10 years – 5 month notice period,
- employment 10 years or more – 6 month notice period.

Personal assistants employed on fixed-term contracts have a maximum of 1-month notice period depending on the union agreement. Retirement age is 65 for all employees.

Employees have a right to a vacation period of a minimum of 25 working days (i.e. 5 weeks) and, if nothing else is negotiated, this rises to 31 working days for employees over 40 years of age and 32 working days for employees over 50 years of age.¹⁴¹

5.8. Is Personal Assistant a Profession with a Shortage of Skilled Workers?

In 2003 Arbetsmarknadsstyrelsen [Swedish National Labour Market Board], together with other government agencies, defined personal assistants as a profession with a shortage of skilled workers. Factors behind this classification were a shortage of workers in so-called disability care and then high turnover within the professions. Surveys, directed to both municipal and private employers of personal assistants, show that most employers have difficulties recruiting staff, predominately in the Stockholm area and within certain sparsely populated areas in the rest of the country. Employers also saw a trend of increasing difficulties. Difficulties of recruiting personal assistants exist throughout the country and, despite a right to personal assistance, persons with disabilities sometimes cannot be provided with this due to shortage of staff.¹⁴²

5.9. What Status does the Profession of Personal Assistant Have?

Research shows that personal assistant is often viewed as a low status profession. Yrkesinspektionen [Labour Inspectorate] states that personal assistant is a highly under-valued profession with a specific, not yet recognized competence. This is a statement echoed by individuals working as personal assistants. They think that the fact that there is no education required or qualification

¹⁴¹ Assistanskoll 2010-03a links to current union agreements bottom of page

¹⁴² Socialstyrelsen 2007 p.18

needed gives an impression that the job can be done by anybody. Personal assistants report that they are the subject of condescending treatment from individuals working in other professions.¹⁴³

“Especially my father, who thought work within home care services had higher status than working as a personal assistant.”¹⁴⁴

Individuals working as personal assistants often claim that this devalued view of the profession is wrong. They argue that they perform an important job, where they get to use and develop their competences, and that life experience is more important than formal training for the job.¹⁴⁵

5.10. Why is a Job as Personal Assistant more Insecure than other Care Work?

The purpose of the LSS reform is that the assistance users themselves decide whom they want to receive assistance from. Therefore, a personal assistant can be given a notice of termination without any other reason than the assistance user’s unwillingness to receive their services anymore. The assistance allowance, which is the basis for employment, is also withheld if the assistance user is submitted to a hospital or any other government funded institution or dies. These conditions result in insecurity for personal assistants, depending on the employment type and the possibility of finding a job with another assistance user.¹⁴⁶

Now, the Ministry of Social Affairs is working on a proposal for all personal assistants, irrespective of their employment type. The proposal stipulates that assistants receive a 1-month notice of termination after an assistance user’s death. In the proposal, the user can also keep his assistance allowance up to six months after he has been hospitalized or taken to an institution. This means personal assistants can continue working for the user during this six-month period.¹⁴⁷

In a survey done by Kommunal [Swedish Municipal Workers’ Union] one out of four members have worried about losing their job during the previous month. Younger members, members employed on fixed-term contracts and members with non-Swedish origin are most anxious. It is understandable that assistance users do not want to keep assistants they no longer trust. At the same time, the insecurity caused by this employment condition can affect the relationship between assistance user and personal assistant.¹⁴⁸

A study executed the south of Sweden shows that less than half of the personal assistants were employed on indeterminate-time contracts (42%), with the rest being employed on fixed-term or hourly contracts or in probationary employment. In spite of this, all of 75% felt they had a desirably secure employment. These contradictory findings can indicate that a large part of the personal

¹⁴³ Socialstyrelsen 2007 pp. 54-55

¹⁴⁴ Larsson, M. 2004 p.137

¹⁴⁵ Socialstyrelsen 2007 pp.54-55

¹⁴⁶ Socialstyrelsen 2007 p.23

¹⁴⁷ Westberg, K. (2010-02-18)

¹⁴⁸ Kommunal 2004

assistants had another job besides being personal assistant, therefore, they were not primarily concerned with employment security.¹⁴⁹

5.11. What Tasks a Personal Assistant is Allowed to Do?

There are no legal regulations limiting what tasks personal assistants are allowed to do. Arbetsmiljöverket [Swedish Work Environment Authority] does not value the work assignments of personal assistants as long as appropriate risk assessments are done and as long as the task is legal.

“Sure, all types of assignments can pop up within assistance, since everybody’s life is different. If I have been working as a carpenter and then became a wheelchair user, I might have done the woodwork on the roof of my house earlier. As far as possible, we shall avoid restricting individuals through execution of authority. /---/ The more detailed [the work descriptions are] the better, so the personal assistants are aware of what is involved in the job. At the same time, it is impossible to cover everything that may happen in somebody’s life, which also should be clear in the work description.”

According to Arbetsmiljöverket [Swedish Work Environment Authority], the limit of work assignments is determined by whether the assistant has knowledge, resources and authority to perform the task. These three conditions are necessary in all professional situations. For example, to exchange motor oil in the assistance user’s car, a personal assistant needs knowledge of how to do this without risks, resources in form of time etcetera and authority from the employer who shall decide that this is part of the work tasks. Arbetsmiljöverket [Swedish Work Environment Authority] does not see any limits outside those three conditions mentioned above. It can be seen in their comment on a suggestion from an assistance user that it should be possible to do bungee-jumping with a personal assistant:

“Well bungee-jumping is possibly something you do by yourself, but you can do parachute jumping as a tandem-jump. If an assistant has the knowledge to do this, the authority from the employer and the necessary time to perform it, it is possible for Arbetsmiljöverket’s [Swedish Work Environment Authority’s] side.”¹⁵⁰

In spite of the fact that there are no limits as to which tasks are included in personal assistance, municipalities frequently restrict which chores assistants are allowed to perform. A survey, done by Socialstyrelsen [National Board of Health and Welfare], shows that certain municipalities issued guidelines. They restrict tasks included in personal assistance, which are incompatible with the right to personal assistance as regulated under LSS. According to Socialstyrelsen [National Board of Health and Welfare], guidelines regulating in detail which tasks are included in personal assistance services obstruct the very aim of assistance.

¹⁴⁹ Socialstyrelsen 2007 p.23

¹⁵⁰ Westberg, K. (2009-04-22)

“General and administrative limitations of what shall be covered by assistance is not acceptable; since the individual shall be provided with self-determination and a large influence, assistance has to be organized after the individual’s prerequisites. This is valid for all rights under LSS, but extra clear in the case of personal assistance.”¹⁵¹

5.12. Is Self-care of Personal Health Care Maintenance Allowed?

According to LASS, assistance allowance shall not be provided to substitute health care activities under the Health and Medical Service Act.¹⁵² When differentiating between activities within personal assistance and health care, one has to recognize activities that are viewed as self-care and activities under the responsibility of medical professionalism. Self-care is defined as health care or medical activity, which an authorized health professional has deemed possible for an individual to perform by him/herself. Self-care, according to this definition, does not fall under the responsibility of the general health care system. It is the responsibility of the authorized health care professional, registered in the health care administrative system, who decides what activities can be performed as self-care. This decision is made in connection with health care planning by the responsible health care professional and based on a risk analysis of the conditions in each individual case.

Exactly what kind of activities can be performed as self-care depends solely on the conditions in the individual case. There are no general regulations. A decision on self-care shall be made in cooperation with the individual and on basis of his/her physical and mental health and life situation. These conditions are decisive if the individual has the capacity to perform the specific activities or to instruct others to safely do so. If the individual is unable to perform the activities him/herself, the assessment is done based on the support available to him/her. Family and personal assistants can gain extensive knowledge of a user’s situation and personal needs and/or can be taught to perform activities, which are normally done by medical professionals. This is also classified as self-care. The deciding factor is whether the activities can be performed safely, which often depends on the quality of the personal assistance.

