## User involvement in the provision of social services in Sweden Focus on personal assistance



## The right to personal assistance



A person has the right to apply for personal assistance if he or she belongs to one of the three groups of individuals as indicated in the LSS-act: *The Act on support and services to certain persons with disabilities* 

- Persons with an intellectual disability, autism or a condition resembling autism;
- Persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness;
- 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.



Persons with a need of more than 20 hours per week for fundamental needs qualify for a personal assistance benefit according to the definitions of the LASS-act:

The Act on the assistance benefit.

The assistance benefit according to the LASS-act is funded by the Social Insurance Agency.

Expenses for personal assistance according to the LSS-act are paid for by the municipality where the user officially is registered.

There should be no deviations in the practical operating mode of personal assistance according to LSS or LASS.

Before calculating the fundamental needs, the user has to meet one of the conditions of inclusion in one of the groups of persons as indicated by the LSS-act.



To establish the 20-hours mark for fundamental needs, the following five situations are taken into consideration:

- Personal hygiene;
- Eating;
- Dressing & undressing;
- Communication with others;
- Other help which requires detailed knowledge of the person's impairment.

The 20-hour mark has to be reached by a need in at least one of these five situations. After establishing the fundamental needs, the other needs are calculated.



### Assessment



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

The assessment process is normally done through open ended interviews conducted by an official of the municipality and the Social Insurance Agency, where the applicant describes his or her everyday life, including activities they could and would do if provided with assistance.

Recently, a project has been initiated which aim at developing a "neutral" assessment tool to enable more uniform assessments and biennial reassessments.

New assessments are only carried out after application from the user.

Each decision can be appealed against, both within the decisive body as through the system of civil courts.



## Assistance benefit



After assessing the needs of the assistance user, he or she gets a number of assistance hours per month allocated.

The Swedish state sets out a standard hourly amount of the assistance benefit, 252 SEK in 2010.

87 % of this amount is meant to be destined for salaries, bonuses for unsocial working hours, holiday pay, salary taxes, social fees and retirement insurance contributions. The remaining 13 % is to cover the other costs due to the provision of personal assistance:

- Assistant costs;
- Education;
- Work environment efforts;
- Assistance costs;
- Administration.



If specific conditions are met, the user can apply for a raised assistance benefit. This amount can as a maximum be 12 % higher than the standard amount (282 SEK in 2010). Those conditions are:

- Need of assistants with a specific education;
- There is a vice-supervisor or service guarantor assisting in the daily routines between user and assistants;
- More than half of the assistance is provided during unsocial working hours.

In contrast to users who get the standard benefit and only have to report their use in number of hours, must users that receive the raised benefit account for the spending of the funds, divided in 6 categories.





#### Municipalities:

- Everything is centrally organised;
- No effort from the user demanded;
- Replacement staff is available.

- Poor influence on who is to provide the personal assistance;
- Uncertain whether the assistant's scheme fits your lifestyle;
- No control over your economic means.



#### **Cooperatives:**

- Control over staff, schemes and economic means;
- Participation in the policies and activities of the cooperative;
- Often is legal help available.

- A bigger effort from the user is expected;
- You have to be conscious about the use of your economic means;
- Replacement staff is rarely available.



Private for profit companies:

- The different service levels can be adapted to the needs and demands of the user;
- Their profit motive ensures a secure economic situation for the user;
- Often is legal help available.

- Control Their profit motive can limit your use of economic means or the fluctuation of assistance hours;
- No influence on business decisions in the company;
- Not always in control of your economic means.



Employ the assistants yourself:

- Full control over your assistance situation;
- The assistance benefit is even paid during the user's hospital stay or when the user dies (notice period);
- Less strict legislation regulating the employment.

- You have to account for the use of the funds after a 6-month period;
- The user can not employ an assistant with whom he or she shares a household;
- Because you want to take on all responsibility, you need to be updated on all changes in legislation, tax regulations and trade union agreements.



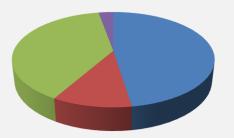
## The number of assistance users



#### The number of assistance users

- In January 2010, there were 15,799 users of personal assistance according to LASS;
- In average 110.7 hours per week are allocated;
- In December 2009, there were 3,400 users of personal assistance according to LSS;

#### **Assistance providers**



- Municipalities (47,5 %)
- Cooperatives (10,7 %)
- Private comp. (38,9 %)
- Own employers (2,8 %)



## **Customer satisfaction**



Research at Gothenburg University has proven that inhabitants of the city who let the municipality organise their personal assistance, are substantially less satisfied than other users.

In 1995, the JAG-cooperative asked 66 users about their assistance situation. The same questions were asked again in 2005 to 55 of these users still alive:

- In 1995 only 20 % of those above 18 lived on their own
  in 2005 they were 66 %;
- The demand for short term relief residence had reduced remarkably;
- Family care allowance, relief service and home care are practically never used by the persons interviewed 2005;
- Four users had quit the personal assistance system.



In 2005 a parliamentary committee questioned 915 random users who did not employ the assistants themselves:

- More 70 % of the users was able to chose the assistance provider freely;
- About half of them had considerable influence in the recruitment of personal assistants: 43 % at the municipalities, 89 % at the cooperatives and 81 % at the private companies;
- Education for personal assistants is only provided at 5 % of the municipalities, 29 % of the private companies and about half of the cooperatives;
- There was a written agreement between user and assistance providers for 91 % of the cooperatives, 86 % of the private companies, but only 48 % of the municipalities.

