



Introduction to the Swedish System

The cornerstone of Swedish disability policy is the principle that everyone is of equal value and has equal rights. The fundamental responsibility of ensuring good health and social and financial security for people with impairments is shared by national, regional and local government. This responsibility also includes boosting each individual's prospects of living an independent life. The aim of the policy is to close the gap between people with disabilities and people with no disabilities.

While central government is in charge of legislation, general planning and distribution as well as social insurance, local authorities (municipalities) are responsible for social services, and regional government (county councils) for health care. Municipal social services and the health and medical services of county councils are governed by framework legislation which specifies the framework and objectives of activities but which also affords municipalities and county councils ample opportunity to interpret the law and shape their activities according to their own guidelines.

In Sweden, the National Board of Health and Welfare and a number of other government bodies are responsible for issues relating to people with impairments.

These responsibilities are divided according to a certain principle stating that regular authorities also have a responsibility to cover disability issues. Thus, authorities in the field of education are responsible for questions concerning the rights to education for people with impairments, the labour market authorities are responsible for issues related to impairment/disability and the labour market and so on.

These bodies are tasked with safeguarding the rights and interests of people with impairments by co-ordinating, supporting and promoting such issues in their dealings with other authorities. In addition, the Swedish Agency for Disability Policy Coordination (HANDISAM) has a central role in promoting a society in which everyone can participate on equal terms, regardless of functional capacity.



Swedish Disability Policies Today

The principle regarding the equal worth and rights of all human beings is the foundation on which Swedish disability policies rest. The government, municipalities and county councils together have the basic responsibility for ensuring that people with disabilities are guaranteed good health and economic and social stability, and also for enabling the individual to lead an independent life. The gaps that exist between those with disabilities and other people should be closed. Shifts in the economy should not prevent the goal of equal living conditions from being fulfilled. One of the basic duties of society is to ensure its citizens/members access to its resources and the possibility to shape their lives as they wish.

The aim of the national action plan involves a strong assertion that disability issues should be taken into account in all areas of society and not be limited, as they have traditionally been, to health- and medical care. The government and its agencies have a special responsibility in putting this plan into action.

The goals of the national disability policies are laid out in the action plan. These are:

Social solidarity based on diversity that society should be organised so as to ensure that disabled people of all ages become part of the community equal living conditions for girls, boys, men and women with disabilities

Disability politics should place special emphasis on:

- identifying and dismantling obstacles for full participation in society for people with disabilities
- preventing and fighting discrimination against people with disabilities
- providing children, youth and adults with tools for independence and self-determination

The Aim Is Independence and Self-Determination

Through increased accessibility, people with disabilities are given opportunities to better take part in society, which is a necessary prerequisite for reaching the goal of equal living conditions. Legislation and supervision are important tools for achieving this. The basis for health- and medical care, service and social service, together with education, is regulated in a number of laws, such as the Social Services Act (SoL), the Health- and Medical Services Act (HSL) and the Education Act (Skoll). The measures of society should reinforce the opportunities of the individual to live an independent and self-governing life. As a result, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) have been created to complement the above-mentioned laws. This is a law that gives people with severe disabilities the right to some basic measures when the basic support provided by other laws is not enough. People with disabilities should also have influence over measures, both in the planning and shaping of them, as well in their implementation. The right to measures is usually not based how a certain disability occurred, but on what needs an individual have, based on her or his disability.

The Important Role of Disability Organisations

The disability organisations have a strong position in Sweden. Their participation in the creation of Swedish disability policies is considered an important part of the democratic process. Many organisations are also given federal funding for their activities and the aim is to support these organisations in their work for full participation and equality in society for people with disabilities. Today,

these organisations conduct far-reaching central, regional and local lobbying activities and are often asked to review proposed laws and regarding different/ various reports. They carry out an extensive information service for the public and for different institutions in society regarding what it means to live with disabilities. They also provide service, in-

formation and legal advice for people with disabilities and their families. In some cases the disability organisations run operations at the request of municipalities or the government. One example of these types of operations is recreational facilities. Most of these organisations are members of the Swedish Disability Federation (HSO).



The National Board of Health and Welfare's Work with Issues

The national responsibility of the National Board of Health and Welfare regarding handicap issues involves both health- and medical care, which is carried out by the county councils and social services, which are taken care of by the municipalities. In order to fulfill this mission, the Board conducts nationwide surveys, follow-ups and evaluations of activities within these areas and also of national reforms. The Board is also responsible for setting standards, i.e. drawing up application prescriptions, General Advice and handbooks for both health- and medical care and the social services. In addition, the Board is responsible for the national supervision of health- and medical care. The County Administrative Boards are responsible for supervising the social services. The development of various quality indicators, policies and guidelines for municipalities and county councils are other examples of general tasks performed by the National Board of Health and Welfare. As support for this work, centres for epidemiology (EpC), social economic studies, national statistics and the development of methods in social work have been established. As regards specific work involving handicap issues, the Board performs the following tasks:

- Variations in activities between different municipalities are mapped in annual reports, which also include basic statistics regarding these activities over time, as well as costs.
- The Board allocates subsidies to the handicap organisations. All in all this involves more than 50 organisations nationwide and the total sum is about 170 million SEK per year.
- Special projects dealing with various issues – for example, personal assistance, daily activities, parents with intellectual disabilities and their children.
- Several projects involve the situation of people with psychological disabilities. The Board has developed and evaluated activities involving personal representatives and case managements for persons with psychiatric problems and is also involved in the national effort regarding this issue.
- Another important issue is the living conditions of this group of people. This is something that the Board should investigate continuously and it is therefore developing better tools for following the development nationwide. The Board has a special so-called sectorial responsibility in this area. In connection to various reforms, the Board is often given the task to allot subsidies for promoting development and to follow up and evaluate the effects of the nationwide
- The Board is responsible for official statistics concerning health- and medical care and the social services.
- For the Board, habilitation and rehabilitation are prioritised areas. For example, it follows up the standardisation regarding these issues and takes initiatives for supporting the nationwide development.
- The Board has a database describing rare diseases functional impairments. This database is to provide support and information for different professional categories that meet people with unusual impairments and their relatives.

Participatory Research is Increasing

It is increasingly felt that research should take the situation and experiences of the individual that is being studied as its point of departure. *Participatory Research* is the most common term for this strategy, which aims to empower groups of people with different types of disadvantages. This participant-based research is both ideologically and politically oriented and is so far conducted on a small scale.

International Classification of Functioning

The new international classification system, International Classification of Functioning, Disability and Health (ICF), has been in use for a couple of years, but it is not very wide-spread in Sweden. This system uses positive terms, such as function, structure, activity and participation and can be used for studying all people, not just those with functional impairments.



Measures under the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS)

The Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) is a law that sets out rights for persons with considerable and permanent functional impairments. Its ten measures for special support and service are to provide such persons with good living conditions.

The LSS entitles persons to the special support, and special services, that they may need over and above what they can obtain under other legislation. The LSS supplements other legislation, and does not involve any curtailment of the rights provided under other legislation. A request for support and service from a person who is qualified for help under the Act is to be first considered under the LSS to see whether the measure is stipulated in the Act; this is generally regarded as being to the individual's advantage.

Who Is Covered by the Law?

The LSS applies to

1. persons with an intellectual disability, autism or a condition resembling autism
2. persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness
3. 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.

What Measures Are Available?

1. Counselling and other personal support

The right to qualified expert help from staff who, in addition to their professional skills, have special knowledge of what it is like to live with major functional impairment(s). This support may be provided by e.g. a social worker, psychologist, physiotherapist, pre-school consultant, occupational therapist or dietician. Counselling and support is to be a supplement to, and not a replacement for measures such as habilitation, rehabilitation and social welfare services.

2. Personal assistance

Persons with major functional impairments and an extensive need of support and help in their daily lives may be entitled to personal assistance from one or more personal assistants. The municipality is financially responsible for those who need assistance for less than 20 hours a week.

A person, who needs personal assistance for his or her basic needs for more than 20 hours a week, may be entitled to assistance benefit. The right to this benefit is set out in LASS – the Assistance Benefit Act (1993:389). The Social Insurance Administration takes the decision regarding assistance benefit. The municipality is financially liable for the first 20 hours in such cases too. Personal assistance is to have been granted before the person has reached the age of 65, and the number of hours of assistance cannot be increased after his or her 65th birthday.

3. Companion service

Those not entitled to personal assistance may instead be entitled to companion service. The companion service is to be a personal service, adapted to individual needs, designed to make it easier for the individual to participate in the life of the community.

4. Personal contact

A personal contact is a companion who can help the individual to lead an independent life by reducing social isolation, helping him or her to take part in recreational activities and providing advice in everyday situations. This support can sometimes be provided by a family, known as a support family.

5. Relief service in the home

A relief service can be provided on a regular basis as well as for unexpected situations. It is to be available around the clock.

6. Short stay away from home

Short stays away from home are to provide the individual with recreation and a change of scene, while giving relatives a break. A short-term stay can be in a respite home, in another family or in another way, e.g. a stay at a youth camp or holiday camp.

7. Short period of supervision for schoolchildren over the age of 12

Schoolchildren over the age of 12, who are no longer covered by general child-care services, can receive supervision before and after the school day and during school holidays.