Both medication and medical treatment can be the objects of self-care. The medical professional making the decision on self-care, and thereby delegating the responsibility of performing it, is responsible for the delegation being done in a manner safeguarding the assistance user. The decision on self-care contains information about:

- what activities are considered self-care.
- if it is the individual him/herself who shall perform the self-care, or perform it together with somebody else.
- how information and instruction will be provided to individuals performing self-care.
- what actions shall be taken and whom to contact if an individual has been injured or is risking an injury or disease as a consequence of self-care.
- what actions shall be taken and whom to contact if the individual’s situation changes.

¹⁵¹ Socialstyrelsen 2005; Westberg, K. 2008-09-17

¹⁵² SFS 1993:389; SFS 1982:763

- how and when the decision of self-care shall be reviewed.
- when a revision of the self-care shall be done.¹⁵³

Försäkringskassan [Social Insurance Agency] concurs to the guidelines issued by Socialstyrelsen [National Board of Health and Welfare] when assessing and deciding on personal assistance.¹⁵⁴

5.13. How do Assistance Providers Manage Self-care?

An example of self-care tasks that assistants can perform:

“Giving medication or certain types of injections, if the assistance user can instruct the assistant. Wound dressing, managing a tracheotomy, respirator or other medical technological apparatus can also be delegated to assistants. Assistants are provided with training in how to manage the respirator or other technological apparatus that is the object of delegation.”

A nurse or doctor from the health care system in the municipality or county council are responsible for delegation and decide the period it is valid for. Delegation is confirmed in a written document and the medical professional issuing it is responsible for its renewal. In STIL, the supervisor (i.e. assistance user) is responsible for reporting new or changed conditions or new personal assistants who need delegation. Personal assistants need to show that they understand the task to be approved for delegation. They can also refuse it if they feel unable to perform it.

If delegation of self-care is given to an assistance user’s assistants, it is important to have good quality assistance and reliable assistants. This can cause problems when a personal assistant with delegation is sick or needs to take time off.

“[The substitute assistant] needs to be someone with delegation. The assistant cannot give a verbal delegation to another assistant. As many as possible of the assistance user’s assistants need to have delegation for it to work smoothly.”

There is no conflict with unions, health care professionals or work environment inspectors over self-care issues:

“I have not heard of any conflicts, but the assistants can find it unpleasant if somebody refuses treatment, e.g. with a cough assist machine, and they feel responsible but the assistance user has the same right as anybody else to refuse treatment. In one example, an assistant found it unpleasant to give wine through one of our supervisor’s PEG tube [feeding tube placed through the abdominal wall]; the feeding was delegated to the assistant. However, the responsible nurse said it was his right to have it.”¹⁵⁵

¹⁵³ Socialstyrelsen 2009b

¹⁵⁴ Försäkringskassan 2003:6 ver.5 p.86

¹⁵⁵ Communication with Suzanne Elmqvist, STIL 2010-03-09

5.14. Does a Double-financed System Exist for Personal Assistance in Sweden?

Sweden has a system where tax reduction is provided for domestic services. However, assistance allowance is exempt from taxation so it cannot be used in combination with tax reductions.¹⁵⁶ Personal assistance is financed in whole either through Försäkringskassan's [Social Insurance Agency's] assistance allowance or through direct payment from the municipalities. The hourly flat rate of the assistance allowance, as well as the direct payment provided by municipalities, is set at a level to cover the full cost of personal assistance. Assistance users shall not have to fund necessary assistance by other means.

It is common for companies providing personal assistance to also sell domestic services with tax reduction. This is not a problem if personal assistance is provided according to how this is specified in the legal reform. However, when municipalities issue guidelines unjustly restricting the tasks within their personal assistance services, in combination with purchasing these services from a company active within domestic services, it causes a dubious situation. A company contracted by the municipality is, in this situation, bound by a contract stipulating their personal assistance tasks, even if this is legally wrong. In this case, the assistance user has no option other than to choose to transfer his/her personal assistance from the municipality to another provider, unless he/she wants to pay for services which should be provided as personal assistance.

5.15. Can a Personal Assistant be Self-employed?

A personal assistant can be self-employed and choose to receive payment through an already existing own company. However, it is doubtful if it is possible to be self-employed with the sole purpose of selling your own personal assistance services. According to Skatteverket [Swedish Tax Authority] a personal assistant would probably have to sell their services to at least five different assistance users, each one of them acting as enskild näringsidkare [sole trader].

"If on the other hand you work for assistance provider, you are not viewed as independent since you are working in the company as other employees. The situation is similar to medical doctors who rent themselves to the county council; they are not allowed to get registered either."¹⁵⁷

¹⁵⁶ Försäkringskassan 2003:6 ver. 5 p.130

¹⁵⁷ Stiletten 2007 pp.18-21

5.16. What is a Vice Supervisor/Service Guarantor?

A comparison of the personal assistance providers registered in Assistanskoll's database shows that 119 out of 145 provide a guarantor or vice supervisor if the assistance user wants this.¹⁵⁸ The support exists foremost among cooperatives, but also in some private companies.

"Gnosjö Assistans AB has delegated the supervision to the customer. When the customer neither has the possibility nor the ability to perform daily supervision of the assistants, there is an appointed vice supervisor. The vice supervisor can be a family member, or a personal assistant with the added position as a vice supervisor for the assistance user."¹⁵⁹

The JAG user cooperative has had this support system since their start in 1994. At JAG, the function is called 'service guarantor', acting as supervisor instead of the assistance user. The service guarantor is under contract with JAG and responsible for the continuity, security and quality of the assistance. Included in the service guarantor's tasks are recruiting and supervising the JAG member's assistants, guaranteeing that the members get their granted assistance and that it is of good quality as defined under LSS and by JAG's aims. The responsibility to adhere to labour market legislation and union agreements is delegated to the service guarantor.¹⁶⁰

The service guarantor is a guarantee that every member in the cooperative will receive the assistance he/she needs. The service guarantor has to be an individual who knows the assistance user well. He/she is also working as a personal assistant for the member, at least as a temporary or substitute assistant. The aim of the guarantor is to make sure the member receives personal assistance enabling him/her to live a self-determined life. If the service guarantor cannot solve a situation in any other way, he/she has to work as an assistant. He/she can therefore be on a constant standby.¹⁶¹

The cost of salaries within the JAG user cooperative is in average 90% of the assistance allowance, 227 SEK per hour, approximately 23,3 € (exchange rate according to xe.com at 2010-03-01). Included in this is the fee of the service guarantor of a maximum of 6 SEK per hour, approximately 0,6 € (exchange rate according to xe.com at 2010-03-01), which is a compensation for daily supervision, scheduling and staffing responsibility. The service guarantor has to work as a personal assistant if he/she is unable to fulfil his/her staffing responsibility in any other way. The JAG user cooperative does not have a pool of temporary assistants.

"Our members in general have such extensive and complex needs that the assistants have to go through a long training period. Therefore, we cannot have temporary workers who are not trained to assist this specific member. Instead, we have the service guarantors who have the final responsibility that the members receive their assistance."¹⁶²

¹⁵⁸ Communication with Philip Day, Assistanskoll 2010-03-10

¹⁵⁹ Gnosjö Assistans AB 2010-03

¹⁶⁰ JAG 2010-03a

¹⁶¹ JAG 2010-03b

¹⁶² Westberg, K. 2007-11-03

While JAG user cooperative has a long experience of personal assistance and service guarantors due to their members' more complex and extensive disabilities, vice supervisors were not an integral part of STIL's personal assistance model. Today, assistance users needing support in their role as supervisor can get it from a vice supervisor in STIL. Also children with personal assistance through STIL always have a vice supervisor.¹⁶³ The responsibility and assignments of a vice supervisor in STIL can vary since they are designed to suit the individual assistance user's needs. At their basis, however, is the standpoint that STIL's members shall take on as much of the supervision as possible. It is therefore common for a vice supervisor and the assistance user to perform tasks together. The tasks a vice supervisor can take on are almost the same at STIL's and at JAG's, except for the service guarantor's standby duty. Vice supervisors at STIL do not have standby duties, but can instead be responsible for establishing a pool of temporary or substitute assistants.¹⁶⁴

5.17. Can the System with a Vice Supervisor Lead to Conflicts and, if so, How are These Dealt with?

There are no particular problems reported in connection with the use of service guarantors and vice supervisors. In some cases, a vice supervisor has become too dominating preventing the assistance user from asserting their wishes. This can cause problems, especially if the vice supervisor is a parent or a close family member. STIL has experiences of cases in which a vice supervisor has mismanaged his/her role but where the assistance user still wants to maintain that person as vice supervisor. If the situation cannot be solved by dialogue, someone at STIL's office has to take on the vice supervisor role while a new vice supervisor is recruited.

