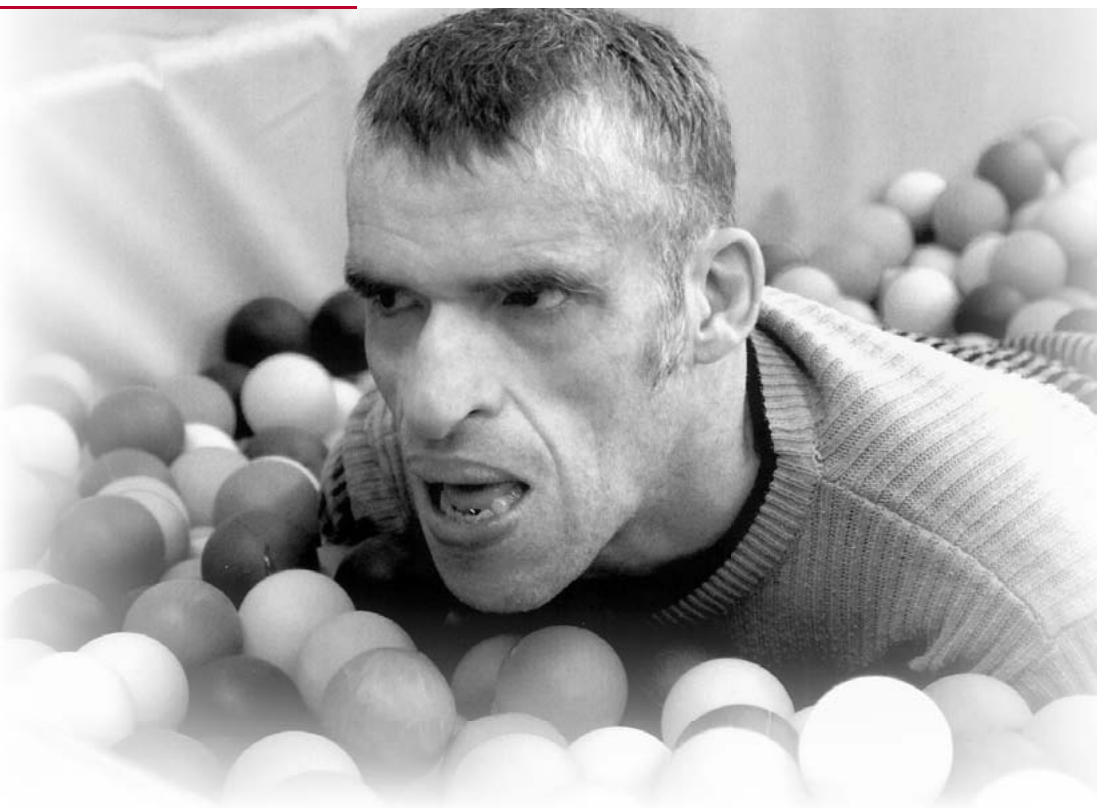


Sweden



Care Work with People with Disabilities

Birgittaskolan i Linköping



Lifelong Learning Programme

Education and Culture DG

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Care Work with People with Disabilities in Sweden

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Introduction

Dear Student,

A very warm welcome to Sweden! We are delighted you have chosen to come here for your practical placement and hope you have a worthwhile and interesting time.

Sweden is located in northern Europe on the Scandinavian peninsula. The closest neighbours are Norway, Finland and Denmark. Sweden is a constitutional monarchy with a central government appointed by the Riksdag which is the country's highest decision-making body. The population of Sweden is 9 million and the capital is Stockholm.



Stockholm and the Royal Palace

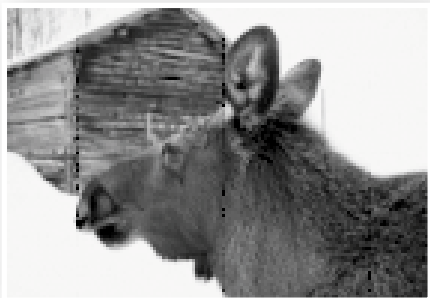


The Swedish flag

Sweden is an oblong country (1 571 930 km.) divided into 21 counties which all contain a number of municipalities. The largest municipalities are the cities of Stockholm, Gothenburg and Malmö. Sweden celebrates its National Day on 6 June. The currency is Swedish kronor.

