



## **ANED country report on the implementation of policies supporting independent living for disabled people**

**Country:** Sweden

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## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

The Swedish Personal Assistance Act of 1994 has in many ways been extremely successful in enabling disabled persons to live in the community, in self-determination and dignity, with choices equal to others, and to take their rightful place as children, parents and citizens. It is a reform that is the envy of many representatives of the international independent living movement and stands out like a 'golden standard'.

Still, for the Swedish independent living movement and the politicians that support them, there is both the task of defending and developing the reform. There have been criticism on the increase of costs of the reform, and the legislation is currently under investigation (SOU 2008:77) and a reformed law will be presented, possibly during 2010. A few restrictions and attempts to cut costs are introduced in the new law but on the whole the personal assistance act is now accepted and supported by a big majority in politics and among ordinary people.

It is important however to remind oneself that personal assistance is only one important step and that a lot more can be done to make our society inclusive and open for all. Many reforms that aim to make the society more accessible and reforms aimed at increasing individual capabilities are necessary for disabled persons in order to achieve full citizenship. Even today many disabled persons face exclusion from mainstream society and attend special classes for pupils with physical disabilities ("RH-klasser") and cognitive disabilities (*särskola, school apart*) instead of extra support in ordinary classes. (In theory and by law it is the child and his/her parents who choose the school, and nobody can be forced to go to special needs school. If the parents decline 'särskolan' the child is entitled to exactly the same support in regular school. In practice there is however often a pressure and encouragement to relocate the children to special school to get access to better help resources and more financial support)

A system of special transport has been built up instead of making accessible public transport in the shape of taxi, bus and subway. In Sweden, there exist strong legislatures intended to make society accessible, but compliance with these laws are many times scarce or non-existent. For instance, legislation intended to make public transportation accessible was enacted in 1979, and still most public transportation is inaccessible for most disabled persons. According to current discrimination legislation, inaccessibility in Sweden is not defined as discrimination and suggestions in this direction was lifted out of a recent discrimination legislation for further investigation.

It is also worth mentioning that technical and human personal assistance exist in separate systems. You are allowed to choose and employ your assistants, but you cannot choose your wheelchair or hearing aid depending on your individual preferences. At the moment a disabled person have no right to claim any specific assistive aid or substantial influence over your assistive aids, as is the case with personal assistance. In some places in the country trials have been initiated to allow for a greater influence over the assistive aids by the user. The goal would be a similar solution with cash payments both for technical and human personal assistance.

The independent living situation in Sweden is comparatively good when looking at the personal assistance situation. The citizenship perspective is well expressed in the legislation that control personal assistance (LSS). But this perspective must also spread to other important areas for independent living, like transportation, housing, assistive technology etc.



## PART 2: LEGAL AND POLICY CONTEXT

In Sweden, there are several laws regulating the support disabled persons can receive from society as different means of assistance for independent living. The “Social Services Act” (SoL) is the baseline legislation for social services for all people in society, both with and without disabilities. Assistance under the SoL legislation must provide reasonable living conditions. The local authority conducts an individual review of the applicant's needs. This might include, for example, help in cleaning, washing, shopping, cooking or other personal care.

A group of people with more significant assistive needs and a more extensive need for support or services, is covered by the “Act on support and service for certain individuals with disabilities” (LSS 1993:387). This Act provides for ten different initiatives: advice and support, companion service, assistance from a contact person, relief service in the home, short-term stays outside the home, short-term supervision for school pupils over 12 years of age outside the home, foster homes or specially serviced housing for children and young people who need to live outside the parental home, specially serviced housing for adults or other specially adapted housing for adults and also daily activities for people of working age not in gainful employment and who are not receiving training and cash payments for personal assistance.

The latter is possibly the most significant initiative and is regulated in a separate legislation, the assistance benefits act (LASS), with the possibility for persons with extensive assistive needs to employ personal assistants (see below for a more detailed description of this initiative). Anyone who needs more than 20 hours assistance per week for their basic needs are entitled to assistance allowance under LASS. The Swedish Social Insurance Agency administer assistance allowance under LASS. The local municipality has the responsibility and administers personal assistance under LSS. The municipality has an obligation to provide financial support for reasonable costs for personal assistance for the portion not covered by the assistance allowance under LASS. The individual can apply for personal assistance with the municipality or with the Swedish Social Insurance Agency. The municipality must notify the Social Insurance Agency if a person needs more than 20 hours assistance per week for their basic needs.