8. Living in family homes or in homes with special service for children and young persons

Children and young persons who cannot live with their parents may be entitled to live with another family or in a home with special service. This is to be a supplement to the parental home, both for children who can live with their parents

some of the time, and for those who cannot live with their parents at all.

9. Residential arrangements with special service for adults or other specially-adapted residential arrangements

These can be various arrangements but the most common types are group accommodation and service housing. The individual may also be entitled to specially-adapted housing to which they are referred by the municipality.

10. Daily activities

People of working age who have no gainful employment and are not participating in a course, are entitled to daily activities if they are part of groups 1 and 2 under the LSS.

Care – Recreation – Cultural Activities

Care is also included in the measures Relief Service, Short Period of Supervision, Short Stay Away from Home, and Living in Family Homes or in Housing with Special Service. Care entails that a person is provided with the support and help that he or she needs in daily life, and in order to feel safe.

Recreation and cultural activities are included in the measure Homes with Special Service for Children, Young Persons and Adults.

What Do the Measures Cost?

The special measures are in principle free of charge to the individual, with a few exceptions. A person entitled to assistance benefit from the Social Insurance Administration must pay the equivalent amount to the municipality if the municipality provides the assistance.

Someone living in residential arrangements with special service for adults may be charged reasonable fees for accommodation, recreation and cultural activities. Parents of children staying in family homes or in homes with special

service are to contribute to a reasonable extent to their children's clothing, recreational activities etc.

Influence and Co-Determination

Each individual is to have **as much** influence and co-determination as possible regarding the support provided under the LSS. The individual is to be provided with special measures only when he or she personally requests it. Someone under the age of 15 and who is clearly unable to take a position on the issue is to receive the measures when a guardian (up to and including age 17), trustee or administrator so requests.

Municipalities are also to collaborate with organisations representing persons with functional impairments.

Individual Plan

Someone receiving measures under the LSS is also entitled to request that an individual plan with approved and planned measures is drawn up in consultation with him or her. The plan is to be based on the individual's own wishes and can include a number of measures, provided by one authority or more. The municipality has a special responsibility for coordinating the measures described in the plan.

Right to Appeal

A person who is not satisfied with a decision on a measure under the LSS can appeal this in an administrative court of appeal, in the first hand the County Administrative Court.

Responsibility and Supervision

As a rule, the county council is responsible for the measure "Advice and Other Personal Support". The municipality is responsible for the other measures.

Under the LSS, the County Administrative Boards are the supervisory authorities in the counties for both municipal and individual measures, and are responsible for inspecting them. The County Administrative Boards also have a duty to provide information and advice to individuals and municipalities. They are to promote collaboration in planning between municipalities, county councils and other official bodies.

The National Board of Health and Welfare is responsible for central supervision of the application of the Act. The Board is to monitor, support and evaluate the activities, take initiatives for change and provide information.



The Prevalence of Impairments and Disabilities in Sweden

It is important for a number of reasons to be aware of how many people have an impairment; for example, when planning measures and outreach activities and when estimating costs. One reference often used in Sweden in these contexts is Statistics Sweden's (SCB) supplement to the regular Labour Force Surveys. The report issued in 2007 shows that about 919,000 people in Sweden between the ages of 16 and 64 have some type of impairment. This corresponds to about 16 per cent of the population in 2006. The estimate covers the following diagnoses/impairments:

Table 1. Total number of individuals with impairments in 2006 by gender and per cent of the population.

Impairment	Men	Female	Total
Asthma/allergy	18,5	21,8	20,2
Damp/ADHD/Aspergers	0,2
Diabetes	10,1	6,1	8,0
Dyslexia	6,8	4,5	5,6
Deafness	2,3	1,3	1,8
Epilepsy	1,5	1,2	1,3
Heart disease	6,9	3,8	5,2
Impaired hearing	10,7	6,7	8,6
Gastrointestinal disease	4,4	7,0	5,8
Pulmonary disease	1,6	1,6	1,6
Psoriasis	5,1	6,1	5,6
Psychiatric impairment	7,9	10,6	9,3
Intellectual impairment	0,7
Physical impairment	29,5	34,1	31,9
Speech disorder	0,9	0,6	0,7
Impaired sight/blindness	6,7	5,7	6,2
Other	5,0	10,1	7,7

From: Statistics Sweden's (SCB), Supplement to the Regular Labour Force Surveys (2007)

However, a disability is not only defined by the existence of an impairment; it also requires some sort of disabling barriers. Therefore, this is a relatively rough measure. The same report, however, notes that about 556,000 people have a reduction in their ability to work. This is equivalent to 9.5 per cent of the population in 2006.

Some Groups Are Not Included in the Statistics

The sample in the study is limited, which means that people with unusual, less well-known diagnoses are not represented at all. The same applies to people with multiple impairments.

Extensive Impairments

One group that is not paid much attention in the study is people with very extensive impairments. Another way of finding out how many of these people there are might be to look at how many people have been granted assistance benefit under the Assistance Benefit Act (LASS). This benefit is intended to pay for personal assistance for people with impairments who need another person's help for more than 20 hours a week. In 2006, this benefit was granted to 14,319 persons, which gives some idea of the size of the group. There are probably other persons with extensive impairments who do not have assistance for various reasons, however. For example, their impairments could be so extensive that they cannot live at home.



Where Do Children, Young People and Adults with Extensive Functional Impairments Live?

Sweden no longer has any institutions for people with functional impairments. There are, however, residential arrangements with special service, which are measures regulated in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS) as well as the Social Services Act (SoL).

Children and Young People

In modern-day Sweden, most children and young people with extensive functional impairments grow up with their parents and siblings. There are no institutions for children or young people with functional impairments. Those children and young people who cannot live in their parental home – either because of extensive medical needs or because they attend school in another area – can receive help under the measure known as *Living in Family Homes or in Homes with Special Service for Children and Young Persons* (Section 9 point 8 of the LSS). The measure is to be flexibly applied and should be adapted to the needs of the child and his or her family. In October 2006, about 150 children and young people lived in family homes and just over 1,000 children and young people lived in homes or in residential arrangements with special service. Residential arrangements with special service are designed like an ordinary home and are to function as much like a home as possible. A small number of children or young people live together in a fat or house, with round-the-clock support from staff.

Adults

Adults with functional impairments who need support and help can have a wide variety of residential arrangements. One

way is to live in their own home, like most adults. Individuals who need help and support in daily life can receive it through home help service, a service regulated in the Social Services Act. Home help service is provided to make daily living easier for the individual, and it includes service measures as well as personal care. Those who have a more extensive need of support and help can request the measure personal assistance (see separate information sheet).

Residential Arrangements with Special Service under the LSS

Residential arrangements with special service can be either group accommodation or service housing, and are located in ordinary housing areas – a block of flats or a house. The fat is the person's private home, and the staff providing service and support must be aware of the person's need of integrity and privacy, even though the person needs extensive help. The fat is to have all the facilities that you would find in an ordinary fat – rooms for socialising and sleep, a room or part of room for cooking, a toilet and shower/bath.

Almost 21,000 people, mostly people with intellectual disabilities, lived in residential arrangements with special service in October 2006.

Group accommodation contains a maximum of five or six connecting separate flats in ordinary residential areas. Adjacent to the individual fat are facilities for communal activities and staff on duty. Individual and collective help is to be provided, and varies according to the needs of the residents. Staff are generally available 24 hours a day. **Group accommodation** is the most common alternative

to the institutions which used to be the most common type of living arrangement for intellectually disabled people.

Service housing is available to people who want to lead more independent lives, regardless of their need of help and support. It consists of separate flats spread out in a larger area, such as a block of flats, and communal facilities are sometimes available here too. Both individual and collective support is provided. Staff can be available 24 hours a day.

A specially adapted private home has no staff, but the individual may receive

help from the home help service, companion service or through personal assistance.

According to follow-up studies, all of these types of housing are able to provide extensive and good-quality care, even to people with severe functional impairments. The aim in Sweden is that every individual should be able to move to a home of his or her own and live in it with proper individualised support. With adaptations and technical aids it is possible to make up for intellectual or physical disabilities.



Daily Activities

Work is an important factor for participation in the life of the community. A job does not only provide income, it also provides people with a social context and an opportunity for personal growth.

The goal of the Swedish labour market policy is that everyone should have a job. However, unemployment is higher among those with functional impairments compared to the average for people of working age.

Municipalities are responsible for ensuring that people with functional impairments who do not have a job are provided with a meaningful occupation or daily activities. This is regulated both in the Social Services Act (SoL) and the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS).

Daily Activities under the Social Services Act

Under the Social Services Act, the Social Welfare Board in a municipality is to ensure that those who encounter difficulties in their daily lives for physical, mental or other reasons are provided with meaningful occupations. Municipal measures may be of an overarching nature and can provide general support such as collaboration with the local business community and labour market authorities. The measures might also be individually based decisions on e.g. daily activities after an assessment of the individual's needs. The municipality might also be run as an open activity that the individual can participate in.

Daily Activities under the LSS

Daily activities under the LSS are measures to which people with intellectual disabilities, among others, have been entitled since 1968. The measure is primarily oriented towards people of working age who have no job or other meaningful occupation, and who are not participating in a training course or other type of education.

This measure can be granted to persons who have

- an intellectual disability, autism or a condition resembling autism
- a considerable and permanent intellectual impairment after brain damage as an adult caused by external force or physical illness.

An assessment is also carried out to determine whether the individual needs the measure. This need should not have been met in some other way.