If the assistance user has a trustee or legal guardian he or she can act as a vice supervisor or demand that a vice supervisor be appointed.

"If a legal guardian says that a certain person shall be vice supervisor, STIL cannot refuse even if we should be of the opinion that the assistance user is capable of acting as supervisor. We had a legal guardian who demanded that there should be a vice supervisor even though we thought the assistance user would be able to handle it. We wanted to wait and see but had to submit to the legal guardian because he/she represented the assistance user."¹⁶⁵

¹⁶³ STIL 2010-03

¹⁶⁴ Communication with Suzanne Elmquist STIL 3010-03-09

¹⁶⁵ Communication with Suzanne Elmquist STIL 3010-03-09

6. Market Forces in the Care: Private (for Profit) Organizations

In this chapter we look at the private sector of personal assistance services, at how many private companies have entered the assistance market, their business types and their sizes. We also discuss who founded, took over and merged them. Assistance users seem to lean towards choosing private companies as providers, so we will have a look at quality and price of assistance produced by these.

As the personal assistance market is growing, the effects of privatization are perceived differently by politicians, customers and public. The effects also cause mergers and specialization. In a maturing market segment as assistance, measures preventing monopolies are important. So is the companies' system for guaranteeing good quality services.

Contrary to recipients of home care services, assistance users can freely choose their provider. It influences how the market develops. We take a look at the assistance users' choice, whether or not they change providers, the reasons and commonality of transferring one's assistance to a new provider.

We present the very few instances where providers offer both housing and personal assistance services. Finally, we report findings on assistance users' quality of life, the price of assistance services and the availability of contracts between assistance users and providers, as well as their content.

6.1. How many Private (for Profit) Companies Exist? What Size are They, Where are They Located? Who Founded Them? Who Owns them?

At the end of the year 2006, approximately 450 companies and cooperatives provided personal assistance paid by assistance allowance through Försäkringskassan [Social Insurance Agency]. The size of these companies varied greatly, from providers with one singular customer to large companies with over 1.000 customers. During the autumn of 2007 a survey was sent to 230 of these providers. It showed that 65% of the respondents were private companies - aktiebolag, handelsbolag, kommanditbolag – [trading or limited partnerships], 13% were enskilda näringsidkare [sole traders], 19% cooperatives or ekonomiska föreningar [economic associations] and 2% were something else. More than a quarter of them reported that they provided personal assistance to one single assistance user, and an additional quarter reported providing assistance to two to five individuals. Only 10% provided personal assistance to more than 50 customers.¹⁶⁶

On the Assistanskoll website, 175 companies and cooperatives are listed. This is the most comprehensive listing of providers of personal assistance, according to the recent Government proposal.

¹⁶⁶ SOU 2008:77 pp.480-482

“450 private companies provided personal assistance in 2006. According to the information from the Independent Living Institute, there are 24 private assistance providers with at least 200 personal assistants employed. Eleven assistance providers have more than 100 customers. As for assistance providers, which can be classified as medium sized or small, there are 75 providers with fewer than 60 personal assistants employed and 113 providers with fewer than 20 customers. Note that this is not a conclusive account of all assistance companies.”¹⁶⁷

Assistance users themselves start cooperatives, while founders vary among private companies. Sometimes they are started by a personal assistance user as for example PPA-bolagen, started by Per Pontus Andersson (29 customers in 2008), and VH Assistans, started by Veronica Hedenmark (170 customers 2008).¹⁶⁸ Relatives of personal assistance users also start companies.

“Din Förlängda Arm [Your Extended Arm] was founded in 2003 by Peter Näslund after his partner got MS in 1997. At the beginning, the municipality provided assistance but this did not function well. After a few years thoughts of starting a private company arose. Since Peter had worked as a special transport driver for many years, he knew many individuals with disabilities in the same situations as his partner. Peter started Din Förlängda Arm in the autumn of 2003 with some ten customers.”¹⁶⁹

In the autumn of 2009, Din Förlängda Arm had around 100 customers. Another company started by relatives is Assistansia. It has developed into Sweden's largest private company in personal assistance with over 1.300 customers. In 2008, Assistansia was bought by Argan Capital, a risk capital company.¹⁷⁰

The companies providing personal assistance have been founded and developed by entrepreneurs as Karsten Inde (physical therapist), who started Frösunda LSS AB in 1994. In 2001, he sold the company and started another private assistance company, Olivia Assistans. These companies are the second and third largest private companies providing personal assistance today, with approximately 800 and 250 customers respectively. Frösunda LSS AB was sold in 2008 to the Danish risk capital company, Polaris Equity. In 2008, the Swedish risk capital company, Procuritas, acquired 70% of the newly started company, Olivia Holding of which Olivia Assistans formed a part.¹⁷¹

6.2. Do Personal Assistance Users Choose Private Companies more Often Now than Ten Years Ago?

According to Försäkringskassan [Social Insurance Agency] the number of assistance users choosing private companies as providers has steadily increased. In December 2009, 48,6% of the assistance

¹⁶⁷ Prop. 2009/2010:176 p.69

¹⁶⁸ Westberg, K. 2008-02-08; Färnström, G. 2008-05-29

¹⁶⁹ Din Förlängda Arm 2010-04

¹⁷⁰ Assistansia 2010-04

¹⁷¹ Westberg, K. 2008-04-07; Westberg, K. 2008-04-09

users had municipalities and 37,7% had private companies as providers. 10,8% had their assistance through user cooperatives. About 2,8% - employed their own assistants.¹⁷² The percentage choosing municipalities as providers is steadily decreasing, while the percentage choosing a user cooperative or becoming employers of their own assistants stays constant. The only providers increasing their share of the market are private companies. During the first years, after personal assistance became a legal right, the municipalities provided approximately 70% of all assistance. However, by 2004, their share had shrunk to approximately 60%.¹⁷³

6.3. Are There any Differences in Quality between Personal Assistance Services Received through Public or Private Providers?

A research at Gothenburg University shows that assistance users, living within the City of Gothenburg and receiving personal assistance through the municipality, are less satisfied than users who receive assistance through other providers. The fundamental difference between the municipality and other providers is the perspective on personal assistance. The municipality focuses on providing personal assistants who can perform certain tasks for persons with disabilities. The main focus of the private companies and user cooperatives is to delegate as many responsibilities as possible to the assistance users themselves, something that is obviously appreciated.¹⁷⁴

In 2005, the recently completed Parliamentary Committee on personal assistance sent out a questionnaire to 915 randomly picked individuals receiving personal assistance through municipalities, cooperatives or private companies. According to this, more than 70% of the respondents had had the possibility to choose an assistance provider. Approximately half of the respondents state that they can influence the requirements used for recruiting their assistants (43% in municipalities, 89% in cooperatives and 81% in private companies). The trend of differing between public and private providers is also visible when it comes to deciding when assistance is provided and what tasks the assistants should do. There are no recorded differences in the respondents' views on the competence of the assistants. The competence was rated as satisfactory (35%) or high (50%) between different providers. There were, however, large differences in the responses on the availability of training and education for assistants. While half of the respondents from user cooperatives meant that their assistants are largely offered additional training and education, 29% of the respondents from private companies and only 5% from the municipalities were of this opinion. According to Försäkringskassan's [Social Insurance Agency] regulations, a contract should be drawn up and signed by the personal assistance user and the provider. This was the case for 91% of the respondents from user cooperatives, 86% from private companies but only 48% from municipalities.

