



REPORT ON A VISIT TO SWEDEN BY THE EXPERTISE CENTRE INDEPENDENT LIVING

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INTRODUCTION

The Expertise Centre Independent Living has already issued two reports on personal assistance in Sweden (please see the June and October 2009 newsletters).

After redaction of these reports it soon became clear that we were unable to investigate important aspects due to the linguistic barrier. It seemed to us the right thing to do was to have some fundamental questions answered by Swedish users of personal assistance. This led to the idea to submit a research proposal and to present it to Swedish experts. Several candidates responded to our call, which was also published in our last newsletter, and so we were faced with the task to choose amongst these very fine candidates. Ultimately we selected the proposal of the Independent Living Institute. We shall present the results of this investigation at the conference the Expertise Centre Independent Living will organize in June 2010.

In order to discuss the agreement with the Independent Living Institute one of our staff members went to Stockholm. At the same time our staff member visited some cooperative societies. Björn Jideus of the cooperative society JAG and Nicoletta Zoannos and Suzanne Elmqvist of the cooperative society STIL were so kind to dedicate their time in order to explain the functioning of their organization. Also Davy Gaeremynck, a Flemish expat who nowadays works for ILI but who was formerly employed at STIL, was prepared to elucidate us on several issues.

We gratefully thank all those who have contributed to the realization of this article through their cooperation!

In the formerly published articles about Sweden it was always mentioned that it is possible to work with personal assistants without being one's own employer. The employership can be outsourced to a cooperative society, a private for-profit organization or the municipality. In this text you can read about how all of this actually works: how someone can independently determine the conditions of his or her assistance (how, what kind of, where and when) without acting as his or her own employer, who receives the assistance budget, how much is spent on salary – indirect costs – administration, how a cooperative society works.

In the first part we describe the process of needs assessment, in the second part we go deeper into the notion of employership and in the third part we provide additional information with regard to the statute and the position of the personal assistants.

In case you would like to have a more detailed overview about the way assistance of disabled people is organized in Sweden and other countries, then we suggest you read the following articles which have been published previously by the Expertise Centre Independent Living:

- Current situation in 8 European countries
- Follow-up study Personal Assistance in Sweden

I. NEEDS ASSESSMENT

The first step you need to take when you need assistance in Sweden is to pay a visit to the municipality. The municipality should investigate your need for assistance or support and express it in a number of hours of assistance per week. This is done upon a home call. If the municipality estimates you need more than 20 hours of assistance per week you are transferred to the 'försäkringskassan' (i.e. the Swedish social security system). In that case you fall under the LASS legislation, which is a national government competence. You may also apply for assistance yourself. If you need less than 20 hours of basic assistance you will fall under the LSS legislation, which is a municipal competence.

This basic assistance concerns fundamental needs such as personal hygiene, food etc.¹

Next to the number of hours needed for this basic assistance the municipality (for LSS users) as well as the social security (for LASS users) determine the actual hours of assistance needed. In reality, however, it is noticed that the municipalities are not too keen on this and that they prefer to recommend or offer you another service than personal assistance.

The interview with the municipality or the social security results in an agreement in which it is stipulated how many hours of assistance per week you are entitled to. With this agreement you can present yourself at an employers' association or you may engage assistants yourself.

The maximum amount which corresponds with this needs assessment is the actual number of hours of assistance provided multiplied by a fixed amount: 247 Swedish Kroner, i.e. 23.75 Euro. This amount is paid to the employer (being yourself, the municipality, a cooperative society or a private profit organization).

The needs assessment is not carried out using an unambiguous, identical measuring tool and may thus differ according to the region. At the moment efforts are undertaken to create more uniformity by introducing such an unambiguous and identical measuring tool. According to several sources the introduction of the latter however is said to be used as a pretext to restrain the number of hours of assistance granted. More specifically there is a greater focus on the determination of the aforementioned number of hours of basic assistance.

¹A. Ratzka, personal communication with J. Van Hauwermeiren J., 31 March -2009.