Sweden attracts many tourists, not least to admire the beautiful countryside. According to the right to roam free (allemansrätten) all have the right to access certain public or privately owned Swedish land to enjoy the countryside, pick berries etc so long as they do not damage or harm anything nor pick wild flowers that are protected. Access is not permitted to private areas. There are wild animals such as the king of the forest, the moose, roaming the Swedish woodland.

In the north of Sweden there are mountains suitable for downhill skiing during the winter months and through the summer there are a number of beautiful rambling paths. The Svealand coastline is famous for its fantastic beauty and to the south and inland there are two large clean, fresh water lakes. The southernmost county in Sweden is called Skåne and the Öresund Bridge connects mainland Sweden with the continent.



Moose



Woodland and meadow

The purpose of this booklet is to give you an overview and insight into care work with disabled people in Sweden.

This is a very interesting area to work in and there are new initiatives and opportunities developing all the time. Every effort has been made to provide you with up to date information, however you could be made aware and introduced to new legislation, policy and practice during your placement which may have been implemented since this booklet was produced.

There is a lot of information in the booklet which will be of use to familiarise yourself with prior to your visit, also it is hoped it will be a useful reference during your placement.

We wish you a pleasant and enjoyable stay in Sweden and hope you have a successful practical placement.

This manual details the organisation in Sweden for the care of people with impairments; their rights and the opportunities afforded them in Swedish society.

Follow Fredrick and his family through each chapter.

In year 2000 Swedish family Svensson had a baby boy, Fredrik, who was later on diagnosed to have an average-level CP together with a minor mental disability. Fredrik will in the future need a wheelchair to help him with mobility and those ones who are not acquainted with him will find it slightly difficult to understand his speech. His parents are concerned for his future: what chances will their son have for meaningful and full life – and how will Fredrik manage in this society once becoming an adult?

Promoting the Status and Social Inclusion of People with Disabilities within EU

1. Rights, Status and Social Inclusion of People with Disabilities in the European Union

1.1. The United Nations

Universal Declaration of Human Rights

In 1948 The General Assembly of **the United Nations** proclaimed "**The Universal Declaration of Human Rights**" which is the most fundamental document that also defines the rights of people with disabilities.

All human beings are born free and equal in dignity, without a distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory which a person belongs to, whether it is independent, trust, non-self-governing or under any other limitation of sovereignty."

In 1971 United Nations' General Assembly issued "**The Declaration on the Rights of Mentally Retarded**

Persons" and in 1975 the "**Rights of Disabled Persons**". Both declarations included normalisation and integration as the guidelines. The aim put forward in these declarations is that of guaranteeing all people equal possibilities of participating in social life. *Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.*" (*Rights of Disabled People 1975*)

Furthermore, the **Rights of Disabled People** argues for their right to necessary services and social protection "*...disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible... and ...have the right to medical, psychological and functional treatment, including prosthetic and orthopedic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement*

services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration....

...have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment..."

The position of people with disabilities was kept in public awareness by several means. The UN proclaimed 1976 as the **International Year of Disabled Persons**, calling for an action plan at all levels, from international to regional, for the purpose of promoting the equalisation of opportunities, rehabilitation and the prevention of disabilities.

World Programme of Action Concerning Disabled Persons

After the International Year of Disabled Persons more extensive and specified development took place. The General Assembly formulated the **World Programme of Action Concerning Disabled Persons (1982)** to promote their rights and position in societies on a global level. The programme's agenda was more detailed and focussed. It included a broader approach with expressions such as the "full participation" of disabled people in social life and the development of "equality," i.e. equal opportunities in a broad sense as well. The programme also defined key concepts such as "impairment", "disability" and

"handicap" – and prevention as the strategic objective. Rehabilitation was also defined in a clearer way – as a set of services that function as measures in the facilitation of the disabled persons' full participation and equality. This action plan also put emphasis on education and employment, as well as on removing barriers that often manifest themselves as negative approaches to and attitudes towards this question.

The United Nations' World Programme of Action Concerning Disabled Persons was an action plan for Governments. To provide time for putting the Programme of Action into effect, the UN proclaimed the **United Nations Decade of Disabled Persons 1983-1992**. Governments could implement the Programme within ten years.

At the end of the Decade of Disabled Persons in 1992, the General Assembly proclaimed the 3rd of December as the **International Day of Disabled Persons**. To enhance public awareness the Day has varying themes on issues that are relevant to people with disabilities. **In 2007 the theme was "Decent work for persons with disabilities"**.