There were also differences in answers to questions about satisfaction. Only 48% of the respondents receiving personal assistance through the municipalities were fully satisfied with the personal assistance provided. The numbers of fully satisfied customers in private companies were 70% and in user cooperatives 74%. Slight differences existed based on gender and age. In general, assistance

¹⁷² Personal communication with Bassem Saleh, Social Insurance Agency 2010-03-17

¹⁷³ Försäkringskassan 2005, p.7

¹⁷⁴ Roos, J.M. 2009, p.6

users older than 55 years seemed to have less freedom of choice and possibilities of influence than younger users. This was valid for both influencing the recruiting and for choosing the assistants. Some minor differences existed between men and women. Male assistance users had largely more providers to choose from. They also had more possibilities to choose assistants.¹⁷⁵

6.4. Are Personal Assistance Hours Produced in the Private Sector more Expensive than Hours Produced by the Public Sector?

Personal assistance hours produced in the private sector are cheaper than hours produced by municipalities. To provide the assistance hours, public providers usually have to use a part of the regular municipal budget to top up the assistance allowance received from Försäkringskassan [Social Insurance Agency]. At the public tender of personal assistance, the district of Södermalm in Stockholm administers approximately 26.000 assistance hours under LASS with a budget of approximately 90 million SEK, approximately 9.230.770€ (exchange rate according to xe.com at 2010-03-01). After the assistance allowance is deducted, this leaves a deficit of approximately 7 million SEK, approximately 717.948€ (exchange rate according to xe.com at 2010-03-01). The reasons behind this are: the municipalities costs of surplus personnel, high overhead costs due to facilities and higher levels of remuneration in the union agreements between municipalities and unions than in union agreements between unions and other providers.¹⁷⁶ Frösunda LSS AB, which secured the contract, is convinced they can produce the assistance hours within the assistance allowance's flat rate received from Försäkringskassan [Social Insurance Agency].

“By working qualitatively and continuously with every assistance [user] one make it possible to operate the business activities within the frame of the flat rate. Frösunda applies the union agreement signed between Kommunal [the Swedish Worker's Union] and Vårdföretagarna [the Association of Private Care Providers]. This means that we seldom have surplus personnel, which, of course, saves costs.”

However, the Swedish Association of Local Authorities and Regions is of the opinion that there are also other reasons behind the higher costs of assistance hours among their members. One of these is cost of personal assistants' sick pay, which they have to pay for their own employed assistants as well as for assistants employed by private providers. This cost is not covered within the flat rate.

“Municipalities can be stuck with unsocial hours while private providers get the daytime hours [when assistance users choose to have two or more providers]. We do not know how common this is, but it causes irritation when it occurs. The personnel can be more expensive, partly because certain private providers have not signed union agreements, but also because the union agreement for municipalities regulates conditions of employment different from union agreements for private providers. This applies e.g. for remuneration for on-call hours and

¹⁷⁵ Roos, J.M. (2009) p.151

¹⁷⁶ Westberg, K. (2009-11-22)

*salaries during periods of notice of termination. The majority of municipal employees have indeterminate employment with at least a one-month period of notice.*¹⁷⁷

6.5. What are the Effects of the Deregulation/Privatization of the Market? How do Politicians, Customers and the General Public View the Fact that an Increasing Part of the Market is Covered by Private for Profit Companies?

A debate on “cheating companies” has now and again come up and has received a great deal of attention. During 2004, a series of newspaper articles on private companies drawing new customers appeared. These companies were supposedly offering them to receive a part of the assistance allowance after salaries and expenses were deducted. The critique was also directed at owners of certain companies for making huge profits and trying to evade taxation.¹⁷⁸ As pointed out by Riksrevisionen [the Swedish National Audit Office], the possibility to use the assistance allowance for other things than costs connected to assistance was due to a legislative loophole. . In 2004, the Parliamentary Committee on personal assistance proposed a legislative reform.¹⁷⁹ Skatteverket [the Swedish Tax Authority] states that the most common error is undisclosed salaries. Another specific taxation error is that companies regularly put aside a fixed sum of the hourly flat rate. They justify it as savings to cover assistants’ costs of future travels etcetera.

*“There have been instances where money has been set aside during several years and not returned for taxation when the assistance user changed provider or died.*¹⁸⁰

This issue was also investigated by the 2004 Parliamentary Committee. On the 1st of June 2008, a legislative amendment was enacted. It forbid the use of assistance allowance for covering other costs or remunerations than those connected with the personal assistance and made assistance allowance (after deduction of costs of assistance) a taxable income.¹⁸¹

6.6. What do we Know about the Development of the Market Segment, Mergers and other Signs of a Maturing Market? What are the Pros and Cons of Risk Capital Activities in the Swedish Personal Assistance market?

During the years 2007-2009, the risk capital companies entered the personal assistance market in Sweden. They became controlling shareholders of three of the largest private assistance companies: Assistansia, Frösunda and Olivia. Several mergers have taken place since then. In June 2009, Humana

¹⁷⁷ Westberg, K. (2008-10-25)

¹⁷⁸ Pilkvist, K. & Marander, E (2007)

¹⁷⁹ Andersson, J. (2005-07-18)

¹⁸⁰ Westberg, K. (2010-04-27)

¹⁸¹ Prop. 2007/2008:61

Group controlled by Argan Capital, provided assistance to some 1350 customers; Olivia Holding, controlled by Procuritas, supported some 550 customers; and Frösunda LSS AB, controlled by Polaris Equity, provided assistance to 1.100 customers.¹⁸²

According to the professor Per Strömberg, Institutet för Finansforskning [the Institute for Financial Research] the personal assistance market in Sweden is fragmented, with a multitude of minor assistance companies. At the same time, due to stable income from government funding, it is a market largely unaffected by the booms and recessions present in open market business cycles. This provides a good base for granting financial loans. These market characteristics, as well as expectations of an increase in municipalities putting their care up for public tender, attract risk capital.

“Risk capital business reached Sweden in the middle of the 1990’, now the natural market segments have been explored. Initially, the focus was on the manufacturing industry and during the last five to ten years, it has shifted to the service sector. Simply, the time has come for this market.”¹⁸³

Generally, there have been few protests. Even the unions feel that risk capital can be developing the sector.

“Concerning risk capital companies, we feel this can be a complement to other forms of ownership; they have ability to take an active owner responsibility and have capital to invest, which enable them to develop large and viable companies.”¹⁸⁴

Intressegruppen för Assistansberättigade – IfA [the Interest Group for Individuals with a Right to Assistance] is concerned that the diversity of providers and the freedom of choice of the assistance user, can be threatened if unreasonable profits were to become a general phenomenon. This can undermine the legitimacy of the reform among the general public. The organization also warns about the risk of monopolies.

“It would be unfortunate if new monopolies developed as we have managed to escape the former monopoly of the municipalities. Also, the situation could arise where a couple or three large assistance companies create an oligopoly controlling the market.”¹⁸⁵

6.7. Who is Responsible to Prevent Local or National Monopolies from Developing?

If a merger between two companies creates or strengthens a position, which restrains effective competition, it can be stopped by the District court in Stockholm after an application by Konkurrensverket [Swedish Competition Authority]. This is a rare occurrence and has happened only

¹⁸² Assistanskoll (2009-06)

¹⁸³ Westberg, K. (2008-03-28)

¹⁸⁴ Westberg, K. (2008-04-12a)

¹⁸⁵ Westberg, K. (2008-04-12b)

five times since 1993. According to Konkurrensverket (in 2008), the competition within the assistance market is good and there is no present danger of monopolies. Even the control of large market shares such as up to 40% is not viewed as a problem by the authority.

“We have to look at the customers’ opportunities to choose other providers and what possibilities other providers have to enter the market. On the 26th of May 2008, we decided to leave Frösunda’s purchase of Personal Care without measures as this was not viewed as a problem because of the many alternatives present on the market.”

6.8. Do companies Have to Accept every Type of Assistance User or Can they Specialize?

The municipality has to accept all assistance users as customers but private companies are allowed to reject assistance users. Sveriges Kommuner och Landsting [Swedish Association of Local Authorities and Regions] reports that the municipalities sometimes have to provide assistance for assistance users rejected by private companies. The rejected users are considered too expensive due to a need of extra personnel outside the assessed assistance hours from Försäkringskassan [Social Insurance Agency].¹⁸⁶

Some companies specialize in personal assistance for customers with specific needs or from a specific age or language group. This enables them to recruit personal assistants with specific skills fitting their customers’ needs as well as to provide training or have support staff available with suitable expertise.