For example:

It used to be so that you could get a number of hours of assistance for eating. If you were able to lift your hand but needed assistance to prepare food, then the hours that you needed for that purpose fell into the category of basic assistance. It already occurred that these hours were no longer taken into account.

The result is that people not only receive less hours to organize their assistance, but also that they fail to attain the 20 hours-limit which means that they fall under LSS, which is a municipal competence. And as clearly stated before in this article the municipality does not carry out its tasks in the same way as the national social security system does.

The discussion about a new needs assessment tool is a very animated one and moreover it is a recent one. Users who risk to receive less hours of assistance as well as personal assistants whose jobs are in danger anxiously observe this evolution. Most surely the last word hasn't yet been said about this.

II. EMPLOYERSHIP

General

Imagine that you have been granted 100 hours of assistance per week by the social security. With that decision you may go to an employers' association. In 2008 11% chose a cooperative society, 35% chose a private for-profit society and 52% chose to work with the municipality. Only 3% of all users takes up the role of the employer.²

If you choose to outsource the employership the following situation is approximately what happens next.

First you make an agreement with an employers' association. Once the contract has been signed the association may start appointing the assistants (the freedom of choice that the user has when it comes to deciding about the who, what and when of the assistance depends on the employer that has been chosen).

Ultimately the 5th of each following month you must report to the employers' association by means of a time table (on paper or by means of an electronic form) the number of hours of assistance that have been provided. Let us say that this number amounted to 430 hours during the last month. By the 10th the employees of the employers' association make sure that this information is reported to the social security (this has to be done in a special format). Subsequently, the employees must pay/ take care of taxes and social security contributions.

²A. Ratzka, personal communication with J. Van Hauwermeiren J., 31 March -2009.

On the 20th social security pays the money to the employers' association. The number of hours provided will then be multiplied by a fixed amount of € 23.75. The total amount, in this case 430 hours * € 23.75 = € 10,212.5, is transferred to the employers' association. By the 25th of the month they pay the salaries of the personal assistants with this money.

It is allowed to exceed the number of hours granted. This poses no problem, you may e.g. consume less hours of assistance in the following month. After 6 months there is a final calculation and by then you must make sure that you have not exceeded the total number of hours granted.

If your situation changes you may ask for a reassessment of your needs. Every two year you are invited to reevaluate the number of hours yourself.

Cooperative society

❖ JAG:

The organization:

JAG has 400 members and all of those are persons with multiple impairments of which one is an intellectual impairment. Together they employ some 3.500 personal assistants. About 40 persons work directly for JAG.

Given the fact that all JAG members have an intellectual and quite often a communicative impairment there is always made use of service guarantors (SG's). They are legal representatives, parents, family members or personal assistants. They guarantee the quality of the assistance that the users receive. If e.g. an assistant falls ill, they will provide replacement. If there is nobody else available, the SG will take care of the task. In fact it is the municipality which is responsible for providing the replacement. But JAG members often require specific assistance from people they know. So this is not at all self-evident (The persons taking care of the replacements on account of the municipalities are often people who work in so-called home services and who usually do not leave much room for an equal say on the part of the user).

JAG is a broad organization which consists of 4 units:

- First there is the JAG association. Its board of directors is composed of 5 users (assisted by the SG's) who gather a few times per year. It is their task to influence policy making in favor of the JAG members.
- Then there is the JAG cooperative society. Its board of directors also counts about 5 members who gather every two months. Not the users but the service guarantors are part of this board, the reason being that the users have serious multiple communicative disabilities which is incompatible with the fact that the cooperative society should be able to make quick decisions.

- The cooperative society used to be the assistant's employer. However, nowadays it is a private society associated to the JAG cooperative society which acts as the employer. The government pointed out the fact that there was too much money in circulation which was not taxed. From that arose the demand to make a private for-profit organization responsible for the employership. So it is this private company which is now the employer of 3.500 personal assistants.
- Next to that there is still the JAG Foundation. This foundation takes care of specific education and trainings for personal assistants and Service Guarantors. This training is compulsory for all new assistants and/ or Service Guarantors. In the training there is much focus on the user.

JAG also has a day centre which is open for members during day time. This centre is financed by the municipality.