1.2. The European Union and People with Disabilities

◆ **The European Union** recognises the United Nations' rules on the Equalisation of Persons with Disabilities as the basis for the development of disability policy in Europe.

In 2003 the Commission stressed its belief that the *“emphasis on the rights based approach to disability should be reflected in the evolution of an international human rights standard relating specifically to disability”*.

The EU has specific legal grounds upon which to act in respect to advancing disability rights. Article 13 of the EC Treaties enables the Community to combat discrimination on the grounds of disability. Articles 21 and 26 of the Charter set out the rights of people with disabilities. Article 26, in particular, recognizes *“the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community”* as a fundamental right.

The European Union Disability Strategy stresses the need for a renewed approach, focusing upon the identification and removal of various barriers that prevent disabled people from achieving the equality of opportunity and full participation

in all aspects of social life. However, the primary responsibility for action rests with the Member States. The Community Disability Strategy focuses on

- ◆ strengthening the co-operation between and within the Member States
- ◆ increasing the participation of people with disabilities
- ◆ mainstreaming Disability in Policy Formulation

As responsibility to promote rights, position and equal opportunities of people with disabilities lays with national Governments, following chapters describe national policy in Sweden and its service provision and income security available.

2. The Concept of Disability in Sweden

◆ The cornerstone of Swedish disability policy is the principle that everyone is of equal value and has equal rights. National, regional and local government shares the fundamental responsibility of ensuring good health and social and financial security for people with disabilities. 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 disabled and non-disabled people.

The allocation of responsibility is that 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 the disabled. These bodies are tasked with safeguarding the rights and interests of disabled people by co-ordinating, supporting

and promoting such issues in their dealings with other authorities. This responsibility applies to social services as well as health care, but is currently focused on two main areas: developing a system to describe the living conditions of disabled people, and improving the co-ordination of rehabilitation work.

2.1. General Definition of Disabilities in Sweden

◆ What is a handicap – impairment, approach and values? A handicap first occurs when the person in question meets a hinder in his surroundings, that is the interplay between the individual and the environment. Today's approach to the expressions functional impairment and handicap are based on a basic human viewpoint. The WHO's definition from 1980 is that all people are equal.

Functional impairments are divided into categories, each category have a number of sub categories. The most common division is cognitive neuropsychiatry and mental and physical functional impairments. In this chapter we will describe:

- 1) Learning disabilities
- 2) Physical disabilities
- 3) Multiple disabilities

2.1.1. Learning Disabilities

Cognitive functional impairment – development disorder

Development disorder is not an illness rather a functional hinders which a person is born with or acquires through illness or an accident before the age of 16 years. This is divided into three levels depending upon the degree of functional impairment. These levels are not static and can change over time.

- ◆ Severe development disorder, cognitive development equal to 0-2 years
- ◆ Moderate development disorder, cognitive development equal to 2-7 years
- ◆ Slight development disorder, cognitive development equal to 7-12 years

The most common reason for development disorder is Downs syndrome. There are about 120 children born every year with Downs syndrome. *It is this group of functional impairments that this manual will deal with.*

2.1.2. Physical Disabilities

Neuropsychiatric functional impairment

Neuropsychiatric functional impairments have biological reasons and occur during pregnancy or during the first year of a child's life. This functional impairment is not visible on the surface but manifests itself in the

social confines of the family, friends or within child care facilities and at school. The usual diagnoses of neuropsychiatric functional impairment are autism, Aspergers syndrome, ADHD, DAMP, Tourettes syndrome, speech deficiencies and dyslexia.

Mental functional impairment

Schizophrenia, depression and other mental illnesses (see separate handbook) do not occur more frequently in people with cognitive functional impairments. However, behavioural problems and mental disorders are more common with people who suffer from cognitive problems.

Physical functional impairment

Sight, hearing deficiencies, cerebral palsy and meningomyelocele are examples of physical functional impairments. Every individual functional deficiency can also be divided into different groups. Many of the functional impairments are congenital or appear during the early years. Of course, many functional deficiencies occur with age, for example, hearing, sight or through accident.

2.1.3. Multi-functional Impairments – Multi Handicap

It is not unusual for a person to have a number of functional deficiencies. Sometimes these functional deficiencies have a negative affect on one another, which can lead to a more difficult daily life for the individual.