6.9. How is Quality Guaranteed within Private Companies?

On the 1st of July 2005, formal demands on systematic work on quality were included under LSS . However, there are no detailed regulations on how this should be performed. The Parliamentary Committee, which proposed the enacted reform, reported that there exists no comprehensive view on how providers work to follow up and ensure the quality of their services. However, the Committee’s view was that there exists an automatic guarantee for quality in certain cooperatives where the assistance users act as supervisors to their own assistants, and where they have a direct influence over the cooperative’s activities through their membership. Some providers do regular survey, as for example Frösunda LSS AB. They send out questionnaires to assistance users and their close family/vice supervisor twice a year. This investigation is done by a neutral third party to ensure anonymity.¹⁸⁷

Intressegruppen för Assistansberättigade, IfA [the Interest Group for Individuals with a Right to Assistance] started to certify assistance providers in 1995. Their criteria focus on four areas: the assistance user’s position, the quality of services, economy and employership. Important criteria are:

¹⁸⁶ Westberg , K. (2010-10-25)

¹⁸⁷ SOU 2005:100 p.135

the existence of a written agreement between assistance user and provider, maximum three-month period of notice for the assistance user to terminate the contract, full account of the used hours and economic resources and the presence of a union agreement. At least 70% of the assistance users should respond positively on a questionnaire in order to esteem the quality of the provider acceptable. In March 2008, some 50 providers were certified as providing good quality and as a part of IfA's provider council.¹⁸⁸

PARO, Privata Assistansanordnares Riksorganisation [Private Assistance Providers' National Organization], with some 40 members, offers a comprehensive course on guaranteeing quality. It teaches designing quality management systems for processes within assistance provision. The core is the production of measurable goals. The actual measuring of quality is done by a third party through interviews with assistance users and assistants. PARO wants to offer this opportunity to their members in preparation for a legal reform on a permit to work with personal assistance services. This reform may be enacted on the 1st of January 2011 (see chapter 3).

"We try to design a tool, which also the smallest can afford. We try to cut costs by arranging joint courses and purchasing services from the company performing evaluations. But I see a risk that the smallest companies might not even have the economic resources to carry out the one-year course."

PARO is positive about the introduction of permits through the National Board of Health and Welfare. However, it issues a warning that the smallest providers might encounter problems to live up to the demands.

"We want also the smallest to be able to continue. If demands are made on a certain education level not everyone may be able to meet them, even if they provide assistance of good quality. We see a big risk with a demand for academic degrees since those who run assistance companies might do so based on personal commitment as relatives or assistance users themselves. We mean that it has to be possible to acquire the same competence through experience. Focus should be aimed at the quality of the assistance and not at the opinions on what the company should do. The basis should be that the customer gets the assistance he/she wants and that he/she experiences this as of good quality, as well as that the provider is capable of managing the assistance allowance in a correct manner."¹⁸⁹

6.10. What is the Assessing Official Role in Choosing the Provider? Is there a Need for a Service, which Provides Possibilities of Comparing Assistance Providers?

Östhammar municipality recently decided to include information about Assistanskoll in the printed material presented to the individuals with disabilities who have been granted personal assistance in

¹⁸⁸ Westberg, K. (2008-03-03)

¹⁸⁹ Westberg, K. (2010-04-15)

the municipality. Östhammar has also added a link on their website to Assistanskoll's list of providers within Uppsala County (of which Östhammar is a part).

"We have decided to do this, so the users within our municipality will be able to easily find information about which assistance providers he/she can choose between in order to provide his/hers assistance."

Municipal officials have an obligation to provide information on which providers the assistance user can choose between. This obligation to provide information is irrespective of whether it is the municipality or Social Insurance Agency assessing and granting assistance. It has to be neutral, so the assistance user can independently make an informed choice. Since the official has to provide neutral information, not favouring specific companies or cooperatives, Östhammar means that Assistanskoll, can be of help to many assistance users as a supplementary service.

"I think the webpage looks good and provides clear information. The more information you have before you make your choice, the bigger the chance of being satisfied. In addition, the user knows that he/she can make another choice if everything does not turn out as planned."¹⁹⁰

In the main report of the Parliamentary Committee on personal assistance, Assistanskoll is also mentioned. It is noticed as an interesting initiative that shows in a simple way the assistance user the alternatives existing within the sector. It also provides information on the possibilities and the rights one has. According to the Parliamentary Committee, Assistanskoll provides consumer guidance.¹⁹¹

6.11. What about the Recent Municipal Trend of Putting Personal Assistance Services up for Tender Develop? What are the Pros and Cons?

The municipalities are starting to outsource their personal assistance services . This results in the company that wins the public tender, will provide the assistance for users choosing the municipality. In this case, the company is regularly contracted to provide personal assistance services according to the municipality's guidelines. So far, only three municipalities or districts have outsourced their assistance services, affecting approximately 110 customers. The contracts run for four years and the remuneration is set after Försäkringskassan's [Social Insurance Agency] hourly flat rate.¹⁹²

According to Konkurrensverket [The Swedish Competition Authority] a contract for public tender should be for approximately four years. The basis for the tender should include all requirements and conditions suppliers have to fulfil for their offer to be considered. These should be open, transparent and predictable for applicants. Demands present in the basis for tender can be considered from two perspectives.

¹⁹⁰ Westberg, K. (2010-02-16)

¹⁹¹ SOU 2008:77 p.497

¹⁹² Assistanskoll [aggregated data]

“One of the perspectives is the lowest price where only the price will be considered, and where it is especially important for the basis for tender to secure a certain level of quality. The other perspective is to choose the financially most advantageous offer, which involves balancing aspects of price and quality. In this, the authority shall weigh its criteria and state the priority order.”

The municipality cannot demand the presence of a union agreement as this, according to the European Union court, is viewed as preventing free mobility of goods and services. The process of assessing the offers starts by controlling the fulfilment of demands present in the basis for tender, as well as that the business of the supplier is not in process of liquidation etcetera. The offers passing this vetting are then assessed in an open and transparent process. After it a decision is made. It is the municipality’s responsibility to follow up that the chosen supplier fulfils the terms of contract.

According to Konkurrensverket [The Swedish Competition Authority] cases exist where larger companies agree on which public tenders they will win.

“Unfortunately, it occurs that companies have early contacts and decide in advance which of them shall “win” tenders for public contracts. If the same companies refrain from or win tenders frequently or writings and phrasings within the offers are similar, it can be a sign of this. The public sector is an important customer for certain companies. Individual contracts can be important. In this case, they have strong reasons to cheat their way into contracts with the right municipalities.”¹⁹³

Improved quality, economic costs and other factors can be reasons behind municipalities putting personal assistance services up for tender. This is demonstrated in the recent example from the municipality of Gotland. The chair of the municipality social committee, a representative of the conservative party, Moderaterna, states that the one reason behind their public tender is the dominant position of the municipality as an employer. The public tender has resulted in private companies establishing themselves in Gotland. Another reason is costs . The winning company has to supply personal assistance within the budgetary frame of assistance allowance provided by Försäkringskassan [Social Insurance Agency], while the same services provided by the municipality exceed this with 12,5 million SEK, approximately 1.282.000€ (exchange rate according to xe.com at 2010-03-01).¹⁹⁴ Kommunal [The Swedish Worker’s Union] and the left wing political parties are critical of the decision.

“Freedom of choice already exists [provided by the right to use assistance allowance freely] and will now instead be limited through the termination of the municipal alternative. It is a well-functioning personal assistance service which is being closed down and a commission of trust which should not be broken in this manner.”¹⁹⁵

¹⁹³ Westberg, K. (2008-06-11)

¹⁹⁴ Westberg, K (2008-06-05a)

¹⁹⁵ Westberg, K (2008-06-05a); Westberg, K (2008-06-05b)

Vårdföretagarna [the Association of Private Care Providers] points out that, although this can be true, it is well compensated for the quality generally increases. When municipalities step out of the role of assistance providers, they are forced to make demands on quality and control the provider's activities. This can be advantageous for the assistance users. Vårdföretagarna [the Association of Private Care Providers] is also of the opinion that the employment security for the personal assistants does not need to decrease, in spite of the indeterminate employment being changed to fixed-term employment. The best security is found in the quality of the service.¹⁹⁶

6.12. Is it Common for Customers to Change Provider? What are the Reasons behind the Change and the Conditions Connected with It?