Who works for JAG:

- 2.5 staff members who search for suitable personal assistants. Contacts are established between the SG and the personnel.
- 10 staff members who take care of the user's administration. All members are assigned to one specific staff member, a person who does the follow-up of their file.
- And then there are the training experts training the PA's, managerial staff members as well as for interest associations and different kinds of projects, etc.

How is JAG financed?

JAG disposes of nearly 70 million Euro per year. This money is used to cover for the assistant's as well as the own personnel's salaries, trainings etc. This money comes from LASS and LSS.

Once the contract between the user and JAG has been signed, the search for assistants can take a start. At JAG it is the person itself in cooperation with the SG who freely decides who becomes an assistant and when, where and how this assistance is carried out. If necessary JAG can help out with the search for assistants. The personal assistants and the SG's must follow a training course. During this course the principles of JAG are explained, as well as what is expected from the personal assistants and the SG's. Once they have been appointed the procedure takes its course as described above .

We have already mentioned that the employers' association (JAG in this case) receives the total amount, i.e. the number of hours multiplied by 247 Kroner (€ 23.75). A JAG user needs 127 hours of assistance per week on average. So 127 hours *52 weeks*400 members* € 25= € 66.040.000 per year.

Usually about 85% of this amount is spent on assistant's salaries, 7% on administrative costs.

JAG spends the remainder of the amount on trainings, assistant's transportation- and other costs, costs related to the adaptation of the work environment in favor of the assistant, etc. This repartition in terms of percentage may differ from person to person. The 7 to 8% administrative costs cannot be decreased so easily. But within the framework of JAG a person may on the other hand choose to spend more on salaries and less on trainings, transportation costs, etc. It was indicated however that JAG informs its members about the usefulness of these trainings and other costs so that not all the money is spent on salaries.

❖ STIL

General:

At the moment STIL has 200 members who employ a total of 1.500 personal assistants (approximately 600 to 700 FTE's). This represents a decrease as compared to last year.

The board of directors is composed of 9 people who gather every 3 weeks and who are all users. 32 people are working for STIL Stockholm and 2 are working for STIL Sundsvall in the north of the country.

Becoming a member of STIL explained from A to Z:

In a first interview a staff member of STIL will try to figure out whether the person supports the Independent Living ideology. Only those who support this ideology can become members. Subsequently the interview focuses on what the person wants to achieve with his or her personal assistants. The working conditions are discussed.

Since it is after all STIL that becomes the employer, consequently the person is informed about the terms of notice of the assistant, holiday regulations, etc. Once these things have been cleared out (this first phase may include several interviews), a contract is established.

After the signing of the contract several start-up training sessions through peer support will take a start. Those sessions are not individually organized, but collectively.

The first and second 'basic training' lasts 3 to 4 days and takes place within six months after the signing of the contract. Everybody is assigned a mentor to whom he or she may turn in case of questions. They e.g. also receive a training for organizing job evaluation conversations with the personal assistants.

On top of that STIL provides continuous support and services. You may at any given moment turn to your mentor, who is in most cases a STIL staff member and peer counselor. If needed you may always make use of the services of STIL, such as the juridical counseling provided by two STIL staff members. There are also other services like e.g.: conflict management in case you have a conflict with your personal assistant, training of personal assistants, searching personal assistants etc. There is some controversy going on about this training. There used to be no such a training because they wanted to avoid situations in which PA's would talk

about the private issues of the user. As a consequence these trainings always take place in the presence of the user. The topics during the training never deal with the individual users but are always discussed on a more general level. These trainings also give more job satisfaction and a higher job status for the personal assistant. STIL is very satisfied with these trainings and other organizations would like to follow these courses as well. STIL sells this course.