Independent of the type of functional impairment a person has, the individual is often in need of some form of help. The extent of the help and the type provided is based on the specific needs of the individual. To guarantee the right to a good life for the individual, legislation has been passed which regulates societal obligations towards the individual.

Those working within the care sector can sometimes be faced with in an ethical dilemma. Various principles oppose one another but the basic principle is that all people are equal; society has a responsibility to for the weak and those in greatest needs should receive help first.

3. Changing Perspectives in Sweden

3.1 An Altered View of People with Impairments – Intellectual Disability

◆ During the 19th century there came about a breakthrough in the humanitarian view of people. Various charitable organisations emerged to help people who needed help and support. The first group to receive charitable help was the deaf followed by the blind in the form of special education. From the end of the 19th century it can be read in the minutes from the parish catechetical meeting that certain, so-called vapid, idiot or mentally deficient children through education transformed from good for noth-

ings to capable individuals. With the encroachment of industrialisation more and more women began working outside the home and could no longer take care of their own and were forced into leaving them with someone else. Mental institutions grew up over the whole country to take care of children and adults. Women and men lived separated from each other in these institutions. They were housed in large barracks and had no personal property to speak of. Life in these institutions followed strict rules.

After the Second World War an altered view of the intellectual disabled began to make headway in society and legislation. Here are a few important dates:

2000 2007 Sweden's Minister for Elderly Care and Public Health ratified the UN convention for the Rights of Persons with Disabilities. Sweden has been active in the preparations and introduction of this convention. The aim is to list the necessary actions required to hinder discrimination of people with impairments.

1990 1990 The Act concerning Prohibition of Discrimination in Working Life of People with Disability was introduced.

In 1994 further regulations were introduced to strengthen the rights of the impaired, legislation to “live as others”, an Act concerning Support and Service for Persons with Certain Functional Impairments – LSS and an Act concerning Compensation for

Assistance – LASS with integration and normalisation principles being the central concept. The effect this new legislation had was to bring about the closure of large institutions, which were replaced by small group housing complexes with individual apartments. The norm was for a child to live at home with his parents until the age of 20-25 years when he would then move to his own apartment or to group housing with support from society

During the 1990's the special schools were integrated with upper secondary education for pupils with learning disabilities in the same organisation as the compulsory schools

1980 In 1982 the Social Services Act – SOL – came into force. The foundations of this Act are democracy, solidarity, self-determination and responsibility. This involves a paradigm shift in the way things were viewed as now the will of the individual would be paramount in all decisions.

During the 1980's and 1990's treatment centres for young people were closed and replaced by small student homes.

1970 During the 60's and 70's a number of new treatment centres for children and young people were built. The number of places increased from 1,800 to 3,000.

1960 In 1967 all were granted the right to care and school teaching. The special schools were expanded to include training school day centres for adults. The expression mentally retarded was no longer used to be replaced by intellectually disabled and care.

1950 During the 1950's the association föreningen för utvecklingsstörda barn – the National Association for Persons with Intellectual Disability grew up. Some of the primary aims were to protect the rights of the mentally retarded and to see that the parents were not isolated but together could fight for the rights of their children.

1954 legislation relating to care and education was reformed and the expression retarded was introduced into legislation.

During the 1950s sterilisation of the mentally retarded was practiced in great numbers whilst at the same time being discussed and greatly criticised. Sterilisation did not cease until the 1970s.

1940 1944 the first Act was introduced which gave educable mentally deficient the right to education and care.

3.2. Today's Situation/ Life Perspective for a Person with Impairments/ Intellectual Disabilities

3.2.1. Young Children

In principle, all children live at home and are taken care of by their parents. Dependent upon the degree of impairment, parents can receive various forms of support and help, both medicinal as well as of a more physical assistance character or rebuilding/adaptation of the family home. Parents can even apply for care allowance for the additional work involved in taking care of a child with major impairments. This allowance is paid out until the child has reached 19 years of age. Parents of a child covered by the Act concerning Support and Service for Persons with Certain Functional Impairments – LSS – also have the right to 10 contact days per year to participate in various parental training

courses or to visit the child in a day home, school etc.

When the parent's parental leave comes to an end the parent applies for a place with the child day care facilities. Often children with impairments are integrated in the ordinary child groups. The Day care/pre-school that this category of child attends is allowed to employ extra personnel whose role is to support existing personnel and the child in the daily operations of the centre. For children with serious impairments these ordinary day care centres have difficulty in integrating the child in the regular activities therefore there is different types of solutions depending on the municipality the child lives in. Sometimes the family may require support in the daily care of the children on the short term or even longer periods of time. This type of help can be sought through the municipality and can take different forms but usually involves the child moving to temporary care accommodation centres, group housing or with a support family. During the holidays children's colonies and camps are arranged.