Statistics on how often assistance users change provider are not available. However, we have data on how many percent of users is choosing a different type of provider. This shows that an increasing number of assistance users choose private companies, abandoning the municipalities as providers. There are no costs connected with the change of provider. However, contracts containing long periods of notice of termination can be an obstacle. The recently concluded Parliamentary Committee on personal assistance referred to Intressegruppen för Assistansberättigade – IfA [the Interest Group for Individuals with a Right to Assistance], which warns of termination periods longer than three months. The Committee considered the inclusion of limits for contractual and termination periods in the legislation, but refrained from proposing this.

“Since we do not want the government to regulate the conditions of agreement between assistance user and provider in detail, we refrain from proposing to include such time limits in the legislation. There is a risk that a maximum limit will be used as norm. However, we want to emphasize that periods of notice of termination of contract that exceed the period of notice motivated by the personal assistants’ employment contracts, are not congruous with the assistance user’s freedom of choice. As a rule, periods of notice up to three months are reasonable.”¹⁹⁷

Other obstacles for changing providers are if the assistants are willing to follow the user and, thus, change employer and whether or not funds set aside for costs connected with assistance can be transferred to the new provider (see chapter 3 on this in connection to taxation of profit).

6.13. Do Private Companies (for Profit or not) Provide Service and Housing or do They only Provide Personal Assistance?

Before personal assistance was provided in Sweden, persons with disabilities were often tied to their homes as the service they needed was connected to their housing. One of the most important features of the personal assistance is that it is connected to the individual and not to a location. The

¹⁹⁶ Westberg, K. (2008-07-15)

¹⁹⁷ SOU 2005:100 pp.136, 152, 159

right to assistance under LSS/LASS does not include direct payment/assistance allowance for services provided as a part of cluster housing or service housing. In Sweden one also has a legalized right to an allowance for housing adaptations.

In general, assistance providers do not provide housing or services. However, recently two small initiatives have started. In 2008, Vivida Assistans started a project that included housing. According to them, many persons with disabilities have to live in municipal group dwellings, with the disadvantage of losing the right to personal assistance. This was one reason behind their project. They also maintain that parents to children with disabilities requested housing for them. Building of the first unit of six apartments started in the autumn of 2009. Vivida is planning similar units in several other localities. The tenants of the six flats will have their own individual assistants.

GIL, the Independent Living cooperative in Gothenburg has recently secured funding for a project on alternative housing cooperatives. The first cooperative was formed in the summer of 2009 with two flats. A separate housing company rents out the flats, the municipality pays for the joint areas and the personal assistants are employed through GIL. Like in the Vivida project, the initiators are parents of children with disabilities.¹⁹⁸

6.14. What Research on Quality of Life of Persons with Disabilities Exists in Sweden?

Folkhälsoinstitutet [The Swedish National Institute of Public Health] issues reports based on surveys on public health. These are done by the interviewees' self-evaluation. The 2005-2007 survey concludes that approximately 1,5 million persons, more than one fifth of the Swedish population in the age span of 16-84 years, have a disability. According to the Swedish National Institute of Public Health, a large part of ill health can be found among persons with disabilities. Within this group, men and women with physical disabilities were reported as having the highest level of ill health (men – 43%; women – 32%). Their problems varied from general conditions like headache, tiredness and trouble sleeping to severe conditions like anxiety, worry and anguish. The severe conditions were predominant among persons with disabilities lacking access to a basic economic margin. The basic economic margin is defined as the capacity to raise within a week and in case of an emergency 15.000SEK, approximately 1.540€ (exchange rate according to xe.com 2010-03-01). Thoughts of suicide were remarkably higher among persons with disabilities than among the general population, as were suicide attempts.¹⁹⁹

Persons with disabilities are also subjected to violence. Handikappörelsens Utredningsinstitut, HANDU AB [Swedish Research Institute for Disability Policy] reported that in the 2007 survey, a third of the interviewed women with disabilities had experienced threats, violence or sexual harassment from men. One out of two of these women had one or several times suffered physical injuries due to male violence and sexual abuse. One out of ten women had been threatened, forced or physically injured by a man she was dependent upon like chauffeurs of special transport, personal assistants or

¹⁹⁸ Vivida (2010-05); GIL (2010-05)

¹⁹⁹ Folkhälsoinstitutet (2008)

care personnel and more commonly - by friends, neighbours, colleagues or bosses. Women with intellectual disabilities were slightly more subjected to violence than others within the group. In the report, a comparison with a national survey on men's violence against women was made. It shows that women with disabilities were subjected to violence to a higher degree than women in general are. They also felt more fear and shame.²⁰⁰

Persons with disabilities often have a lower level of education and find themselves in a worse economic situation than the rest of the population does. Their employment rate is also markedly lower. The conclusion is that there exists a social gap between persons with disabilities and the rest of the population.²⁰¹

6.15. What Criteria do Private Companies Use for Price Setting?

There is a limit on how much a private company can charge for their services as the flat rate of the assistance allowance regulates the market (direct payment under LSS for assistance from municipalities is regularly provided after the same sum). However, the administrative fees charged for providing assistance and the profit margins, differ from company to company. Some providers charge a fixed hourly sum while others retain the full surplus after paying salaries, assistance and other costs. It was common for providers to charge a specified administrative fee but now, after the legislative reform enacted in June 2008, all surplus is viewed as a provider's income and has to be declared to Skatteverket [Swedish Taxation Authority]. In April 2010, seventy out of a hundred-and-seventy-four providers registered at Assistanskoll stated that customers had individual budgets and the provider charged a fixed administrative fee, including the provider's profit.²⁰² Privata Assistansanordnares Riksorganisation, PARO [Private assistance providers' national organization], with some 40 members, means that the customer should get an appendix to the agreement specifying how large the percentage of the assistance allowance will rise in relation to salaries and employment fees, education and training, assistance costs, work environment measures and personnel costs. Union agreements automatically decide the frames for salaries and employment fee costs, the largest expenditure in assistance provision. The costs connected with assistance depend on the life style of the assistance user. The administration costs can also differ depending on service level or factors like the existence of local offices. Privata Assistansanordnares Riksorganisation, PARO [Private assistance providers' national organization] does not have an opinion on the level of profit made by their members.

"We do not have any opinion on that; the essential issue is to compete with provision of good quality personal assistance to the customer."²⁰³

Olivia Assistans AB, a company not using individual budgets and customer cost reports, claims to make 4-5% profit based on turn-over (as stated in July 2007). The level of provided assistance costs is

²⁰⁰ Handikapprörelsens utredningsinstitut (2007); Folkhälsoinstitutet (2008)

²⁰¹ Folkhälsoinstitutet (2008)

²⁰² Assistanskoll [aggregated data]

²⁰³ Westberg, K. (2010-04-15)

negotiable and varies between 3 and 5 SEK per hour, approximately 0,3 and 0,5 € (exchange rate according to xe.com 2010-03-01). Olivia Assistans does not charge a fixed administrative fee from their customers, but retains the surplus after paying salaries, employment fees and assistance costs are paid. This means that the administrative fee varies from customer to customer. Assistance users choosing to change provider cannot transfer the saved funds when leaving Olivia.