Those who have applied for a measure under the LSS and had their application rejected can appeal the decision and have their right considered by a court of law.

In October 2006, almost 26,000 people took part in daily activities. In 1999, the same figure was just under 20,000.

People attending daily activities are usually recipients of a disability pension. They are sometimes also given a small amount of money each day when they work.

What the Daily Activities Consist of

The overall goal of the activities is to improve the individual's chances of getting a job. For some people with extensive functional impairments, it may not be possible to achieve this goal, so the goal might sometimes instead be to participate in a meaningful occupation during the day. The measure therefore covers both habilitation and more production-oriented activities, and is to

promote personal development and be adapted to the individual's wishes and needs.

The activity varies with the extent of the individual's needs and wishes, and with the different conditions in different municipalities. The activity can take place on special premises or at local businesses.



Personal Assistance and Assistance Benefit

Personal assistance is the service that has attracted most attention in the 1994 disability reform. For many people, this service is a symbol of the entire reform, because the purpose of the disability reform is the same as that of personal assistance – independence, self-determination, full participation and equality in living conditions.

The background to personal assistance was that persons with extensive need of support were not being provided with the kind of service they needed. There were many persons who had no influence whatsoever over the help they received in very intimate situations, and the help was often provided by a large number of different people coming and going in their home.

The idea of personal assistance is to provide support that is tailored to the individual as far as possible, and to optimise the person's influence over how the support is arranged. One way of achieving this is by giving the role of the assistant's supervisor to the person receiving assistance.

Personal assistance is regulated in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS).

The purpose of the assistance benefit is to make it financially possible for persons with severe disabilities to appoint a personal assistant, either on their own or through a provider.

Assistance benefit is regulated in the Assistance Benefit Act (LASS).

Who Is Entitled To Personal Assistance?

Not everyone entitled to support and service under the LSS is entitled to personal assistance or to assistance benefit.

There are certain conditions that make an individual eligible for personal assistance. These conditions are that the person must need personal assistance for certain basic needs in daily life, such as help with personal hygiene, dressing and undressing, eating, communicating with others, or other assistance that requires detailed knowledge of the person's specific functional impairment.

If someone needs assistance with these fundamental needs for more than 20 hours a week, he or she is also entitled to assistance with other things in daily life, such as going shopping, going to the cinema, and during holiday trips.

Children as well as adults can have personal assistance. Individuals must be younger than 65 years old when receiving assistance for the first time. When they are 65 or older, they can keep the same number of hours that they were granted, but the hours may not increase. Those who need more help as they grow older, can be provided with this through the home help service.

What Is the Personal Assistant Supposed To Do?

A personal assistant could be described as a human aid who is to do all that a person is unable to do due to his or her functional impairment. The personal assistant can make up for a lack of mobility, loss of sight or intellectual impairment. The assistance is to be provided in many different situations and places, and by a limited number of persons. The person receiving assistance has the right to decide what the assistant should do, when and how.

The personal assistant is to assist with basic needs in the person's home, but also to be of help in the community, while go-

ing shopping, to the cinema, at work, when meeting relatives and friends, on holiday etc. The assistance has to be provided where the recipient is located.

Divided Responsibility for Personal Assistance

The responsibility for personal assistance and assistance benefit is divided between local government (the municipality) and central government, in this case represented by the Social Insurance Administration.

The Social Insurance Administration makes decisions regarding assistance benefit if a person needs personal assistance for his or her basic needs for more than 20 hours a week. If a person needs assistance for 20 hours per week or less, the decision is made by the municipality.

How Many Hours a Day Can a Person Have Personal Assistance?

Assistance benefit is granted in the form of a number of assistance hours that the person may use within a certain period of time. Assistance benefit is to be provided according to the number of hours required for a person to have his or her ba-

sic needs met, as well as for other personal support.

There is no ceiling, i.e., theoretically, the number of hours can be unlimited, since persons with severe injuries or impairments may need more than one assistant at the same time. There are persons who have personal assistance 24 hours a day, enabling people with severe impairments to live on their own.

How Can the Assistance Be Organised?

The law has been framed to give persons receiving assistance considerable influence over how the support is to be provided.

The assistance benefit can be paid directly to persons with functional impairments, so that they can employ one or several assistants themselves.

The person with functional impairment can obtain the service from the municipality, an assistance company or a co-operative. If the person with functional impairment is the employer, he cannot employ someone in his own family that he lives with. If, for example, a woman wants her husband as her personal assistant, she must ask the municipality, a company or a co-operative to employ her husband as a personal assistant.



People with Intellectual Disabilities

Activities for people with intellectual disabilities used to be administrated by the county councils through a special organization separated from health- and medical care and in close cooperation with the municipalities. By the end of the 1980s, the municipalities started to take over the responsibility for these activities from the county councils. [In the process,] both the responsibility and these activities were decentralized.

There were several reasons for this extensive change. Several laws geared at this specific group together formed a continuous and strong support for this development. The legislation was strongly influenced by the normalisation ideology that characterised the development of the time. At this time, the parents' organisation (FUB) also grew rapidly, both on a national and a local level. It became an important lobbying organisation that promoted the prioritisation of activities for people with mental disabilities both nationwide and locally. Until 1995, the Board was a supervisory authority and conducted very active supervisory activities/supervisions both of the institutions and other activities and this strongly contributed to the decentralisation of the care of those with mental disabilities. Currently, the County Administrative Boards are responsible for this supervision. Another important catalyst for this development was the research conducted concerning handicap issues. [In addition thanks to this research, the development could be continuously evaluated.

Nursing Homes and Special Hospitals Are Deconstructed

During the 1980s, the institutions were beginning to be shut down. At their peak, about 14,000 children, youth and adults were living at various nursing homes in

Sweden. Today, all of them have moved to homes integrated in the community. In many cases this meant that these people moved to the municipality in which they had been born or where their relatives lived, or simply the municipality in which they wanted to live. Evaluations of this deconstruction of the institutions show that it has been beneficial not only for the intellectual disabled persons themselves but also for their relatives and staff.

Today, most people who have an intellectual disability receive support in accordance with the special civil rights law, the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). In Sweden, about 36,000 intellectual disabled persons receive support through LSS. This corresponds to c. 0.4 percent of the population. Over 17,000 of these are children and youth and about 32,000 are adults under the age of 65. Over 40 percent are women.

Daily Activities and Housing in the Community

Children with intellectual disabilities receive childcare through the ordinary childcare services, like any other child. Those who have reached school age attend a special class for those with learning disabilities. These classes are integrated in the ordinary schools. In order to allow the parents time off, there are short-stay homes for their children and also the possibility to get relief in their homes. For children and adults in need of expert help there are habilitation and rehabilitation resources, professionals with extensive knowledge of intellectual disabilities, autism, etc. Today, about 19,000 adults with mental disabilities live in their own homes, in group homes or independ-

ently with, for example, personal assistance. The group homes are located in blocks of flats, row houses and independent houses. An alternative to this is a number of flats located in the same block of flats, with one apartment set aside for the staff and as a meeting place for those who live in the building.

Daily activities are provided in the town or part of town where the person with intellectual disabilities lives. Previously, these activities were often located

at special day centres, but today they are increasingly being integrated into ordinary workplaces. Individuals or small groups of people participate in, for example, service or production, often with personal support in the workplace. Almost all adult persons with intellectual disabilities take part in this type of activities, which amounts to c. 22,000 people. People with intellectual disabilities can also have a salaried position, but, unfortunately, this is uncommon.



Care and Support for People with Mental Illness or Disabilities in Sweden

In Sweden the prevalence of mental illness or mental disorders is equal to that of many other European countries. Table 1 below presents some of the most common psychiatric disorders in the total population which have been estimated from epidemiological research carried out in Sweden and in other European countries.

Table 1. Estimated point-prevalence of psychiatric disorders in the total population of Sweden.

(The range may depend on differences between sex, urban-rural locations etc.)

Diagnosis/diagnostic related conditions	Percentages
Neuroses/anxiety	8–10
Depression	3–5
Psychoses (total)	1–1.5
Schizophrenia	0.5
Long-term mentally ill/disabled people ¹	0.6–1.0
Substance abuse	5–7
All psychiatric disorders ²	13–15

¹ For whom psychiatric care and/or social services are responsible for treatment and social support.
² In need of psychiatric treatment.

Care and Support

The health care system of Sweden is supported and governed through three political levels – the State (Central Government), the Counties and the Municipalities. *The Central Government* is responsible for legislation within the health care system, higher education (universities), research funding (see paper about research) and the health insurance system, which includes disability pensions for long-term mentally ill persons, and general and directed subsidies to counties and municipalities to help them carry out

different public service measures. *The Counties* (21 in total) are responsible for the operative specialised health care activities, for mentally and/or somatically ill people, which include hospitals and primary health care (GPs) and the medical professions working there. *The Municipalities* (290 in total) are responsible for social services for elderly and disabled persons, including mentally disabled persons. This includes social support, rehabilitation measures and medical nursing treatment. These responsibilities were determined/settled in the Social Services Act of 1982.

Between 2–5 percent of the total population seeks psychiatric care over the period of one year. Most of those seeking treatment come from urban areas. In recent years the increase has been substantial for younger people and those with substance abuse.

Long-term mentally ill persons are taken care of both by psychiatric care organisations and social services agencies. A survey in 1997 found that about 43,000 persons were included in that target group (0.5 percent of the total population).