The possibility to obtain different kinds of assistive aids is primarily regulated in The Law of Health and Medical Services (HSL) 1982:763 (some assistive aids in school or work settings are catered for in other regulations and laws)

Other important legislation is The Home Modification Legislation (Lag om bostadsanpassningsbidrag 1992:1574) where the municipality approves grants for reasonable expenditures for the adaptation of housing accommodation to permit people with functional limitations to continue to live in their own homes. Together with Swedish Building Code (Svensk Byggnorm 1977, Plan- och Bygglagen 1987:10) which stipulates wheelchair access to all units in new residential buildings of three or more floors, this creates a relatively good situation on the housing situation for disabled persons. This code for example requires barrier-free passage from sidewalk via large enough elevators to all apartments in all new buildings. Kitchens and bathrooms must have certain minimum dimensions.

There is also a possibility to get an allowance to buy a car, Car allowance (Förordning 1988:890 om bilstöd till personer med funktionsnedsättning) for persons who cannot use public transportation because of a disability. The allowance is destined to the purchase of a car for personal use. Basic allowance is today 60,000 SEK. An additional amount of a maximum of 40,000 SEK is payable subject to income test. Costs for adaptation of a car due to a person's physical needs are covered without limit.



There is also special transport (färdtjänst) available to those finding difficulty using public transport (Lag 1997:736 om färdtjänst). Färdtjänst is an entire system with special solutions for, and only used by, disabled people, with special buses and cars. Only people who are approved for the service can travel, and normally only in your own municipality. Travels have to be ordered in advance, typically the day before or a couple of hours before the travel, and provide a door to door service. Longer distance travels have to be approved a couple of weeks in advance. Disabled visitors from another country or municipality cannot (or in a very few cases) use färdtjänst.

Other relevant legislation is the prohibition of Discrimination in Working Life of People with Disability Act (1999:132) (Lag om förbud mot diskriminering i arbetslivet på grund av funktionshinder) and the The law on equal treatment of students in higher education (2001:1286 Lagen om likabehandling av studenter i högskolan.)

According to law, inaccessibility in Sweden is however not defined as discrimination.



### **PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING**

The National action working plan for disability policy, - Från Patient till medborgare (From Patient to Citizen, Government Bill 1999/2000:79), was adopted by parliament in 2000. The main objective of this plan is that the disability perspective should permeate all sectors of the community. The plan sees a community of diversity as a basis, a society designed to allow disabled persons of all ages full participation in all aspects of life in the community and equal opportunities in life for girls and boys, women and men with disabilities. In order to achieve this goal, all societal stakeholders and all levels of government must share this responsibility and control of the accessibility in their activities. This national action plan for disability policy is the most important policy document in Swedish disability policy during the past years. This legislation also marks a shift in the policy of the aims of the modern disability politics, away from the individualistic perspective, the impairment based view, to a more social and disability based view.

The Swedish Assistance Benefit Act (LASS) of 1994 has been instrumental in the aim to give disabled persons independence, self-determination, full participation and equality in living conditions. The background to the personal assistance reform was the situation where disabled persons had their support services provided by a variety of home help services, and lived in institutions or institution-like group homes, or at home with their parents. People who needed these services had little or no influence over how and when the help was received. Neither did they have much control over who provided the help and as a result a great number of different assistants could pass through their homes. This kind of standardised service forms, often provided within institutional settings, put disabled persons in a passive role of dependency. Service exceeding the bare minimum for existence had to be provided by family or friends.