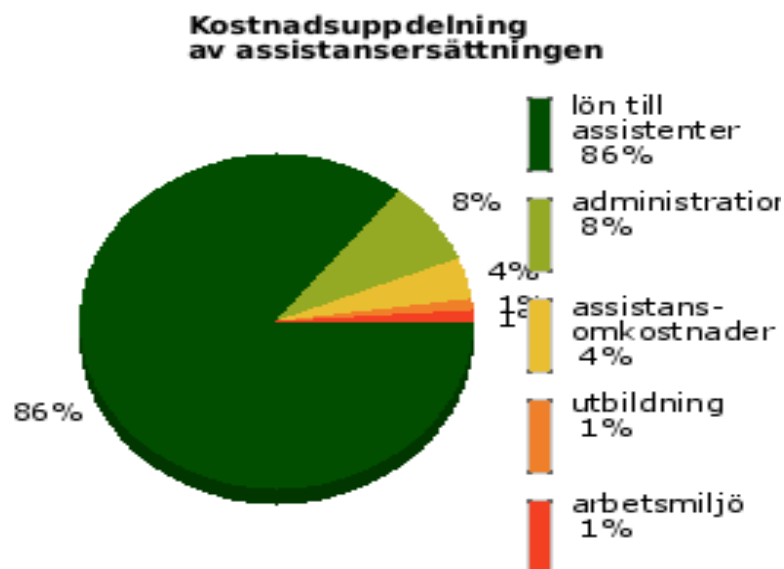
The first start-up training is followed on a regular basis by basic peer support sessions about topics which are determined by the users themselves.

Financing:

Once the contract has been signed you authorize STIL to take up the role of employer. There is a department 'time book keeping' which keeps track of all the hours of assistance provided. The rest of the procedure takes its course as described above.

How is the money distributed?

On the ILI website you can find the following chart:³



Translated from Swedish it comes down to the following repartition:

- 86% is spent on the assistant's salaries
- 8% is spent on administration and so is used to pay STIL
- 4% is spent on support costs
- 1% is spent on indirect costs and costs related to the personnel's work environment
- 1% is spent on education and training

³ <http://www.independentliving.org/assistanskoll/profil-sverige-STIL.html>

These are average values which can differ from person to person.

According to the (ex-)staff members of STIL this is what happens in reality:

For 1 hour of assistance you receive 247 Kroner (=€ 23.75).

These 274 Kroner are spent as follows:

- 19 (7.7%) Kroner is directly spent on STIL's administration.
- 5 (2.0%) Kroner are being put aside for indirect costs.
- The rest is used for the payment of salaries and payroll taxes, which comes down to more or less 200 Kroner (81%).
- The remaining 23 Kroner are deposited on a savings account. This money is used for the payment of e.g. traveling expenses of your assistant, extra money (=salary) for 'inconvenient working hours', i.e. working on Sundays or during night-time or is spent on 'arbets miljö'. The latter constitutes an important factor in Sweden, it refers to all kinds of things that are necessary to provide the employee with a good working environment. So this may mean that the money is spent on hygienic material (gloves, etc) but also other things which might improve the personal assistant's working conditions.

Private for-profit

Since 2000-2001 private for-profit employers' associations have been founded. The biggest of these has some 1.000 members.

In general it is assumed that the increased competition is responsible for the increasing freedom of choice for users of personal assistance.

It also forces the established cooperative societies to think about strategies to keep and even expand their clientele.

In some cases things have happened which were unacceptable.

Some organizations charge about 85% for PA's salaries and 7 to 8 or even 9% for their own administration. The remaining amount is however not spent on trainings, transportation expenses etc, as do cooperative societies. They gave part of the money back to the user so that they could pay for trainings etc. themselves. What actually happened was that often members would receive a fixed amount of untaxed money which was used for their own use. As a result there has been quite some discussion about this matter.

In the meantime this problem has been extensively criticized and studied. To counter this problem, most probably in the future all costs (not only the personnel costs) will have to be declared to the paying body.

Municipality

The majority of users still arranges their assistance through the municipality. Yet opinions about the quality of their service are not all positive, on the contrary even.

The users can in principle determine the how, when and who of their assistance. But they can only choose from a limited number of persons. It is possible to bring on an assistant on their own initiative but that is not self-evident and the assistants of their choice are often less paid.

III. PERSONAL ASSISTANTS

Personal assistants have always had a statute, from the outset of the STIL experiment in 1987.

Personal assistants are represented by a trade union. The employers have their employers' association (KFO). The salary agreements are laid down in labor contracts.