Costs

The costs for medical care in Sweden, which is paid for by the counties, are € 16,7 billion/year(2005), which is nearly 10 % of the GDP. The net expenditure for psychiatric care for the Counties is about € 1.6 billion/year. Unfortunately, it is impossible to separate costs for mental care within the social services from other costs. An investigation in 1997 aimed at determining all community costs for all mental disorders estimated these costs to be € 5.5 billion/year.

The Development of Care and Support for Mentally Ill Persons

In 1967 the responsibility for the mental hospitals was transferred from the State to the Counties. At that time there was a capacity to treat about 35,000 patients (4 patients/1,000 inhabitants) and 70 percent of that capacity was located at mental hospitals. The closing of the mental hospitals continued from the later part of the 60s to the mid90s. Today (2007), there are no mental hospitals left in Sweden, but psychiatric wards in general hospitals have the capacity to receive 4 800 patients (0.5 patients/1, 000 inhabitants) in total.

The decrease of beds available for psychiatric patients, long-term mentally ill persons in particular, at hospitals has been met by an increase of housing alternatives provided by the social services.³ Almost the same numbers of people were institutionalised during the period between 1994 and 2002 as in previous years, but the institutions within the social services are usually more homelike than former psychiatric in-patient institutions. The development of this shift is shown in fig. 1.

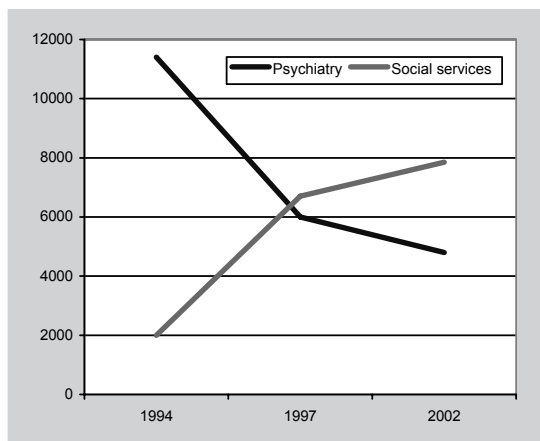


Fig. 1. Number of people in night- and day-care institutions within psychiatric care and social services in 1994, 1997 and 2002.

In the beginning of the 70s Sweden reconstructed its adult psychiatric care organisation. Influenced by the Community

Mental Health Program in the US, out-patient services were established throughout Sweden. This reconstruction programme - the so-called "sectorisation" of the psychiatric organisation - was accomplished in 1985. At that time, Sweden was divided into some 135 catchment areas, every area served by a clinic which had (and has) the responsibility for all out-patient services, based on some 600 out-patient receptions as well as in-patient (hospital) services. Due to rationalisation and large-scale thinking the number of clinics now (2006) has decreased to some 100.

A special governmental investigation and evaluation of the conditions of long-term mentally ill persons in particular conducted in the beginning of 1990 concluded that the care and social support for these persons were not sufficiently realised. Neither the psychiatric care nor the social services fulfilled their commitment to give proper care and support to the target group. A proposal was made which entailed a reformation of the measures for the target group, including changes of the current legislation and an introduction of some new laws. In 1995 changes in the law together with economic reinforcement directed to the target group constituted what was named the *Community Mental Health Care Reform*.

The aim of the reform was to bring home to the local community persons that had been treated for a long time in psychiatric hospitals and nursing homes (about 3 000 persons) and to force social services agencies and psychiatric units to co-ordinate their efforts for these people. Also, the social services were supposed to be responsible for the support of all long-term mentally ill persons in the community with housing, daily activities and rehabilitation.

Investigations showed that the reform process was not satisfactory. Again, the government decided to reinforce the process by directing grants to the psychiatric care organisation and the social services. In 2004, a special co-ordinator was given the task to stimulate measures for persons with long-term mental illness during 2004

³ E.g. nursing homes, supported living.

– 2006.. The National Board of Health and Welfare is responsible for supporting the social services and psychiatric care in their efforts directed to long-term mentally ill people as well as other psychiatric patients during the years 2007 – 2010.

Legislation Concerning Mentally Ill Persons

The *Swedish Disability Act (1994)* aims to give support and service to people with disabilities, including those with disabilities due to psychiatric disorders. The law states a number of specific forms of measures that people with disabilities can receive, including counselling and support, personal assistance, housing with special services personal, contact service and companion. The act complements other legislation and may not entail any curtailment of assistance to which the individual is entitled under other laws. Moreover, it is a civil rights law and decisions can therefore be appealed in the administrative courts.

The *Health Care Act* regulates the care of persons in need of medical or psychiatric treatment, either by nurses in sheltered

homes within social services or by specialised psychiatric care in these homes or in clinics.

The *Social Services Act* stipulates that it is the duty of the municipal social services to conduct outreach activities among people with psychiatric disabilities. Social services are also responsible for planning their assistance programmes for these people in collaboration with the psychiatric care organisation and other social bodies and organisations.

The *Municipal Financial Responsibility Act (1995)* states that it is the responsibility of the municipalities to pay for the care of patients who, after three consecutive months of in-patient treatment by a psychiatrist, have been deemed as fully medically treated within the psychiatric in-patient system but are still being cared for in hospital because they cannot be transferred into community-based independent living or sheltered housing. One of the aims with the municipal financial responsibility is to stimulate the development of new forms of housing within the community for people with mental disabilities who have been under long-term institutional care.



Transport Service and Inter-municipal Transport Service

Transport service is a form of transportation that is supposed to complement public transportation. This is a service for those who have extensive difficulties getting around on their own or travelling by public transportation. The journeys can be made by taxi or in specially adapted vehicles.

Inter-municipal transport service is a form of transportation that primarily involves journeys between different municipalities. A journey by inter-municipal transport service is usually made with regular forms of transport, such as airplane or bus, with or without a companion. In some cases the entire trip can be made by taxi or in a specially adapted vehicle. The inter-municipal transport service should reimburse any additional costs for persons with extensive functional impairments.

The municipality in which the individual is listed as a resident issues per-

mits for travels by transport service and/or inter-municipal transport service. The municipality may also delegate this task to the authority responsible in the county.

The executive officer analyses the needs of the individual in question. In order to be granted transport service a person should have considerable mobility problems or problems travelling by public transportation due to a functional impairment that is not temporary.

If the applicant is under the age of 18 the inquiry should include a comparison with children of the same age who do not have a functional impairment. If the applicant for transport service needs a companion during his or her trips, the permit should include the companion as well.

Those travelling by transport service should pay a fee corresponding to normal expenses when travelling by public transportation.



Habilitation, Rehabilitation and Technical Aids

The aim with habilitation and rehabilitation is that persons with functional impairments should be able to live a self-determining and, as far as possible, independent life on the same premises as other people. Habilitation and rehabilitation are usually used as umbrella terms for all medical, psychological, social, technical, pedagogical and work-related measures that can be taken to support those who are ill or injured, in order to help them develop or regain as much of their functional abilities as possible and, thus, create the necessary conditions for a good life.

Duty to Offer Measures

According to the Swedish legislation regarding medical care, habilitation, rehabilitation and technical aids are part of the responsibility that the county councils and municipalities have for health- and medical care. This responsibility involves a duty to offer measures from different areas of competence as well as different activities to those in need of them. The process of habilitation and rehabilitation may involve medical, social, psychological, and pedagogical assessments and treatment. The measures may consist of assessments of functions and functional training, but may also involve support to help individuals learn new strategies and/or receive technical aids and instruction in how to use them. Supporting relatives and collaboration with other organisations inside and outside of the medical field, such as school, the social insurance agency and the employer are other important parts of the work.

Interdisciplinary Collaboration

Several different professionals with different specialities work together focusing on the needs of the person with disabili-

ties in order to provide comprehensive support based on a holistic perspective. In other words, this is a cross-disciplinary collaboration where co-workers with different specialities work toward a common goal and with a common follow-up and evaluation. Some examples of the different professionals involved in this work are occupational therapist, welfare officer, speech therapist, physician, psychologist, physiotherapist, nurse and remedial teacher. This work should be conducted in close collaboration with the person with disabilities. Follow-ups and evaluations should be conducted regularly and should be the base for future planning.

A Comprehensive Assessment

Technical aids play an important role in habilitation and rehabilitation. In order for these aids to be useful, it is necessary to make a comprehensive and competent assessment of the entire life of the person with disabilities and it is also crucial that the need of technical aids is related to other rehabilitation measures.

Coordination Necessary

Habilitation, rehabilitation and the use of technical aids should be planned in collaboration with the person with disabilities and when measures have been planned and a decision has been made to use them, they should be documented in a special plan. The purpose is to coordinate the different habilitation-, rehabilitation-, and aid measures that the individual is in need of.

High-Cost Protection

For measures within health- and medical care there is a high-cost protection system (the individual does not have to pay

more than a specified sum per year), which also includes habilitation and rehabilitation. Technical aids, however, are not included in the high-cost protection and the costs for the individual depend on which county council the individual belongs to.