When Fredrik was

a few months old his parents began to suspect that everything was not as it should be. He did not develop as expected, was in fact a late developer. The parents talked of their concerns when they visited the child health centre that sent a letter of referral to the children's clinic at the hospital. An examination was carried out which included both medicinal as well as psychological. It was discovered that Fredrik cerebral palsy. How this would affect Fredrik's life in the future was not a situation that could be foreseen. Fredrik's parents came into contact with a social worker at the children's clinic would met with them on a regular basis. After a while when Fredrik became a couple of years old he was given a place at a day care centre. The municipality employed an assistant who worked at the centre those days Fredrik attended. To allow Fredrik's parents more time with each other and Fredrik's siblings, Fredrik was allowed to attend a temporary care centre one weekend a month. Fredrik enjoyed this as he had more friends and there were always activities at the temporary care accommodation centre.

3.2.2. School Age Children

Education and studies influence the whole way of life of everyone and play an important role in reducing social disparities and creating equal opportunities in society. The quality of one's education determines the choice of profession and work. Furthermore, an education nearly always leads to increased social and cultural activities. Education also provides pleasure and a feeling of solidarity. A good education as well as recurrent studies can be decisive factors in one's life. People with disabilities are entitled to the same opportunities as everyone else. The National Agency for Special Educational Support, Sisu. Sisu's task is to improve the possibilities for disabled young

persons and adults to obtain a good education. School is compulsory in Sweden between the ages 7-16.

Children with impairments may need to attend various special classes, but as far as is possible these special classes are integrated in the municipality's regular schools. In certain cases a child's impairments may only require an adaptation of the classroom to suit the individual, which may involve technical equipment whilst other impairments demand more extensive actions, for example rebuilding the school or other pedagogy. An example of this can be hearing aids such as induction loops in a classroom, rebuilt classrooms for disabled RH classes, Asperger classes, small classes with disturbed students etc. For deaf and blind children there

are special schools located in a couple of places in Sweden.

Children with intellectual disabilities have their own 9-year curriculum, with two courses, one intended for those with extensive learning difficulties and special school for students with milder intellectual disabilities.

The training school focuses on the aesthetic subjects, communication, psychomotor skills, every-day activities and comprehending reality.

The special schools are similar to regular schools including subjects such as mathematics, Swedish, social studies, science subjects, art, handicrafts, sports and home economics.

After the special school a student can continue with upper secondary education for pupils with learning

disabilities and choose between a number of trade programmes. These programmes follow the same structure as those at the regular upper secondary school and include the core subjects: English, Swedish, social studies, mathematics, religion, sports and aesthetic activities with vocational subjects aimed at the trade programmes such as engineering, industry, commercial etc.

The students who have attended the training schools will receive an individually-adapted trade training course.

Children up to the age of 12 are normally included in the municipal child care system. For school children over the age of 12 the municipality is responsible for providing the child with a place in the leisure-time centre for schoolchildren.

When the time came for Fredrik

to start school he was placed in the same class as his friends in the neighbourhood. This was important to both Fredrik and his parents as the intention was for Fredrik to live a life as similar as possible to other children of his age. Fredrik's class is called a RH class which means that all the children in the class have some sort of disablement. It is a small class with 6 children, one teacher and two student assistants to help the children. Everything works well and Fredrik is happy at school. In the afternoons Fredrik attends the leisure-time centre for schoolchildren which is in the same location and has the same staff as the school. When the time comes for Fredrik to attend the senior school he will have to change schools as regular tuition has become too difficult for him. He will join a special school class at senior school level in the city. This is a small class and Fredrik likes both his

new teacher and the assistants. After school Fredrik joins his friends in the youth recreation club. Their favourite pastime is baking and playing music. A couple of times in the term a disco is arranged together with students who attend senior and upper secondary school levels at other special schools. One weekend every month Fredrik goes to a temporary care accommodation centre. When Fredrik began senior school, he moved to a different temporary care accommodation centre adapted to young people.

Fredrik begins upper secondary school for pupils with learning disabilities which he will attend for four years. His graduation will involve much celebration. All the students will sit in a cart decorated with flowers and branches and on their heads they will wear their student caps. In the afternoon awaits a party in the garden with family and friends.