The Swedish Personal Assistance Act of 1994 has enabled disabled persons who depend on others in their daily activities, to live in the community, in self-determination and dignity, with choices equal to others, and to take their rightful place as children, parents and citizens. The Act legally entitles currently about 15,000 eligible persons to a non taxable, fully accountable budget from the tax-funded national the Swedish Social Insurance Agency for purchasing personal assistance services to support a person in all aspects of life. The budgets' amount is based not on income or wealth but solely on need of practical assistance by others as determined by physical, cognitive or psychiatric limitations, a person's family obligations, work and leisure activities. Also, amounts of payments do not depend on the type of service provider the recipient chooses. Consumption of assistance hours currently averages 108 hrs /week. (Försäkringskassan, 2009a; 2009b)

Recipients are free to purchase assistance services from local governments, private for-profit companies and assistance user cooperatives or to employ their personal assistants themselves. With Personal Assistance individuals with an extensive need for support was given control over their assistance. Through the direct payments scheme the individual's influence over how the assistance was carried out, was strengthened on all levels. Family members can be employed as personal assistants

The payments amount to an annual 20 Mrd SEK (2007) and have turned former objects of public care into customers and employers; recipients can freely choose their service provider or employ their assistants themselves. A competitive market has resulted with 230 local government service providers and some 450 private companies. This new market employs a total of 60,000 persons (in comparison, the City of Stockholm, the country's largest employer, has 50,000 employees) enabling disabled people and their family members to return to work and providing jobs to mainly younger people in transition from school to working life, immigrants or women with small children – people who otherwise are likely to live on unemployment insurance or social welfare.



According to studies, taxpayers have saved a minimum of 29 Mrd SEK since 1994, compared to the costs of local governments' homehelp services, since the production of personal assistance costs less in this competitive market than homehelp services' production in the protected public sector. (Ratzka, 2007; Socialstyrelsen 2008)



## **PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY**

### **Personal Assistance Allowance, PAA (Assistansersättning)**

You are entitled to this allowance if you have substantial impairments and require personal assistance to help you manage your everyday life. Personal assistance is defined as a programme of personally designed support to be given in various situations by a limited number of people. Although entitlement to this allowance is not subject to an age limit, you must not be over 65 when the allowance is granted. You must need personal assistance with basic needs (e.g. with personal hygiene, dressing and undressing, eating, communicating with others) for an average of more than 20 hours per week.

### **Assistive aids and technology (Hjälpmedel)**

Assistive devices are largely provided by the county councils and municipalities in accordance with the "Healthcare and Medical Treatment Act" (HSL). Under the Act in Sweden, disabled persons usually obtain their assistive devices via healthcare and medical treatment or as assistive devices at work. Assistive devices are supplied to a large extent by county councils and local authorities under the HSL. The assistive devices you need are prescribed by a healthcare professional, typically an occupational therapist or a physician.

### **Housing adaptations (Bostadsanpassning)**

The municipality approves grants for reasonable expenditures for the adaptation of housing accommodation to permit people with functional impairments to continue to live in their own homes. Housing adaptation is a common intervention to remove environmental barriers and enhance daily activities.

### **Car allowance (Bilstöd)**

You may be able to get a car allowance if you have considerable difficulty in getting around on your own or using public transport. Parents with a disabled child may also be entitled to car allowance in some cases if they need the car to be able to travel with the child. Car allowance may also involve a grant for another means of transportation, such as a moped or a motorcycle.



## 4.1: PERSONAL ASSISTANCE SERVICES

### Assistance allowance (Assistansersättning)

A person can obtain assistance allowance if he/she have substantial and durable impairments and need personal assistance to cope with their daily life. To obtain the allowance a person must need assistance with his/her basic needs for more than 20 hours a week. Those who need personal assistance for their basic needs are also entitled to assistance for other personal needs. Family members can be employed as assistants and can get full payment for any help they provide as assistants.

If a person needs assistance for more than 20 hours a week with basic needs such as washing, dressing, eating, communicating and moving about, he/she can obtain assistance allowance. A person must also belong to one of the following three groups:

1. Persons with a cognitive impairments, autism or related disability.
2. Persons with a considerable and durable impaired intelligence after brain damage in adult years caused by violence from an external source or physical illness.
3. Persons with other durable physical or mental disabilities, which are evidently not caused by normal ageing.