The Difference between Habilitation and Rehabilitation

The difference between habilitation and rehabilitation is that habilitation is geared towards persons with functional impairments that are due to inborn or early ac-

quired injuries and/or illnesses. The purpose of it is to widely promote the development of the best possible functional ability to the person with disabilities. The purpose of rehabilitation, on the other hand, is to holistically help the person with disabilities to regain the best possible functional ability, as well as psychological and physical well-being, when he or she has an impairment or loss of some functional ability due to an injury or illness. The aim of both habilitation and rehabilitation is to prevent and reduce the difficulties that functional impairments may cause in daily life.



The Cost of Services for persons with Disabilities

People with functional impairments or long-term illness are entitled to help under the Social Services Act (SoL) and the Health and Medical Services Act (HSL). These laws primarily provide for home help measures or special housing. People with major, permanent functional impairments are also entitled to special measures under the Act concerning Special Support and Service to Persons with Certain Functional Impairments (LSS). The goal is to make daily life easier for people with extensive functional impairments and promote full participation in the life of the community.

The municipalities are responsible for most measures under the SoL, HSL and LSS. Central government has main responsibility for costs under the Assistance Benefit Act (LASS).

The municipalities' overall operational costs for care of persons with disabilities in 2006 amounted to SEK 36.1 billion (3.9 billion Euro) (Table 1). Most of this, 80 per cent, was the cost of measures under the LSS and the municipalities' share of the costs of the LASS. Twenty per cent of costs for care of the disabled are for measures provided under the SoL and HSL. Outside the social services, there are also costs for municipal and national transport services, that 2006 has been calculated to approximately SEK 350 millions (38 million Euro). In addition to the above the central government has costs for the LASS.

Table 1. Municipal costs¹ for help to people with functional impairments and for local and national transport services, 2006.

Area of operation	SEK billion	Share of total costs (%)
Measures under the SoL and HSL	7.1 (0.77 Euro)	20
Ordinary housing	3.9 (0.42 Euro)	11
of which home help	2.6 (0.28 Euro)	7.2
Special accommodation	2.7 (0.29 Euro)	7.5
Open activities	0.5 (0.05 Euro)	1.4
Measures under the LSS and LASS	29.0 (3.1 Euro)	80
Housing with special service	15.1 (1.6 Euro)	42
Daily activities	4.6 (0.50 Euro)	13
Personal assistance	5.6 (0.61 Euro)	16
Other activities under the LSS	3.7 (0.40 Euro)	10
Total	36.1 (3.9 Euro)	100
Municipal and national transport services	0.35 (0.038 Euro)	100

¹ Gross costs minus the following items: internal revenue., sales revenue from other municipalities and county councils and compensation from the Social Insurance Administration for LASS.

Source: Statistics Sweden Municipal use of resources 2006.

Services for persons with disabilities is the municipal activity that is growing fastest and consuming more and more resources. Since the turn of the century, services for persons with disabilities has increased its share of municipal resources from 8.9 per cent in 2000 to 11.0 per cent in 2006. In a national perspective, services for persons with disabilities is 1.6 per cent of GDP. This proportion has been rather steady since 2003.



The Development of Disability Policies in Modern-Day Sweden

During the past 50 years, the development of Swedish disability policies has been connected to that of welfare policies. As a result of this connection, Swedish disability policies have also been linked to distribution policies. Since social insurance and health- and medical care, for instance, are public and connected to citizenship, the risk of people being excluded from the social security systems has decreased. Another important perspective - for those with disabilities is that support is provided based on needs, not income. These facts that the distribution of aids is based on needs means, for example, that an individual will be provided with the wheelchair he needs, which means that the aids can be quite advanced.

Rehabilitation Becomes Important

Since Sweden did not take part in World War II, its production industry remained intact. The technical and medical development, together with public efforts, paved the way for new possibilities for people with disabilities. For example, during the 50s rehabilitation gained ground. This was due to the fact that technical aids were developed and also that efforts were made to provide jobs on the regular job market. The major breakthrough for the creation of national/progressive labour policies did not, however, occur until the 1960s. One important reason for this breakthrough was that labour policies were linked to financial policies. As a result, labour policies and vocational training became important tools for creating mobility on the labour market, also for people with disabilities. Labour market issues were also crucial in initiating

the collaboration of the disability organizations.

Linking Handicap to Environment

Traditionally, the situation for people with intellectual disabilities has been viewed mainly from a medical perspective and it has thereby been connected to the physical condition of these individuals. Sweden became influenced by the new view of disabilities that was gaining ground. In the 70s, the environmentally-based concept of handicap got its breakthrough. This was a definition that emphasized the importance of the surrounding environment for the occurrence of disabilities. The term handicap was no longer to be linked solely to individuals but should instead take into account the difficulties those persons encounter in their daily lives, due to physical or psychological reasons. In other words, handicaps occur in relation to the problems the environment may cause for those with disabilities. In this way, the term “handicap” becomes related to the environment and also connected to politics, as political decisions regarding the shape of society can prevent handicaps from occurring. Today, the term handicap is beginning to disappear and is being replaced by the term disability.

The Dismantling of the Institutions

During the 60s, the existence of the institutions was starting to be questioned and normalisation and integration were the main goals. Many people with severe disabilities, mainly those with intellectual disabilities or mental illnesses, used to

live in institutions. In the 1960s there were approximately 14,000 spots available for people with intellectual disabilities and about 36,000 spots at closed facilities for those with mental illnesses. Today, no people with intellectual disabilities live in institutions and there are about 5,000 spots left at closed facilities for people suffering from mental illnesses.

The development of individual measures has been prioritised in Swedish handicap care, while the general adaptation of society has not been very prominent so far. Today, we have human rights legislation concerning individual measures and a major effort regarding the general measures has recently been launched through a national action plan.



The Assistance Benefit Act (1993:389)

Swedish Code of Statutes SFS 1993:389

Issued:
27 May 1993

Updated:
Up to and including SFS 2007:203

Introductory Provisions

Section 1 This Act contains regulations relating to benefit out of public funds for persons with certain functional impairments for the cost of personal assistance (assistance benefit).

Section 2 Issues concerning assistance benefit are dealt with by the Swedish Social Insurance Agency.

The Social Insurance Act (1999:799) contains provisions regarding who is covered by this Act. The Social Insurance Act also contains provisions concerning benefits when staying abroad and notification, etc. Act (2004:827).

Assistance Benefit

Section 3 Anyone covered by Section 1 of the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments is entitled, except in cases such as are referred to in Section 4, to receive assistance benefit pursuant to this Act for her or his daily life if he or she needs personal assistance for her or his basic needs for an average of more than 20 hours per week.

Assistance benefit will be provided for a period after when the person entitled to benefit has attained the age of 65 only if

1. benefit has been granted before he or she attained the age of 65, or
2. the application is received by the Social Insurance Agency no later than the date prior to the 65th birthday and is thereafter granted.

The number of assistance hours may not be extended after the person entitled to benefit has attained the age of 65.

Personal assistance in this Act means the same thing as in Section 9 a of the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments. Act (2004:827).

Section 4 Assistance benefit is not to be provided for the time when the person with a functional impairment

1. is cared for in an institution which is owned by the central government, a municipality or a county council,
2. is cared for in an institution which is funded by grants from the central government, a municipality or a county council,
3. lives in a group home, or
4. is staying in or participates in child care, school or daily activities pursuant to Section 9, subsection 10 of the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments.

If there are special reasons, assistance benefit can also be provided for a period when a person with a functional impairment is being cared for short-term at a hospital or participates in activities according to the first paragraph, subsection 4.

Assistance benefit is not provided for nursing measures under the Health and Medical Services Act (1982:763). Act (1996:535).

Applications, Decisions and Related Matters

Section 5 An application for assistance benefit shall be made in writing to the Social Insurance Agency.

If anyone has applied to a municipality for help by a personal assistant or financial support for such assistance pursuant to the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments, the municipality shall notify the Social Insurance Agency if the individual concerned can be presumed to be entitled to assistance benefit. In such a case, the Social Insurance Agency shall consider the issue of assistance benefit even without an application.

Assistance benefit may not be provided for a longer period back than one month before the month when the application or notification was made. Act (2005:332).

Section 6 Assistance benefit shall be granted for a certain number of hours a week, month or longer period, although at most for six months, when the individual is in need of personal assistance in her or his daily life (approved assistance hours).

The Government or the authority appointed by the Government issues additional regulations concerning the calculation of assistance benefit. Act (1996:535).

Section 7 The entitlement to assistance benefit of a person who receives such benefit shall be reviewed after the passing of two years after the issue of entitlement to benefit was most recently considered and whenever the circumstances have changed significantly.

For a person who receives assistance benefit after he or she has attained the age of 65, reconsideration may only be conducted in the event of a fundamental change of circumstances.

A change in the assistance benefit in the event of essentially changed circumstances shall apply from the beginning of the month when the reason for the change occurred. Act (2000:1031).

Section 8 If it cannot be decided without a substantial delay whether a person is entitled to assistance benefit but there are probable grounds for such entitlement, the Social Insurance Agency shall decide that a reasonable amount of benefit shall be paid if this is of essential importance for the person with a functional

impairment. The same applies if it is evident that a person is entitled to assistance benefit but that the amount of benefit cannot be decided until after a substantial delay. Special conditions for such benefit may be laid down.

If it is decided later that assistance benefit is not to be granted or that a smaller sum shall be granted, the person entitled to benefit is not liable to pay back the benefit paid in cases other than those referred to in Section 16. Act (2004:827).