3.2.3. Adulthood

Depending upon the extent of the handicap adult life will vary. When the time is right al will move from their parent's home to some sort of housing to suit the individual. All are guaranteed a meaningful daily activity based on the needs of the individual. This can involve working, participating in activities at the daycare centre. A daycare centre can also vary as the activities can be different, for example running a café, a store or doing sub-contracted work for businesses whilst other daycare centres are more involved in ADL training. During their leisure time they can participate in normal leisure activities such as joining a study circle, different sports – football, riding or getting involve in various types of music activities or mixing with friends and going on shorter or longer trips during the holiday period.

When Fredrik was 21 years old

he began talking about moving away from home. His sister who is two years younger has already started looking for an apartment. Fredrik thinks this is unfair; he is, in fact, older. Fredrik parents contacted a Needs Assessment administrator at the municipal social welfare office and informed them of Fredrik's desire and to hear of the possibility of him moving away from home. The Needs Assessment administrator conducted an investigation, which showed that Fredrik had the right to accommodation with special services. At the moment there are no suitable accommodations available. The administrator explains that it is important that Fredrik gets accommodation that suits his needs. In the meantime Fredrik remains living with his parents. During the day he works at the municipal social welfare office cafeteria, which he very much enjoys. He travels to work using the transportation service for disabled persons. One weekend every month Fredrik goes to a temporary care accommodation centre; the same accommodation centre that he has been attending since senior school. Six months after Fredrik and his parents sought accommodation they were informed that an apartment had become available in a group housing complex which would suit Fredrik. They go to visit the apartment which is located in the suburbs of the city. There are 6 apartments and a base apartment which is a common area for both personnel and the residents. Fredrik's apartment comprises of a large room with sleeping area, a small kitchen and a large bathroom adapted to disabled persons. From the first moment he sees it Fredrik likes the apartment. He has also been promised new wallpaper in the main room which he can choose himself.

4. How to Meet the Needs of People with Disabilities in Sweden

◆ When a child is born it is sometimes possible to see right away that the child has a functional impairment and will need extra support to cope with daily life. In the case of other children it is not discovered for a while at the child welfare centre, day care centre or in school that everything is not as it should be. After which a medical, psychological and pedagogical examination is carried out to assess the child. Children with functional impairments are referred to a rehabilitation centre. Child habilitation focuses on children and young people between the ages of 0-20 years who are disabled, suffer from development disorders and neuropsychiatric diagnoses.

The World Health Organisation defines handicap as being “It is not your functional impairment that determines if you have a handicap. It is rather deficiencies in the physical, social or psychological environment that creates the handicap.”

4.1. Habilitation

◆ Habilitation is a medical specialty with knowledge of the various problems that functional deficiencies can involve. A functional impairment can be more or less disabling depending upon the

every day environment the individual lives with. Habilitation aims at giving children, young people and adults suffering from functional impairments the best possible functional abilities and best possible conditions in order to take part in society on the same terms as others. The word habilitation means to make fit as opposed to the word rehabilitation which means to readapt. Habilitation actions can take the form of medical, pedagogical, psychological and also social. Those working within habilitation work as a team with various specialities such as doctor, occupational therapist, physiotherapist, psychologist, social worker, specialist educationalist, speech therapist and even sometimes technicians. An habilitation plan is drawn up together with the family. The plan is revised continuously to suit the child's age and changing needs. The contribution by the specialist educationalist is to support the day care centre and operations in the school.

The difference between habilitation and rehabilitation is that habilitation is aimed at people with congenital and often life-long functional impairments or with functional impairments that have arisen early in life. Functional impairments can result in reduced mobility, sight, hearing, and understanding, a perception of surroundings or relationship with

other people. Habilitation actions are aimed at building up and reducing the difficulties which functional impairments create in the daily life. The degree of help varies depending on the type of functional impairment: physical, social or learning process.

Every county has its own aid centre where people with functional deficiencies can be referred, mainly for disability and pedagogic aids.

The aid centre test suitable aids, such as wheelchairs, lifts, computers etc. These aids can be borrowed free of charge. Certain aids, such as cutlery, tap openers and smaller repairs, for example repairs to a wheel of the wheelchair must be paid for by the individual. Follow-ups of how the aids function in daily life occur continuously. The need for aids can change; perhaps the individual needs a new type of aid.