Personal assistance for basic needs means assistance in washing and dressing, eating, communicating with others and moving about, or other assistance that requires detailed knowledge of the users impairments. If a person need assistance with basic needs for an average of more than 20 hours a week, he/she may also be eligible for personal assistance for other help in daily life, for example, cooking, shopping, taking part in leisure activities or working, parenting etc

The impairments must be substantial and cause considerable difficulty in daily life.

There is no lower age limit for obtaining assistance allowance and it is possible to continue receiving assistance allowance after the age of 65 provided that it has been granted before that age.

A person cannot obtain assistance allowance if he/she lives in group housing or are cared for in an institution. If there are special reasons, a person can, however, receive assistance allowance when he/she are cared for at a hospital for a shorter period. The amount of hours per week a person is granted is decided by an administrator at the Swedish Social Insurance Agency together with the user who estimates his/her assistive needs. Different certificates from medical or social professionals also form a background.

In December 2008 15 293 persons received assistance allowance, 47 percent women and 53 percent men. Since the beginning it has always been more men than women granted assistance allowance. Also the number of hours per week differs between men and women. In December 2008 the average was 108 hours a week for the whole group. Historically men have been granted an average of between four and five support hours more per week but in December 2008, the difference had decrease to about three hours. The total numbers of hours in 2008 was 84 million which is an increase of more than 4 million hours (6 percent) compared to the year 2007. (Försäkringskassan, 2009a; 2009b) Systematic differences between men and women are also found in other social insurance programs. In the case of personal assistance there is a small but systematic difference that have rather complex explanations, where some factors are disability specific and others can be explained by how gender determines the perceived role in the family.





Regional differences, age and family situation, are examples of factors that also affects the outcome. (RFV, 2004)

The government sets a standard amount for assistance allowance every year. In 2009, the amount is SEK 247 per hour. A person can apply for a higher amount if he/she has special reasons. The highest amount in 2008 is SEK 276. Special reasons may, for example, be that the user needs a specially trained assistant who demands a higher payment than the standard amount.

The concept of personal assistance is that it should be personal support that gives the individual greater opportunity to live an independent life. Personal assistance means personally designed assistance provided in different situations by a limited number of people. It means that users have control over how services are organised and can custom-design their services according to their individual needs and also decides who is employed as personal assistant, when and how aid should be given.

This means that a person can choose to be an employer and employ one or more assistants, form an association or a co-operative with other disabled persons, which employs several assistants or use a private company or the municipal assistant organisation. There is nothing to prevent a user from employing an assistant at the same time as he/she receives assistance through the municipality or another organisation. It is the number of hours per week that sets the limit.

A person can also obtain assistance allowance if he/she decides to use a member of his/her own household as an assistant. The member of the own household shall then be employed by the municipality or another assistance provider



## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

### Assistive aids and technology

Assistive devices are largely provided by the county councils and municipalities in accordance with the Health and Medical Services Act. Under the Act in Sweden, disabled persons usually obtain their assistive devices via healthcare and medical treatment or as assistive devices at work. Assistive devices are supplied to a large extent by county councils and local authorities under the "Healthcare and Medical Treatment Act" (HSL). The assistive devices you need are prescribed by a healthcare professional, typically an occupational therapist or a physician.

Responsibility under HSL includes assistive devices for daily living, for care and treatment and also personal assistive devices for school and education. Work assistive devices for people with a reduced working capacity are the responsibility of social insurance offices and employment agencies. The provisions and routines relating to the allocation of assistive devices are applied very differently across the country. In certain parts of Sweden, around you have to pay a substantial amount of money for hearing aids for both ears and a 'rental' fee per year for an electric wheelchair. In other parts of the country, the same assistive devices can be provided at little or no charge.

It is also worth mentioning that at the moment you have no right to claim any specific assistive aid or substantial influence over your assistive aids, as is the case with personal assistance. In some places in the country trials have been initiated to allow for a greater influence over the assistive aids by the user. The goal would be a similar solution with cash payments both for technical and human personal assistance. (SIAT, 2000)

County councils and municipalities are spending an estimated 6-8 billion SEK annually on assistive aids. But the statistics on the costs is inadequate, partly because it is hidden in a number of different systems and a lack of routines for gathering such statistics.