Section 9 Anyone who receives assistance benefit, if her or his circumstances change in such a way that entitlement to the benefit is affected, shall immediately notify the Social Insurance Agency of this change.

If the person in receipt of assistance benefit has a legal representative by virtue of the Parental Code, the legal representative is responsible for making this notification instead. Act (2004:827).

Payment

Section 10 Assistance benefit shall be paid monthly, in an amount corresponding to the number of approved assistance hours for which assistance has been provided. The assistance benefit shall be paid in the amount per hour determined by the Government for each year.

If there are special reasons, the Social Insurance Agency may, following an application, decide that a person entitled to benefit should receive benefit of a greater amount than determined by the Government. However, this amount may not exceed the amount determined by more than twelve per cent.

Payments that the individual personally makes shall not in any case be regarded as a cost for personal assistance,

1. to anyone with whom he or she lives in a common household, or
2. to a personal assistant for work that is performed during working hours that exceed the time referred to in Sections 2–4 of the Working Hours, etc. in Domestic Work Act (1970:943).

Payment of assistance benefit for a particular amount may be based on an estimated number of assistance hours for that month. A settlement for major deviations shall then be made no later than in the second month after that in which the preliminary payment was made. A final settlement shall be effected no later than two months after the end of each period of time for which assistance benefit has been granted. Act (2004:827).

Section 11 If a municipality provides the person entitled to benefit with help by a personal assistant, the Social Insurance Agency may decide that the assistance benefit shall be paid to the municipality to the extent that the benefit corresponds to the municipality's charge for assistance. Act (2004:827).

Section 12 If as a consequence of infirmity due to old age, decease, the prolonged abuse of addictive substances or for some other similar reason, the person entitled to benefit is not capable of dealing with the assistance benefit her- or himself, the Social Insurance Agency may decide that the benefit shall be paid to a municipal authority or to some other person to be used to defray the cost of personal assistance to the person entitled to benefit. Act (2004:827).

Routines and related matters

Section 13 Issues such as are referred to in Sections 6-8 shall be determined in the Social Insurance Agency by the social insurance committee. However, the committee may transfer powers to make decisions to an officer at the Social Insurance Agency pursuant to Section 8. Act (2004:827).

Section 14. The municipality in which the person who applies for, or receives, assistance benefit is a resident shall, if this is necessary, be questioned about the matter pursuant to this Act.

Section 15. The municipality in which the individual concerned lives shall be notified of a decision relating to assistance benefit and of a decision pursuant to Sections 11 and 12.

Repayment

Section 16 The Social Insurance Agency shall decide on the repayment of assistance benefit if the person who has received benefit or her or his deputy has supplied erroneous information or has failed to carry out her or his obligation to make a return or to give notification or in some other way has caused the benefit to be provided incorrectly or in excess. The same shall apply if the benefit for other reasons has been provided incorrectly or in excess and the person who has received the benefit or her or his deputy reasonably should have realised this. If there are special reasons, the Social Insurance Agency may waive the requirement for repayment entirely or partly.

When a payment is made later to someone who shall pay back the benefit pursuant to the first paragraph, the Social Insurance Agency may keep back a reasonable sum as a deduction for what has been given in excess. Act (2004:827).

If a person who is supposed to repay money according to the first paragraph has met an agreement with the Social Insurance Agency about a payment plan or has been given an extension regarding the money owed, interest shall be added to the sum in question. The interest shall be calculated according to an interest rate that is always two per cent higher than the lending rate of the Government. The interest shall be calculated from the day when the agreement about a payment plan was met or when the extension was given, but not for the time prior to when the money should have been repaid.

If a sum of money that has been reclaimed according to the first paragraph is not repaid in time, a penalty interest shall be added to said sum. Regarding the application of penalty interest, relevant sections of the interest law shall be employed.

If there are special circumstances, the Social Insurance Agency may entirely or in part waive its claim for interest according to the third and fourth paragraphs. Act (2007:203)

Appeals and Related Matters

Section 17 The provisions of Chapter 20, Sections 10-13, of the National Insurance Act (1962:381) regarding the reconsideration and alteration of a decision by the Social Insurance Agency as well as an appeal against a decision by the Social Insurance Agency and a court shall be applied in matters relating to assistance benefit.

A decision on a matter relating to assistance benefit shall apply immediately unless something else is indicated in the decision. Act (2004:827).

Other Provisions

Section 18 In regard to benefit by virtue of this Act, the following regulations contained in the National Insurance Act (1962:381) shall be applied, namely

Chapter 20, Section 3, third paragraph regarding withdrawal or reduction of benefit,

Chapter 20, Section 5, regarding limitation of time,

Chapter 20, Section 6, regarding prohibition of attachment and of transfer,

Chapter 20, Section 8, first-third paragraphs and Section 9 regarding the liability to make returns,

Chapter 20, Section 8, fourth paragraph regarding investigation measures.

Act (2004:827).

Section 19 For anyone who has been granted personal assistance under this Act, the municipality where the person entitled to benefit is resident, shall compensate the costs for the first 20 assistance hours per week. Act (1997:722).

Section 20 When a person has been granted assistance benefit according to Section 6, the Social Insurance Agency will notify the municipality where the person entitled to benefit is resident of the decision and the amount that the municipality shall pay. The municipality shall also be notified about changes to the decision provided these are of significance to the municipality's payment obligation.

The municipality shall each month pay the specified amount to the Social Insur-

ance Agency. The municipality is entitled to gain access to the final statement to be made according to Section 10. If the municipality has paid an excessive amount of benefit the excess amount shall be repaid to the Social Insurance Agency. Act (2004:827).

Transitional Provisions

1996:535

1. This Act enters into force on 1 July 1996.
2. Decisions on assistance benefit that were made prior to 1 July 1996 may, notwithstanding the provisions of Section 7, be reconsidered by the Social Insurance Agency without two years having elapsed since the issue of the entitlement to benefit was last considered.

1998:100

This Act enters into force on 1 July 1998. As regards the reconsideration of a decision that was made prior to the entry into force, Section 17 applies as formerly worded.

1999:819

1. This Act enters into force on 1 January 2001.
2. Older provisions shall still be applied to issues concerning assistance benefit for the period preceding entry into force.

2000:1031

1. This Act enters into force on 1 January 2001.
2. A person who prior to 1 January 2001 has received assistance benefit under this Act but for whom the benefit has ceased owing to that he or she has attained the age of 65, is entitled following a new application to once again receive benefit at the earliest from 1 January 2001. The benefit shall be based on the decision that applied immediately prior to the 65th birthday. Such an application shall have been received by

the Social Insurance Agency no later than by 31 December 2002.

2004:644

This Act entered into force on 1 July 2004. Older provisions shall still apply to applications or notifications that were made prior to the entry into force.

2004:827

1. This Act enters into force on 1 January 2005.
2. As regards reconsideration or appeals against decisions that have been made by a social insurance agency the provi-

sions prescribed by item 4 are employed and transitional provisions to the Act (2004:781) amending the National Insurance Act (1962:381). Moreover, the provisions contained in item 5 of the same entry into force and transitional provisions concerning rejection decisions have been issued by a social insurance agency.

2005:332

This Act enters into force on 1 July 2005. Older provisions still apply for applications or notifications that were made prior to its entry into force.



Act (1993:387) Concerning Support and Service for Persons with Certain Functional Impairments

Swedish Code of Statutes SFS 1993:387

Issued:

27 May 1993

Updated:

Up to and including SFS 2008:77

Introductory Provisions

Section 1 This Act contains provisions relating to measures for special support and special service for

1. persons with an intellectual disability, autism or a condition resembling autism
2. persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness
3. 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.

Section 2 Unless agreed otherwise pursuant to Section 17, each county council shall be responsible for measures pursuant to Section 9, subsection 1.

Unless agreed otherwise pursuant to Section 17, each municipality shall be responsible for measures pursuant to Section 9, subsections 2-10. Act (2005:125).

Section 3 What is prescribed for county councils in this Act also applies to municipalities that are not included in any county council.

Section 4 This Act does not constitute any infringement of the rights which an individual may have by virtue of any other Act.

The Objectives and General Orientation of the Activities

Section 5 The activities pursuant to this Act shall promote equality in living conditions and full participation in the life of the community for those persons referred to in Section 1. The objective is to make it possible for the individual in question to live as others do.

Section 6 The activities pursuant to this Act shall be of good quality and be conducted in cooperation with other relevant official bodies and authorities. The activities concerned shall be based on respect for an individual's right to self-determination and privacy. As far as possible, it shall be ensured that the individual concerned shall be allowed to influence and jointly determine the measures to be provided. The quality of the activities shall be systematically and continuously improved and assured.

For the activities pursuant to this Act, the necessary staff needed to enable good support and good service and care shall be provided. Act (2005:125).

Eligibility for Measures

Section 7 Persons who are referred to in Section 1 are eligible for measures in the form of special support and special service pursuant to Section 9, subsections 1-9, if they need such assistance in their daily lives and if their needs are not satisfied in some other way. Persons who are referred to in Section 1, subsections 1 and 2, are also entitled, if the prerequisites are the same, to measures pursuant to Section 9, subsection 10.

The measures shall ensure that an individual shall have good living conditions. The measures shall be continuous and

co-ordinated. They shall be adapted to the individual needs of the recipient and be framed in such a way that they are easily accessible for those who need them and enhance the ability of the latter to live an independent life. Act (2005:125).