“No, because we view it as the company’s money. Customers do not have particularly much influence over the company’s economy. The essential is that the customers, during their time with us, are provided with assistance of high quality and that the assistants get good supervision and support from their supervisor.”²⁰⁴

6.16. What do Contracts between Assistance Users and Private Companies Regulate?

The guidelines from Försäkringskassan [Social Insurance Agency] state that a contract has to exist between assistance users and their chosen providers, including municipalities. However, the regulation does not specify the content of this contract.²⁰⁵ Privata Assistansanordnares Riksorganisation, PARO [Private assistance providers’ national organization] issues a standard agreement between customers and providers with a three-month termination notice. It states that a plan for implementing the assistance regulating the provision of goals has to exist. Also, the contract states that the provider has an employer responsibility and a responsibility to administer the assistance allowance/direct payment for assistance, scheduling, salary setting and recruitment of assistants. At the same time, the customer is acting as a supervisor for the assistants unless otherwise agreed. If the customer asks for this, providers shall agree on a fixed administrative fee per hour in an additional article to the contract. This article regulates what is included and specifies the particular costs.²⁰⁶

The recently concluded Parliamentary Committee on personal assistance analyzed 138 contracts between assistance users and providers that were written in 2004 - 95 contracts from private companies, 24 from municipalities, and 16 from cooperatives. The analysis contained questions regarding employer responsibilities, remuneration, quality and formal procedures. The conclusion was that neither uniformity nor trade practice existed. A comparison of contracts within the different types of providers demonstrated that cooperatives’ contracts showed the biggest similarity and showed generally more consideration for the assistance user’s interests. The Parliamentary Committee speculated that this can be a natural consequence of assistance users predominately being members of the cooperatives and having experience in participating in the organization of their own assistance.

The Parliamentary Committee stated that a contract only shows the result of an agreement between an individual assistance user and a provider. It does not show if the provider has forced or influenced

²⁰⁴ Westberg, K. (2007-12-05)

²⁰⁵ Försäkringskassan 2003:6 ver.5 p.126

²⁰⁶ Westberg, K. (2010-04-15)

assistance users into a certain direction. Assistance users may have wanted to negotiate the removal of a specific influence for the restoring of another. It also cannot be ruled out that assistance users in individual cases do not want to exercise more than a marginal influence.²⁰⁷

²⁰⁷ SOU 2005:100 pp. 156 ff

7. Influence on the labour market

This final chapter takes a short look on how the effects of the development of the profession of personal assistant have influenced the Swedish labour market and whether this influence is used as a political argument.

Finally, we present some analyses of the hourly and socio-economic costs of personal assistance in comparison with municipal home care services.

7.1. Is the Development of Personal Assistance as a Profession and the Creation of 70.000 Jobs, an Argument in Swedish Politics?

According to Socialstyrelsen [the National Board of Health and Welfare], personal assistance does not only provide increased quality to the users but also to the personal assistants. Personal assistants are a professional group in which satisfaction is high. It is also a profession open to everybody because of the assistance users' freedom to choose their assistants.

“It offers an opportunity for new groups to enter the labour market and I believe it is a work situation many appreciate, since you know that you are satisfying an individual’s needs and the value of what you do becomes clearly visible. There is a personal relationship within the given limits. This alternative is better for many individuals than the more collectively organized care. We usually do not take account of this type of effects on society within socio-economic studies, but it is there. If we were to analyze these aspects, assistance would score even higher in our report.”²⁰⁸

Kommunal [The Swedish Municipal Workers Union] uses the labour market argument to protest against the cuts in personal assistance. They claim that, if the cuts proposed by the recently concluded Parliamentary Committee on personal assistance become reality, 13.600 personal assistants will lose their jobs (the figure is an estimate of 69% of approximately 70.000 assistants).

“We have calculated that the decrease in hours due to a homogenous assessment represents unemployment for 11.000 assistants. If the right to double assistance is cut by 20%, 1.300 assistants will lose their employment and an additional 1.300 if the fifth basic need of “detailed knowledge” [of the assistance user’s impairment] is discarded [as a ground for personal assistance]. What opportunities will these assistants have when entering the expected mass unemployment?”²⁰⁹

²⁰⁸ Socialstyrelsen (2008); Westberg, K. (2008-07-24)

²⁰⁹ Kommunal (2008); Westberg, K. (2009-01-20)

7.2. What are the Socio-economic Costs of Personal Assistance Compared to Municipal Home Care?

Municipal home care services cost 10% more per salaried hour than personal assistance but on average 70% more per received service hour. The difference is due to the fact that home care personnel only spend approximately half of their working time actually providing services to the users. The rest of the personnel working hours is spent on travel between users and other surrounding issues.

The flat rate remuneration for personal assistance per hour in 2006 was 219 SEK, approximately 22,5€ (exchange rate according to xe.com 2010-03-01) with a maximum for increased assistance allowance of 245 SEK, approximately 25 € (exchange rate according to xe.com 2010-03-01). This sum does not include costs of substitute assistants. Corresponding hourly costs of actually received hours of municipal home care are estimated to on average 247 SEK, approximately 25,3 €, and varying between 215 SEK and 295 SEK per hour, approximately 22 € and 30,3 € (exchange rate according to xe.com 2010-03-01). The costs of municipal home care were approximately 13% higher per hour than costs of personal assistance. It is due to slightly higher salary costs, other operational costs and overheads as well as joint municipality costs.

While the actually received hours of municipal home care are only slightly higher than personal assistance, the real costs per produced municipal home care hour are essentially much higher. In 2006, municipal home care per produced hour costs on average 372 SEK, approximately 38 € (exchange rate according to xe.com 2010-03-01), varying between 267 SEK and 574 SEK per hour, approximately 27,4 € and 58,9 € (exchange rate according to xe.com 2010-03-01). This is partly because recipients of home care regularly receive fewer hours. If personnel is working full time, they will provide service to a multitude of users, causing large chunks of time to be spent on transports between them. Much depends on distance between the users, i.e. how densely populated the municipality is, and on the possibility of planning the visits after geographical acquaintance.²¹⁰

An independent research, commissioned by the Independent Living Institute in 2008, shows that the actual socio-economic savings, because of personal assistance under LASS and provided by non-municipal providers, are approximately 29 billion SEK, approximately 2.974.400 € (exchange rate according to xe.com 2010-03-01). The savings would have been approximately 77 billion SEK, approximately 7.897.400 € (exchange rate according to xe.com 2010-03-01) either if all personal assistance had been provided by non-municipal providers or if personal assistance provided by municipalities was as cost-effective as assistance provided by non-municipal providers. This indicates that, compared to an alternative system of municipal home care, the system of personal assistance services results in significant savings of socio-economic costs. The report was based on an estimation in which the hourly costs of the two types of services are compared per year and based on data provided by Statistiska Centralbyrån, SCB [Statistics Sweden] and Försäkringskassan [Social Insurance Agency]. This goes for all variables, except for the hourly costs of municipal home care. Municipal

²¹⁰ Socialstyrelsen (2008) pp. 8, 104

home care hours were estimated using data from selected municipalities provided by Sveriges Kommuner och Landsting, SKL [Swedish Association of Local Authorities and Regions].

However, the estimated savings presented in this report should be viewed as preliminary as they are based on the assumption that personal assistance services and municipal home care services are of equivalent quality. A more comprehensive socio-economic analysis, including also socio-economic incomes, is likely to show even bigger advantages of personal assistance services.²¹¹

²¹¹ Nybom, M. & Pettersson, J. (2008)

8. Conclusions

- The current Swedish legislation with regard to personal assistance was implemented after a pilot project in 1994. Initially, it met with much resistance. The disabled people's movement had since long-time pleaded in favour of a system of cluster housing and was first unwilling to stray from that path. The trade unions feared that disabled people would not be able to act as good employers and in general, it was thought that personal assistance would only offer a solution to the 'elite'. After the pilot project and various independent investigations, all those arguments were put aside. This and the political support have made it possible for 19.000 people today in Sweden to benefit from the system of personal assistance. This however does not imply that the facilities have disappeared altogether. In 2008, 22.300 people with an intellectual impairment made use of small collective homes of maximum five persons per home, in which each person disposes of an individual room.
- The quality of personal assistance can only be measured from the individual assistance user's perspective. Research and surveys show that the level of influence that the assistance user has over his/her personal assistance corresponds to the level of quality; the more influence, the higher the quality experienced.
- Personal assistance is not a means tested in Sweden . It is viewed as a legalized social right. A social rights legislation provides individuals with a specified right to the social services named in the law. If an application for these rights is rejected, the decision can therefore be appealed within the administrative court system. However, LSS and LASS also define the group of individuals entitled to the rights under these laws. This results in a large group of disabled individuals not having access to personal assistance services because they are assessed as not being a part of any of the three categories of specified personal requirements. Also, individuals who acquire personal assistance needs after the age of 65 are excluded.
- The assistance allowance is based on an hourly flat rate, which covers all costs concerning the employment of personal assistants (salaries and employer fees) as well as overhead costs of administration, costs concerning the provision of assistance (e.g. assistants' travel, food and lodging on trips), work environment costs etcetera. If an assistance user, due to special circumstances, has higher costs than the calculated average covered by the flat rate, he/she can apply for an increased rate of up to 12%. Assistance users, who have less than 20 hours of fundamental needs but qualify for personal assistance under LSS, can choose to receive this assistance in kind through municipally organized personal assistance services, or as direct payment in order to buy such services from private providers or to organize their assistance themselves. According to the legislative preambles and Socialstyrelsen [National Board of Health and Welfare], direct payment for personal assistance through the municipalities should be provided at the same level as assistance allowance. The experience is that this is the case, which is not surprising as personal assistance services provided by the municipalities are more costly than such services provided by non-municipal providers.