### Housing adaptations

The municipality approves grants for reasonable expenditures for the adaptation of housing accommodation to permit people with functional impairments to continue to live in their own homes. Housing adaptation is a common intervention, in Sweden granted by municipal authorities, and performed in order to remove environmental barriers and enhance daily activities. Housing adaptation grants are to be used for essential operations, such as the conversion of kitchens and bathrooms, wider door openings, the removal of door sills, the installation of ramps, improvement of pathways, removal of carpeting in the case of allergy sufferers, etc.

Grants are available for people with all types of functional impairment, for example reduced mobility, impaired vision, allergies, epilepsy, stoma or cognitive impairments. Grants are not subject to a means test, and there must always be a direct link between the steps taken and the functional impairment. Grants are not available in the case of temporary impairments.

Grants are made to private persons who either own the property concerned, are tenants or have tenant-ownership rights (bostadsrätt). The permission of the landlord is required in the case of rented or tenant-owned accommodation.

Applications is submitted to the municipality, which also issues application forms. The district occupational therapist at the local medical-care centre usually help the applicants to fill in the form when applying for a medical certificate.( NBH 2000a;2000b;Fänge & Iwarsson, 2005) The total number of grants has increased from 67,200 in 2006 to 72,700 during 2007.



The total cost of the municipalities has also increased from 897 to 958 million SEK. The average cost per case is 13,200 SEK for 2007 which is a slight decline compared with 2006 when average cost was 13,400 SEK.

Most of the grants are intended for small amounts. Approximately 61 percent of the contributions is less than 5,000 kronor and only about 2% exceeding 100,000 SEK.

Of the housing adjustments made in the house built in 1995 or later, the most common adjustment is thresholds, that makes up for approximately 28 percent of the total number.

Other common adaptations are bathrooms and kitchens, automatic doors and installation of ramps. (Boverket, 2007)

The waiting time for housing adaptations to be agreed vary a lot in different municipality and no good statistics for the country as a whole are available.



## **PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE**

### **STIL**

STIL or the Stockholm Cooperative for Independent Living, was from the very beginning in 1984 created and managed by disabled persons to provide personal assistance services (PAS) to its members. In STIL, the members with disabilities pool the funds that the national insurance agency allots to them for PAS services. The cooperative hires the personal assistants, who are supervised by the individual members who use their services. Personal assistance services are provided wherever they are needed, including the workplace. Existing members train new cooperative members in how to manage their PAS, and on-going peer support helps members solve any problems to become even better managers of their own PAS. STIL provides a model for a user-run PAS cooperative that has been adopted throughout Sweden and internationally.

<http://www.stil.se/default.asp?headId=3&subId=59&pId=59>

### **JAG**

JAG stands for "Jämlikhet , Assistans och Gemenskap" which means: Equality, Assistance and Community". One part of JAG is an association that works with issues related to personal assistance and disabilities, such as interest politics and information.. The other part of JAG is a cooperative of users of personal assistance. The association JAG and the cooperative JAG are both organized in the form of national, non-profit associations.

Only a person with multiple, severe disabilities including some kind of intellectual disability can become a member of JAG. Others can become supporting members, without the right to vote. Only a member of the association JAG can be member of its Board of Directors. JAG's members are, with few exceptions, represented by their legal guardians.

[http://www.jag.se/eng/eng\\_index.html](http://www.jag.se/eng/eng_index.html)

### **Independent Living Institute**

The Independent Living Institute (ILI) is a policy development center specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity. The ultimate goal is to promote disabled people's personal and political power. Towards this end they provide information, training materials and develop solutions for services for persons with extensive disabilities in Sweden and internationally.

<http://www.independentliving.org/indexen.html>

### **IFA**

IFA is an association for people who need personal assistance. IfAs purpose is to pursue and develop disabled persons rights to personal assistance and assistance-reimbursement by both interest politics and support to individual users assistance.

<https://www.intressegruppen.info/?page=php-startsidan>



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- An abundance of information on independent living in Sweden is available at  
<http://www.independentliving.org/library.html>
- Especially about the situation on the development of independent living in Sweden  
<http://www.independentliving.org/25years2008doc>