Section 8 Only if he or she so requests, shall an individual be provided with the measures pursuant to this Act. If the individual concerned is under the age of 15 or manifestly lacks the ability to form an opinion on the matter, a person having custody, a personal representative, legal guardian or trustee may request the measures on her or his behalf.

Measures for Special Support and Special Service

Section 9 The measures for special support and special service are

1. counselling and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and lasting functional impairments,
2. help from a personal assistant or financial support for reasonable costs for such help to the extent that the need for financial support is not covered by assistance hours pursuant to the Assistance Benefit Act (1993:389),
3. companion service,
4. help from a personal contact,
5. relief service in the home,
6. short stay away from the home,
7. short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,
8. arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home,
9. residential arrangements with special service for adults or some other specially adapted residential arrangements for adults,
10. daily activities for people of working age who have no gainful employment nor are undergoing training. Act (1997:723).

Section 9 a Personal assistance pursuant to Section 9, subsection 2 refers to personally designed support that is provided by a limited number of persons for anyone who owing to major and lasting functional impairments needs assistance with her or his personal hygiene, meals, dressing and undressing, communicating with others or other help that requires extensive knowledge about the person with a functional impairment (basic needs).

Anyone who needs personal assistance for her or his basic needs is also entitled to measures pursuant to Section 9, subsection 2 for other personal needs if these needs are not satisfied in any other way.

Payments that the private individual personally makes shall not in any case be regarded as a cost for personal assistance pursuant to Section 9, subsection 2,

1. to anyone with whom he or she lives in a common household, or
2. to a personal assistant for work that is performed during working hours that exceed the time referred to in Sections 2-4 of the Working Hours, etc. in Domestic Work Act (1970:943). Act (2000:1030).

Section 9 b Measures pursuant to Section 9, subsection 2 refer to the time after the person entitled to the measures has attained the age of 65 only if

1. the measure has been granted before he or she attained the age of 65, or
2. an application for such a measure is received by the municipality no later than on the date preceding the 65th birthday and has thereafter been granted.

However, measures pursuant to Section 9, subsection 2 may not be extended after the person entitled to the measure has attained the age of 65. Act (2000:1030).

Section 9 c Care is also included in the measures pursuant to Section 9, subsec-

tions 5-8 and 10 and also the measure Residential Arrangements with Special Service for Adults. Recreational and cultural activities are also included in the measures Residential Arrangements with Special Service for Children and Young People and also in Residential Arrangements with Special Service for Adults. Act (2000:1441).

Section 10 In conjunction with the granting of a measure pursuant to this Act, the person concerned may request that an individual plan, with approved and planned measures, is drawn up together with her or him. Measures taken by other authorities than the municipality or county council shall also be entered in the plan. The plan shall continually, and at least once a year, be reviewed.

The county council and municipality shall keep one another informed of plans that have been drawn up.

Section 11 If anyone, as a consequence of infirmity due to old age, morbidity, the prolonged abuse of addictive substances or for other similar reasons, is not capable of handling the financial support provided by a municipality, such as referred to in Section 9, subsection 2, the municipality may decide that the benefit provided shall be paid to someone else to be used to defray the cost of personal assistance to the person entitled to support. Act (2005:125).

Section 12 The municipality may decide that the financial support granted by the municipality pursuant to Section 9, subsection 2, is to be paid back if the person who received the support or her or his deputy, by supplying erroneous particulars or in some other way, has caused the financial support to be provided incorrectly or in excess. The same shall apply if the financial support has otherwise been provided incorrectly or in excess and the person who has received the support or her or his deputy should reasonably have realised this. Act (2005:125).

Section 13 The Government, or the authority the Government decides, in regard to activities pursuant to Section 9, subsections 6-10, may issue regulations

for the protection of the life of an individual, her or his personal safety or health. Act (2005:125).

Special Duties for a Municipality

Section 14 A municipality shall do what it can to ensure that measures which shall be included in plans such as are referred to in Section 10 are coordinated.

Section 15 The duties of a municipality include

1. Continuous surveys to ascertain who is covered by the Act and their need for support and service,
2. doing its utmost to ensure that persons, such as are referred to in Section 1, have their needs satisfied,
3. furnishing information regarding objectives and means relevant to the activities pursuant to this Act,
4. ensuring that persons such as are referred to in Section 1 have access to work or opportunity to study?
5. doing its utmost to ensure that public recreational and cultural amenities become accessible to persons such as are referred to in Section 1,
6. notifying the chief guardian, on the one hand, when a person covered by Section 1 can be presumed to need a legal guardian, trustee or personal representative and, on the other, when the appointment of a guardian, trustee or personal representative ought to be terminated, and
7. collaborating with organisations that represent people with extensive functional impairments.

Section 15 a A municipality shall disclose certain personal data regarding individuals that have been granted measures pursuant to Section 9, to the National Board of Health and Welfare for the production of official statistics. The Government shall make regulations regarding which data shall be disclosed. Act (2003:885).

Common Provisions Concerning the Responsibility of County Councils and Municipalities

Section 16 A municipality is responsible pursuant to this Act vis-à-vis those who reside in that municipality. If a person such as is referred to in Section 1 intends to reside/to take up residence in a certain municipality, the latter, if requested, shall give advance notice regarding entitlement to measures on the part of the municipality pursuant to Section 9. When an application for advance notice is being considered, the provisions of this Act shall apply. The municipality shall, without delay, plan and prepare measures to which the advance notice entitles an individual if he or she settles in the municipality. The advance notice remains valid for six months, counted from the date when the measures become available for the individual concerned.

If a need for measures pursuant to this Act emerges during a person's temporary stay in a municipality, the latter shall give the support and the help that are needed immediately. As regards a county council's obligations, what is stated in this section concerning a municipality applies instead to a county council.

Section 17 A county council or a municipality may, though still retaining responsibility, conclude an agreement with some other person or body regarding the provision of measures pursuant to this Act.

A county council and a municipality which is part of a county council may enter into an agreement to the effect that responsibility for one or several functions pursuant to this Act may be transferred from the county council to the municipality or from the municipality to the county council. If such a transfer takes place, the regulations contained in this Act regarding a county council or municipality apply to the person or body to whom the duty has been transferred.

If a county council and a municipality have concluded an agreement pursuant to the second paragraph, the transferor may make such a financial contribution to the

recipient of an amount that is warranted by the agreement. If a transfer has been made from a county council to all the municipalities included in the county council, the municipalities may make a financial contribution to each other if this is needed in order to equalise the cost between the municipalities.

Section 17 a Notwithstanding Section 16, paragraph 1, a municipality may, provided there are special reasons, make an agreement on liability for costs for measures pursuant to Section 9 for an individual who through measures pursuant to Section 9, subsection 8 or 9, no longer resides or will not continue to reside in the municipality. Such an agreement may be met with another municipality or with a private care provider in another municipality. Act (2000:1032).

Charges and Related Matters

Section 18 Those who pursuant to a decision by the Swedish Social Insurance Agency are entitled to obtain assistance benefit pursuant to the Assistance Benefit Act (1993:389) may be charged for personal assistance within the framework of such benefit. Act (2004:826).

Section 19 From those who have a full old age pension pursuant to the Income-based Old Age Pension Act (1998:674) or a full guaranteed pension pursuant to the Guaranteed Pension Act (1998:702) or a full disability pension or a full activity compensation pursuant to the National Insurance Act (1962:381) or have some other income of an equivalent amount, reasonable charges for residential arrangements, recreational and cultural activities may be imposed pursuant to the principles decided by the municipality concerned. The charges may, however, not exceed the actual costs incurred by the municipality. The latter shall ensure that an individual may retain sufficient funds for her or his personal needs. Act (2002:199).

Section 20 If anyone under the age of 18 is cared for in a home other than her or his own by virtue of this Act, her or his parents are liable to contribute to a rea-

sonable degree to the municipality's costs for this care. The municipality may in such a case receive a maintenance allowance in respect of the child concerned.

Section 21 In cases other than those indicated in Sections 18-20, charges or reimbursement for costs may not be requested for measures pursuant to this Act.

Documentation and Deletion

Section 21 a The processing of matters relating to individuals and the implementation of decisions regarding measures pursuant to this Act shall be documented. This documentation shall show decisions and measures that have been taken in the matter and the actual circumstances and events of significance.

Documents that relate to an individual's personal circumstances shall be stored so that unauthorised persons cannot gain access to them. Act (2005:125).

Section 21 b The documentation shall be designed with respect for the individual's privacy. The individual should be kept informed about the journal entries and other notes that are kept about her or him. If the individual feels/is of the opinion that any information contained in the documentation is erroneous this shall be noted. Act (2005:125).

Section 21 c If notes and other information contained in a personal file kept by the or those committees referred to in Section 22 belong to such a compilation of data as referred to in the Processing of Personal Data within the Social Services Act (2001:454), the data shall be deleted five years after the last entry was made in the file. However, these data shall not be deleted for as long as the data about the same person has not been deleted by the committee pursuant to the second paragraph.

Information contained in a compilation referred to in the Processing of Personal Data within the Social Services Act shall be deleted five years after the circumstances to which the information refers has ceased.

The deletion shall be concluded no later than during the calendar year after the obligation to delete arose. Act (2005:125).

