SOCIAL SYSTEM AND DISABILITY POLICY
IN SWEDEN

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Sweden is 1500 km long and has an area of 450,000 qkm. This means, it is 1.5 times larger than Poland and 15 times larger than Belgium.

Sweden has a population of ca. 9.5 million inhabitants. More than 80% of the population lives in cities or small towns, 80% live in the south and 50% live within 30 km of the coast.

Around 500,000 people, approximately 18% of Sweden's population, are member of one of the different NGOs under the roof of the ‘Handikappförbunden’ ("Handicap association"), the big umbrella organisation for disabled people in Sweden.
SOCIAL POLICY

In general:

Sweden is a highly industrialized country with a small population: some 9,5 million inhabitants. Sweden is one of the countries with the highest living standard in the world between others because:

- Sweden was not involved in either of the two world wars;
- The country has always had extensive natural resources at its disposal;
- The country had a huge economic growth between 1960 and 1980.
In general:

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The Swedish system of social policy, and of disability policy, is based on three important principles:

- The principle of egalisation;
- The principle of shared responsibility and decentralisation;
- The limited role and influence of non for profit organisations (NGOs).
The first basic element in the structure of Swedish society and Swedish social policy is the principle of an egalitarian society. The ambition therefore of the general welfare policy is to guarantee financial security and social rights to all citizens, without any application procedure or means-testing. Of course, people with disabilities also can profit of all the benefits and the services of this general system.

The basis of this policy is a tax system
- in which all taxpayers contribute, for the good of all, according to capacity;
- and in which funds are distributed with the objective of leveling out differences in people's living conditions.
One other characteristic of the Swedish society is the division of responsibility: a strong influence of central authorities, combined with clearly decentralized decision-making:

- The state is responsible for legislation, questions of social insurance and general planning. On the state level the objectives of the activities are defined, but regional and local authorities enjoy great freedom to decide on the quality and nature of the practical measures undertaken. They also collect taxes themselves to finance their work.
- The county councils have primary responsibility for health care.
- The local authorities have basic responsibility for education, housing, child care and social services.
LIMITED ROLE AND INFLUENCE OF NON FOR PROFIT ORGANISATIONS

Because of the specific characteristics of the Swedish system for a long time NGOs did not have any real influence on measures and social services. However, because of the trend towards greater decentralisation of responsibility the central authorities' influence has gradually decreased, and greater responsibility has been laid on the local authorities. This has also resulted in private (for profit and non for profit) initiatives beginning to be established in both medical and social activities.
Activities on the national level

Everybody who legally lives or works in Sweden is covered by Swedish social insurance and thereby entitled to receive various benefits from the state.

On national level social benefits are mostly administered by the National Social Insurance Fund. It is mostly financial (cash) benefits that are administered here.
SOCIAL POLICY

Activities on the national level

- **Childcare allowance**: Allowances for parents of children who need special supervision and care for at least six months or parents who have large additional expenses due to the child’s disability or illness.

- **Activity compensation**: This is a benefit for persons between the age of 19 and 29 who will probably not be able to work full-time for at least one year due to a disability, injury or illness.

- **Sickness compensation**: Benefit granted to persons between the age of 30 and 64 who will probably never again be able to work full-time due to an injury, an illness or a disability.

- **Disability allowance**: A benefit for persons aged 19 or older who need additional assistance due to illness or disability or who have additional expenses due to disability or illness.

- **Personal assistance** granted under the Personal Assistance Act of 1994
SOCIAL POLICY

Activities on the regional level (counties)

County councils are responsible for the provision of
- Healthcare;
- Rehabilitation;
- Assistive devices for daily living, for care and treatment and for school and education.
Activities on the local level (municipalities)

Most social services are placed with the municipalities who are responsible for their implementation and who have the freedom of interpretation of the law. How services are provided varies considerably between different municipalities.

Some examples:
- City councils are responsible for the administration of the Social Services Act which regulates the right to social welfare and also to other services, like homecare, a place in a group home or a service home.
- Municipalities are responsible for the provision of support measures like personal assistance for people who need less than 20 hours of assistance per week.
- Assistive devices required by children with disabilities for school
- Help for adaptation of houses if these adaptations are proved to be necessary. In 2008 the average cost for an adaptation was ca. 1 300 Euro.
Residential care (1850-1950)

During the first half of last century Sweden developed a strong system of ‘institutional care’ for people with disabilities.

- At first: creation of private organisations for assistance;
- Later on, public bodies also began to organise disability services.

The support in this period was delivered through large residential institutions, often situated in the countryside.

A range of school institutions, asylums, hospitals and nursing homes was financed by ever-growing state subsidies.
Residential care (1850-1950)

- A well-intentioned protective attitude created walls, physically and metaphorically, around the residential institutions. They became places where large groups were kept under poor conditions.
- Although living conditions in the institutions slowly improved, in the late 1960’s some 14,000 people were still in institutions.
First step towards de-institutionalization (1950-1990)

In the early 1950’s in Sweden two traditions of support for people with disabilities were functioning side by side:
- Residential institutions still were the dominating form of service. People with a more severe disability needed to be taken care of in traditional residential institutions.
- At the same time the idea (the normalization principle) was introduced that society should open up at least for people with a mild disability. Therefore the general welfare services started to support disabled people in their home environment.
Closing the institutions (1994 – 2000)