When Fredrik was only 1 year old

was the first time he came into contact with the habilitation team. There is a special unit which takes care of small children. Families can borrow toys from here. Fredrik very much liked playing with a large ball which he could lie on to train his balance. As Fredrik grew the type of toys changed to suit his needs. The aim of these special toys is to help stimulate his development in the best possible way. Fredrik also had contact with the aid centre for other articles such as wheelchairs. He also met with a speech therapist on a regular basis to help with his speech.

4.2. Rehabilitation

◆ People who, due to injury, illness or handicap, suffer from a function deficiency can receive help at a rehabilitation centre to help train and build up their functions and/or compensate for the function deficiency by using aids.

The aim with rehabilitation is to help the individual maintain existing functions, to prevent loss of functions

and/or train to regain lost functions. People with functional impairments should be able to live as independently as possible, to manage their personal care, work and leisure time. To achieve this various types of training methods, technical aids and adapted housing is used. Training/treatment can take place at an occupational therapy unit, day rehabilitation unit or in the home.

People with the following ailments or diagnoses can receive help and support at rehabilitation centres:

- ◆ Adults with complex care and welfare needs
- ◆ Patients having difficulty with their movement apparatus
- ◆ Patients suffering symptoms from neurological function loss
- ◆ Patients with difficulty in speech, voice and understanding the language
- ◆ Mental ill health

Doctors, occupational therapists, physiotherapists, psychologists, social workers, speech therapists and sometime technicians all work at rehabilitation centres. Together with the user a rehabilitation plan is drawn up. The aid centre is also involved. Each County Council decides the existence and extent of rehabilitation and aid centres in the region.

5. Legislation

5.1. The Social Service Act

◆ In Sweden all welfare care is determined by the Social Services Act – SOL –, which is all-encompassing legislation not determining details but goals. SOL is based on human rights, **all are equal**, regardless of ethnic background and gender. These values shall permeate all activities within welfare. SOL takes an overall view of the needs of the individual. Everyone shall have a reasonable living standard comparable to the standard normally existing in society as a whole. The basic foundation of SOL is that everyone should have the opportunity of living as full a life as the average person, that is to say, ability to show joy, love, grief, anger etc, to have the opportunity of attending school or to participate in daily activities.

Ethics in the workplace is associated with how one is treated; the interaction that occurs when people meet is the core to all welfare work. Swedish legislation is based on a humanitarian view of people, to be subjective; there all individuals are seen as a participating resource. The central principles in the Social Services Act are of own free will, self-determination, participation and influence.

In Sweden all people attain their majority at the age of 18 years. For people with certain functional impairments, for example development disorders or dementia, they may have difficulty in protecting their rights. To safeguard the rights of the individual the court appoints a trustee whose job it is to protect that person's rights.

Those persons working with people with functional impairments often gain an intimate contact with them. Their job descriptions include support provision and help in the home environment to both the individual as well as the family, to provide basic needs, stimulate participation in activities, inform, observe and report any possible help requirements: to give advice, health information and to seek out other help areas. To gain greater continuity each individual is assigned a caseworker, contact man whose responsibility it is to safeguard the needs of the functionally impaired and when necessary to contact the parents, trustee or custodian.

5.2. Act Concerning Support and Service for Persons with Certain Functional Impairments – LSS

◆ SOL is not always enough for people with functional impairments. To achieve the goal of all being equal, SOL must be complemented with the Act concerning Support and Service for Persons with Certain Functional Impairments – LSS. This Act states that it should be simpler for the individual to live as normal a life as possible. The individual has the right to live under the same conditions and in the same way as a person in the same age group would live. To be eligible for support under this act the following criteria must be met:

1. Intellectual disabilities, autism or autism-like conditions of people who became functionally impaired before the age of 16 years of age.
2. People with significant permanent intellectual, functional impairments who have sustained brain damage, in adulthood, due to injuries from external violence are included if they received their injuries after the age of 16.
3. People as a result of other physical or psychological functional impairments which are obviously not related to normal aging, have significant difficulties in managing their daily lives and are therefore in need of extensive support and service. The functional impairment, regardless of it being physical or mental impairment must be long-term and extensive.

This is an Act of Rights and is compulsory for the municipalities.