- The assessment of personal assistance needs is based on self-assessment done by the assistance user. However, as costs of personal assistance have increased, this individualized, more free assessment process has been affected. Demands for an assessing instrument have been made in the political process. This resulted in a proposal where only active time, calculated by the minute, should be counted when assessing fundamental needs (drawing the line between the right to assistance allowance through the social insurance system or direct payment/personal assistance services from the municipalities). At the moment , the first proposal is put on hold and will be subjected for review.

- So far, no demands have been made on general education or job training as a personal assistant. However, there is a risk that the recent work on guaranteeing quality by licensing assistance providers can result in such demands both for personnel working as personal assistants and for assistance providers.

- There are no rules as to what tasks personal assistants may or may not do. The legislation, with preambles and guidelines, as well as Arbetsmiljöverket [Swedish Work Environment Authority] state that assistance can be used for any task. However, many municipalities limit the tasks assistants are allowed to perform, even though this has drawn criticism from the regional supervising authorities, Länsstyrelserna [County Administrative Boards]. Personal assistance from private providers is less limited.

- Delegation of health care activities to personal assistants is not viewed as a problem but as a natural part of delegating the self-care. It is done by a medical professional (doctor or nurse). As there is a tradition of delegating health care activities in Sweden, medical professionals, for example nurses, do not feel their status to be threatened.

- Private companies are very reliable as providers of personal assistance. Research and surveys show that assistance users are essentially more satisfied with private providers than municipalities. They have more freedom of choice and influence. However, careful monitoring of this developing market should be done, as abuse of funds for personal assistance, though present in a few cases, has resulted in the reform being questioned by politicians.

- Only 3% of the assistance users are employing their own personal assistants. Most users are unwilling to take on this responsibility. At the beginning , it was believed that many more assistance users would use the option of employing assistants themselves, but the percentage has remained constant over time.

- Personal assistance has proven to be a labour market tool enabling new groups to enter the labour market.

9. Description of Sources and Entities in the Text – in Alphabetical Order:

Arbetsförmedlingen [Swedish Public Employment Service]: Government agency under the Ministry of Employment responsible for improving the functioning of the labour market.

Arbetsgivarföreningen KFO [Independent employers' organization for co-operative business] represents members which are cooperatives acting as employers within personal assistance.

Arbetsgivaralliansen [the Employers' Alliance] represents members, which are employers within personal assistance in the non-profit sector.

Arbetsmarknadsdepartementet [Ministry of Employment]: Government Ministry responsible for labour market policy and working life policy.

Arbetsmarknadsstyrelsen [National Labour Market Board]: Former Government agency responsible for executing national efforts of labour market politics. These responsibilities are under Arbetsförmedlingen since the 1st of January 2008.

Arbetsmiljöverket [Swedish Work Environment Authority]: Government agency under the Ministry of Employment responsible for issues concerning work environment.

Bolagsverket [Swedish Companies Registration Office]: Government agency under the Ministry of Enterprise, Energy and Communication responsible for registration of all Swedish enterprises, bankruptcies and bans on conducting business.

Finansdepartementet [Ministry of Business and Finance]: Government Ministry responsible for matters relating to economic policy, the central government budget, taxes, banking, security and insurance, international economic work, central, regional and local government.

Folkhälsoinstitutet [The Swedish National Institute of Public Health]: Government agency under the Ministry of Health and Social Affairs responsible for following up, evaluating and disseminating knowledge about methods in the public health sphere and supervising the sectors of alcohol, narcotics and tobacco.

Försäkringskassan [Swedish Social Insurance Agency]: Government agency under the Ministry of Health and Social Affairs responsible for providing financial security in the event of illness, disability and old age as well as for families with children.

Handikapprörelsens Utredningsinstitut, HANDU AB [Swedish Research Institute for Disability Policy] is a research institute representing a high standard both in general professional terms and in specific knowledge about persons with disabilities. The Swedish Association of the Visually Impaired, the Swedish Federation of Disabled Persons and the Swedish National Association of Deaf jointly own HANDU AB.

Intressegruppen för Assistansberättigade – IfA [the Interest Group for Individuals with a Right to Assistance] represents individuals with a right to personal assistance. The organization has 650 members.

Justitiedepartementet [Ministry of Justice]: Government Ministry responsible for matters relating to the police authorities, judiciary system, prisons service, migration and asylum.

Kommunala Företagens Samorganisation KFS [the Swedish Organization for Local Enterprises] represents members, which are companies in the municipal and county council sector acting as employers within personal assistance.

Kommunal [the Swedish Municipal Workers' Union] represents members who are employed as personal assistants.

Konkurrensverket [The Swedish Competition Authority]: Government agency under the Ministry of Enterprise, Energy and Communications, responsible for safeguarding and increasing competition and supervise public procurement in Sweden.

Landsorganisationen – LO [The Swedish Trade Union Confederation] is the central organization for 14 affiliates which organize workers within both the private and the public sectors.

Länsstyrelsen [County Administrative Board]: Government agency under the Ministry of Finance present within each county in Sweden. Acting as a local representative for the parliament and government, responsible for decisions taken by the Government and the Parliament

Privata Assistansanordnares Riksorganisation – PARO [Private assistance providers' national organization], independent interest organization representing private companies providing personal assistance.

Prop. – Proposition is the Government proposal of a bill presented to parliament. This is drafted within the Ministry responsible for the area.

Riksrevisionen [the Swedish National Audit Office]: An independent national body under the Swedish Parliament responsible for auditing the activities of the entire Swedish state and promoting the best use of resources and efficient administration.

SFS – Svensk Författningssamling [Swedish Code of Statutes] is the official publication of all new Swedish laws enacted by the Parliament.

Skatteverket [Swedish Tax Agency]: Government agency under the Ministry of Finance responsible for the operational aspects of taxation.

SKL - Sveriges Kommuner och Landsting [Swedish Association of Local Authorities and Regions]: A special interest organization representing the governmental, professional and employer related interests of Swedish municipalities, county councils and regions.

Socialdepartementet [Ministry of Health and Social Affairs]: Government Ministry responsible for areas relating to social welfare: financial security, social services, medical and health care, health promotion and the rights of children and disabled people.

Socialstyrelsen [National Board of Health and Welfare]: Government agency under the Ministry of Health and Social Affairs with activities and duties within the fields of social services, health and medical services, environmental health, communicable disease prevention and epidemiology.

SOU - Statens offentliga utredningar [Swedish Government Official Reports] is the official series of reports of committees appointed by the Swedish Government for the analysis of issues in anticipation of a proposed legislation.

Statistiska Centralbyrån [Statistics Sweden]: Government agency under the Ministry of Finance responsible for producing official statistics regarding Sweden.

Tillväxtverket [Swedish Agency for Economic and Regional Growth]: Government agency under the Ministry of Enterprise, Energy and Communication responsible for work to achieve more enterprises, growing enterprises and sustainable, competitive business and industry throughout Sweden.

Vårdföretagarna [the Association of Private Care Providers] represents members which are private companies acting within personal assistance.

Yrkesinspektionen [the Labour Inspectorate]: Former regional governmental agency responsible for working environment. Since the 1st of January 2001, this responsibility rests with the Local Work Environment Inspectorates, local bodies of the Swedish Work Environment Authority.

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