- In 1994 a law providing for the abolition of special institutions for people with intellectual impairments was finally passed. Institutional living had gradually to be replaced by integrated housing under the Act concerning Support and Service for Persons with Certain Functional Impairments.
- At the same time (1994) the Direct Payments for Personal Assistance Act was approved.
- In 1997, the Abolition of Institutions Act put the final data for the closure of all traditional institutions at 31 December 1999.
Closing the institutions (1994 – 2000)

As of January 2000, all forms of support to persons with an (intellectual) disability should be channelled through community based services. In this way, a long and intensive period of change in services to people with disabilities in Sweden has come to an end.
DISABILITY POLICY

History

Situation today

At present the living situation of people with disabilities in Sweden is as follows:

- No institutions with more than 10 persons for non-elderly persons with physical disabilities, cognitive disabilities, psychiatric disabilities;
- 10-15% of housing stock is wheelchair accessible
- 19,000 persons receive direct payments for personal assistance services
- 40,000 children and adults with disabilities receive specialized support in their home situation.
Today in Sweden there are different forms of housing of disabled people:

- Around 19,000 people live in a normal family situation with support of general and/or specific social services. Moreover, people with a high need of support can use a PAB.
- Some 20,000 people live in one of two forms of ‘integrated living’:
  - ‘Group accommodations’: a number (5 to 6) of individual apartments situated in the same apartment block with some common rooms and common provision of social services.
  - ‘Service housing’: individual houses and/or apartments situated in the same neighbourhood with individual support that is available day and night.
- A very small group of children lives in ‘family homes’, small and integrated group homes that are similar to normal family life. Most of the these children need a lot of care and support or they are following special education far from home.
Direct payments (PAB) in Sweden

The right to personal assistance

Legislation:

An important reform of the disability legislation took place in 1994. As a result of this reform the right to personal assistance in Sweden is written down in two laws (acts):

- the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). This law applies to disabled people who need less than 20 hours of assistance a week
- the Personal Assistance Act (LASS) was introduced for those in need of personal assistance in excess of 20 hours per week.
Direct payments (PAB) in Sweden

The right to personal assistance

Beneficiaries:

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:

- 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.
Direct payments (PAB) in Sweden

The right to personal assistance

Assessment:

The assessment process until now is normally done through open ended interviews conducted by an official of the municipality and the Social Insurance Agency. The assessment is based on the description of the applicant everyday’s life, including activities they could and would do if provided with assistance. 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.

Recently, a project has been initiated which aim at developing a ‘neutral’ assessment tool to enable more uniform assessments and biennial reassessments.
Direct payments (PAB) in Sweden

The right to personal assistance

Assessment:

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

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

The 20-hour mark has to be matched by a need of at least one of these five criteria.
Direct payments (PAB) in Sweden

The right to personal assistance

Allocation:

After assessing the needs of the assistance user, he or she gets a number of assistance hours per month allocated. Depending the allocated number of hours the PAB (personal assistance budget) is granted and paid:

- By the municipality where the user officially is registered if the need of assistance is less than 20 hours per week (LSS-act);
- By the Social Insurance Agency (LASS-act) if the need of assistance is more than 20 hours per week. In this case the first 20 hours are still paid by the municipality.
Direct payments (PAB) in Sweden

The right to personal assistance

Amount of the PAB:

The Swedish state sets out a standard hourly amount of the assistance benefit: 28 Euro in 2010.

87% of this amount has to be used 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: administration, training of the assistant, costs of the assistant, work environment costs.

Benefits under the legislation are means-tested, i.e. not dependent on assistance users’ or their families’ income and wealth. Payments do not constitute taxable income.
Amount:

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 (31,50 Euro 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.
Direct payments (PAB) in Sweden

Assistance users

In 2010 over 19,000 disabled people were legally entitled to direct payments:

- 15,799 users of personal assistance according to LASS; In average 110.7 hours per week are allocated;
- 3,400 users of personal assistance according to LSS;
Direct payments (PAB) in Sweden

Assistants

There is no specific qualification or training for the job of ‘personal assistant’ and no legal restrictions about the tasks to perform by the assistants.

There are around 80,000 personal assistants employed (= 45,000 full time equivalents).

Characteristics:
- 75% of the personal assistants are working part time;
- Many assistants have a second job;
- Assistants are mostly people in transition from education to labor market;
- Most of the personal assistants are between 25 and 44 years old;
- There is a big turnover: about 40% a year.
- 80% of the personal assistants are women;
- 30% of the personal assistants are immigrants;
Direct payments (PAB) in Sweden

Assistance providers

Market actors

Four kinds of providers of personal assistance:
- Local governments (300)
- Cooperatives
- Private companies (500)
- Budgetholders
Direct payments (PAB) in Sweden

Assistance providers

Market shares

- Municipalities (47.5%)
- Cooperatives (10.7%)
- Private comp. (38.9%)
- Own employers (2.8%)
Direct payments (PAB) in Sweden

Assistance providers

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.
Direct payments (PAB) in Sweden

Assistance providers

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.
Direct payments (PAB) in Sweden

Assistance providers

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.

- 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.
Direct payments (PAB) in Sweden

Assistance providers

Employ 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.
Direct payments (PAB) in Sweden

Requirements, opportunities and risks

Requirements:
- Money follows the user not the service provider;
- Sufficient amounts for direct payments to attract private business;
- Informed consumers.

Opportunities:
- Direct payments offer higher quality at same cost;
- Direct payments offer freedom of choice, a revolution that can spread to the whole welfare market.

Risks:
- Limits to the taxpayers’ willingness to support the program;
- Lack of understanding of the cost-efficiency of direct payments versus services in kind;
- Demographic changes.