Concerning the assistant's salary. There is a difference between workers (hourly wage) and employees (monthly wages). PA's are considered as workers and thus receive an hourly wage. When during weekdays they have to work between 19 and 22 PM they receive € 2 extra on top of their hourly wage. In weekends or on bank holidays, if they work after 22 PM they receive an extra bonus of € 4 on top of their hourly wage.

You present yourself at your employers' association with the agreement that you have received from the municipality or social security and in which is stipulated the number of hours of assistance to which you are entitled.

After having found assistants you sign a contract with them. This contract is signed by the user, the assistant and the employers' association. All three signatures need to be present on the contract, if not the contract is null and void (this is in any case how it works with STIL).

The user determines who works when and how much, but still he or she has to respect the working hours regulations. There are several possibilities:

- You can engage somebody for a short period of time.
- You can draw up a contract with variable working hours.
- You can engage somebody on a full time basis.

In the last two cases it is still possible to either engage somebody with a long-term contract or with 'a long-term contract for as long as the assistance assignment is valid'. The difference being the period of notice. With a long-term contract it is very difficult to fire someone,

which may cause problems in a one-on-one working situation. That is why, specifically for PA's, they have come up with this alternative arrangement which provides for a period of notice of only 14 days (instead of 3 months).

Personal assistant has for a long time been a rather unpopular job. JAG has received some financial means from a foundation in order to make the job more popular through the 'I like my job' campaign. Moreover JAG has seen to it that there be more realistic expectations of the user towards the assistant and vice versa. Finally also STIL has put more effort into the training of PA's as well as trying to ensure that users and personal assistants have more realistic expectations about each other.

CONCLUSION

Out of a population of 10 million people almost 20,000 people in Sweden work with personal assistants. In Flanders, with 6 million people, 1,725 persons work with a PAB and 5,103 people are listed on a waiting list. Furthermore 138 people work with a personal budget (PGB).

1. In Sweden much attention is given to administrative support of the user. In 97% of all cases a cooperative, private society or the municipality takes care of the administrative burden of the employership. As a user you do however remain in control over a crucial element of the employership: you determine the how, what, where, when and who of your assistance, at least when you work with cooperative societies or some private organizations. The municipality hasn't got a very good reputation in this matter. Apart from the administrative help many employers' associations take on other tasks such as the training of and the search for personal assistants and the training of users in order for them to become 'good employers'. Moreover there exist organizations like JAG who specifically focus on persons with a serious multiple deficiency. They offer a tailor-made service so that this specific group does not drop out.

The reason that there are more disabled people making use of personal assistance in Sweden than in Flanders is mainly due to the fact that personal assistance is an enforceable right in Sweden, that an open-end financing is used with regard to it, that the individual budgets are sufficiently high to also enable seriously disabled people to live independently etc. This however does not mean that we can minimize the important contribution of the employers' associations to the support of people with a disability.

Should we conclude that the good organizational framework in Sweden results in more people benefiting from the advantages of personal assistance? And consequently that there exists a potential for Flemish users who can take their life into their own hands with Personal Assistance, provided that more attention be given to support?

2. The admittance of private initiatives on the market has significantly increased the need

for efficiency as well as the freedom of choice for disabled persons. A control on the expenses however proved to be necessary to prevent abuse. There exists an obligation to account as well as an expenditure control for all the forms of employership. With regard to the private (read: commercial) providers there has however occurred a (minor) problem with non-used funds for training and support which had not been transferred to the users. So some form of control appears to be necessary.

3. When it comes to the statute of personal assistance there is much to be learned from the Swedish situation for Flanders. Swedish personal assistants do find themselves in a better position than in Flanders. They have a statute, trade unions and this has been so from the outset of personal assistance. The employers' associations are united and the negotiations about the assistant's salaries are organized as happens in other sectors, i.e. through labor contracts.

This article merely raises the veil. The ongoing investigation carried out by the Independent Living Institute on the instigation of the Expertise Centre Independent Living shall without a doubt contain more interesting facts. The results are expected by the end of May and will be presented at the June 2010 conference.