Section 21 d Documents that have been received or drawn up in conjunction with a measure being provided pursuant to Section 9, subsection 8 may not be deleted pursuant to the provisions contained in Section 21 c. Documents shall also be exempted from deletion pursuant to the provisions contained in Section 21 c considering the need of research for a representative sample of municipalities and county councils and in other municipalities and county councils regarding a representative sample of persons. Act (2005:125).

Committees

Section 22 The management of the activities of the county council or the municipality pursuant to this Act shall be exercised by one or several committees appointed by the municipal council. The Joint Committees within the Care and Nursing Area Act (2003:192) contain special provisions on joint committees. Act (2003:197).

Private Professional Measures

Section 23 Without a licence from the county administrative board, no individual may conduct on a commercial basis activities such as are envisaged in Section 9, subsections 6-10. An application for a licence shall be submitted to the county administrative board in the county where the activities are to be carried out. The county administrative board has the right to inspect the activities undertaken.

Private measures shall be supervised by those committees which are referred to in Section 22 in the municipality where the activities are carried out. If the responsibility for the duties is transferred to the county council pursuant to Section 17, paragraph 2, the activities shall instead be supervised by the corresponding county council committee. The committee has the right to inspect the activities undertaken. Act (2005:125).

Section 23 a The provisions contained in Section 21 a and 21 b apply in relevant respects to private activities. The docu-

mentation shall be stored for as long as it may be assumed it will be of importance for measures in the activity.

Act (2005:125).

Section 23 b A document in a personal file in a private measures shall, if it is requested by the person to whom the file relates, as soon as possible be made available to her or him to be read or transcribed at the place where the file is kept or as a transcript or copy unless otherwise provided by Section 29.

Issues concerning disclosure pursuant to the first paragraph shall be considered by the party responsible for the personal file. If such party is of the opinion that the personal file or any part of it should not be disclosed, he or she shall immediately, with a personal statement, refer the matter to the county administrative board for consideration. Act (2005:125).

Section 23 c The county administrative board may decide that a personal file in a private measure shall be appropriated

1. if the measure ceases,
2. if there is probable reason to assume that the personal file will not be dealt with in accordance with the regulations contained in this Act or in accordance with the regulations made under this Act, or
3. if the person who is responsible for the personal file so requests and there is a manifest need for the file to be appropriated.

A personal file that has been appropriated must be returned provided this is possible and there is no reason for it to be appropriated pursuant to the first paragraph. A decision in a matter regarding return shall be made by the county administrative board upon application by the person who, at the time of the decision regarding appropriation, was responsible for the personal file.

Personal files that have been appropriated shall be stored separately with the archive authority in the municipality where the files were appropriated. Personal files shall be stored for at least two years from when they were received by

the archive authority. An authority caring for a personal file that has been appropriated has, if information from the file is requested for a special case, the same obligation to disclose the information as the party had who was responsible for the file prior to it being appropriated.

Act (2005:125).

Section 24 If there is any serious deficiency in a private measure such as is referred to in Section 23, the county administrative board shall issue an order to the effect that the person or body conducting the activity shall rectify the deficiency.

If the county administrative board's order is not complied with, the board may revoke the licence.

Notices of Deficiencies

Section 24 a Every individual who performs functions under this Act shall ensure that the persons who receive measures pursuant to the Act are provided with good support and good service and live under secure circumstances. Anyone who observes or learns of a serious deficiency relating to an individual who receives measures under this Act shall immediately notify the or those committees referred to in Section 22. If the deficiency is not remedied without delay, the committee shall report the circumstance to the supervisory authority. This notification obligation also applies to a person who deals with matters under this Act or the Assistance Benefit Act (1993:389).

The first paragraph also applies within a corresponding professionally operated private activity. The notification shall be made to the person who is responsible for the activity. The person responsible must remedy the deficiency without delay or notify the supervisory authority.

Chapter 14, Section 1 of the Social Services Act (2001:453) contains provisions regarding the obligation to notify the social welfare committee that a child may need the protection of the committee. Act (2005:125).

Supervision and Related Matters

Section 25 The National Board of Health and Welfare shall centrally supervise the activities pursuant to this Act. The Board shall follow, support and evaluate the activities and also provide information about them and stimulate further development.

Section 26, A county administrative board shall supervise the activities pursuant to this Act in its county and may in the process inspect the activities. In its county a county administrative board shall also

1. provide information and advice to the general public on matters relating to the activities concerned,
2. advise the municipalities in their activities,
3. promote collaboration in planning between the municipalities and county councils in order to be able to satisfy future support and service needs, and
4. promote collaboration in planning between the municipalities, county councils and other official bodies.
Act (2000:526).

Section 26 a Repealed by Act (2002:439).

Appeals and Related Matters

Section 27 The individual has a right of appeal to a general administrative court against a decision by a committee such as is referred to in Section 22 or by a county administrative board if the decision concerns

1. measures for an individual pursuant to Section 9,
2. payment to someone else pursuant to Section 11,
3. repayment pursuant to Section 12,
4. advance notice regarding entitlement to measures pursuant to Section 16, second paragraph,
5. a licence for private activities pursuant to Section 23, or
6. appropriation of a personal file pursuant to Section 23 c, or

7. an order or the revocation of a licence pursuant to Section 24.

Leave to appeal is required in order to appeal to the Administrative Court of Appeal.

As regards appeals against decisions of the county administrative board pursuant to Section 23 b, the relevant parts of the provisions contained in Chapter 15, Section 7 of the Secrecy Act (1980:100) shall apply.

A decision on issues concerning the first paragraph shall apply immediately. However, a county administrative court or an administrative court of appeal may order that its decision shall not apply until it has entered into final legal force.

Act (2005:125).

Section 27 a The police authority shall provide the help necessary to enforce a decision on appropriating a personal file. A request for such help may only be presented if

1. owing to special circumstances it may be feared that the measure cannot be effected without using the special powers of the police pursuant to Section 10 of the Police Act (1984:387), or
2. there are other extraordinary reasons to do so. Act (2005:125).

Penalties

Section 28 A fine is to be imposed on anyone who wilfully or through negligence violates Section 23, paragraph one, first sentence.

Special Charge

Section 28 a A municipality or a county council that fails to provide without unreasonable delay a measure pursuant to Section 9 to which someone is entitled following a decision made by a court, shall be ordered to pay a special charge.

This charge belongs to the State.
Act (2002:439).

Section 28 b The special charge shall be determined to be at least ten thousand kronor and at the most one million kronor.

When the amount of the charge has been determined it shall be taken into consideration how long the delay lasted and how serious it may be deemed to be.

The charge shall be waived if there are extraordinary reasons to do so. No charge shall be imposed in petty cases.

Act (2002:439).

Section 28 c Issues concerning a special charge shall be considered upon the application of the county administrative board by the county administrative court within whose judicial district the municipality is located. An application relating to a county council shall be considered by the county administrative board within whose judicial district the county council's administration is conducted.

Leave to appeal is required for appeals to the administrative court of appeal.

Act (2002:439).

Section 28 d If a municipality or a county council after having been ordered to pay a special charge still fails to provide the measure, a new special charge shall be imposed.

A special charge may only be imposed if an application pursuant to Section 28 c has been served to the municipality or the county council within two years from when the court decision for the measure entered into final legal force.

Act (2002:439).

Confidentiality

Section 29 Anyone who carries out, or has carried out, on a commercial basis, private activities that relate to measures pursuant to this Act may not disclose without authorisation what he or she has learnt in the process regarding the personal circumstances of an individual.

Transitional Provisions

1993:387

Regulations regarding the entry into force of this Act have been made by the Act (1993:388) Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments.

1995:100

This Act enters into force on 1 April 1995. Decisions made prior to the entry into force may be appealed against pursuant to older provisions.

2000:1030

1. This Act enters into force on 1 January 2001.
2. A person who prior to 1 January 2001 has been granted a measure pursuant to Section 9, subsection 2 of this Act but for whom the measure has ceased owing to that he or she has attained the age of 65 is entitled, following a new application, to have the measure reinstated at the earliest of 1 January 2001. The scope of the measure shall be based on the decision that applied immediately before his or her 65th birthday. Such an application shall have been received by the municipality no later than 31 December 2002.

2002:439

1. This Act enters into force on 1 July 2002.
2. Older provisions apply when the issue relates to delay of the enforcement of a decision made before the Act entered into force.

2004:826

This Act enters into force on 1 January 2005. A charge may also be imposed after entry into force as a result of a decision made by a social insurance agency.

2005:125

This Act enters into force on 1 July 2005. The notification obligation pursuant to Section 24 a does not apply for circumstances that only relate to the period preceding the entry into force.

2007:1313

1. This law will enter into force on April 1, 2008.

2. Sorting and elimination based on the provisions of 23a § in its new wording may be done no sooner than April 1, 2010.
3. The provisions of 23a § in its new wording shall not be applied unless the last entry in the document has been done before this law is put into force.
3. As regards a special fee that is to be paid when an affirmative decision made by a municipality or county council is delayed, only the time after the law has been put into force may be taken into consideration in an investigation into whether the reasonable time for execution has been exceeded. The same applies to the special fee that is to be paid due to delay with the execution of an affirmative decision taken by a municipality or a county council or a positive verdict made by a court, if the execution of the decision or the verdict has been interrupted.

2008:77

1. This law will enter into force on July 1, 2008.
2. In accordance with 28f and 28h §§, the first quarter report shall comprise the information that is available to the committee of a municipality or a county council on September 30, 2008.