There are 10 special actions:

- ◆ Advice and other personal support
- ◆ Personal assistance
- ◆ Guidance service
- ◆ Access to a caseworker
- ◆ Relief service in the home
- ◆ Temporary accommodation outside the home
- ◆ Temporary care of school children over the age of 12.
- ◆ Accommodation in a family home or housing with special services for children and young people
- ◆ Accommodation with special services for adults or other specially adapted housing for adults
- ◆ Daily activities

If the individual does not receive the help they seek they can appeal the decision in the first place with the municipality followed by the courts. The individual must participate in all actions and decisions relating to him. If the person in question is under the age of 18 the guardian shall participate. If the person has attained his majority but has difficulties in presenting his own interests, a custodian or trustee shall take his place. Every decision relating to children must be based on what is best for the child.

As Fredrik's intellectual disablement occurred

before his was 16 years of age he belongs to category 1 in LSS. Those actions Fredrik has had approved according to LSS are:

1. Advice and other personal support. Even when Fredrik was small his parents were able to meet with a social worker who gave them expert advice and professional support. These actions are different from those provided by the County Council.

6. Temporary accommodation outside the home. Fredrik has attended a temporary care accommodation centre since he was small until he started upper secondary school.

7. Temporary care of school children over the age of 12. When Fredrik began at the senior school he also attended the youth recreation club after school. This provided similar activities as a regular youth recreation centre.

9. Accommodation with special services for adults or other specially adapted housing for adults. Fredrik moved to his own apartment. The apartment is located in a building where there is also a base apartment for 24 hour personnel.

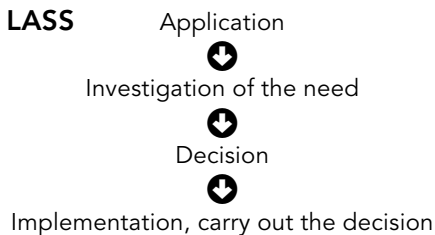
10. Daily activities. Fredrik works at the municipal social welfare office cafeteria. The work is adapted to suit people with intellectual functional impairments.

Statistics relating to the use of LSS , as at 1 October 2006

- ◆ 58-59,000 people received allowances according to LSS. This is the equivalent of 6% of the Swedish population.
- ◆ There were a total of 107,200 actions
- ◆ 25,800 participated in daily activities
- ◆ 20,900 adults receive special services or live in specially adapted housing
- ◆ 17,400 people have a caseworker
- ◆ 10,500 people have access to a temporary care centre
- ◆ 150 children and young people live in an appointed family home
- ◆ 1,200 live in accommodation with special services for children or young people
- ◆ 9,700 people had guidance service
- ◆ 9,500 people received advice and support
- ◆ Almost 30% of all actions according to LSS were given to children and young people under the age of 22
- ◆ People received 6% of the actions over the age of 65

5.3. Act concerning Compensation for Assistance – LASS

◆ Those with serious functional impairments and who require personal assistance to cope with every day life can apply for assistance compensation. If the requirement exceeds 20 hours per week, the regional social security office will decide if the person in question has the right to assistance compensation. The municipality will take if the requirement is 20 hours or less, the decision. To be eligible for assistance compensation a person must be under the age of 65 and belong to one of the three categories mentioned in LSS. In addition, the functional impairment must be judged to be on such a scale that the individual requires extensive basic assistance, for example, to eat, dress himself, and communicate with others. Once a person has been granted LASS, the employment of assistants is up to the individual. They can be employed by the municipality, the person themselves or with the help of a private enterprise.



5.4. The Secrecy Act

◆ The Secrecy Act applies to all those working with the care sector and is there to protect the privacy of the individual. A member of staff is prohibited from discussing a patient to an outsider. Examples of information regarding a patient that is not to be divulged includes a persons characteristics, general state of health, illnesses, medication, social situation and economy. Therefore a patient's records is an important document and classified as secret.

5.5. Act Concerning the Prohibition of Discrimination in Working Life of People with Disability

◆ This aim of the Act is to eradicate discrimination in the working life of people with functional impairments. Functional impairment implies permanent physical, mental or intellectual limitations of a persons functional abilities which due to an injury or an illness, apparent at birth, or has occurred shortly after or is expected to occur.

5.5.1. Direct Discrimination

An employer is not to treat a job applicant or an employee unfairly by

treating him or her inferior to the way in which the employer treats or has treated or could treat any other person in a comparable situation, if the unfair treatment is related to the functional impairment.

5.5.2. Indirect Discrimination

An employer is not to treat a job applicant or an employee unfairly through the application of a regulation, a criteria or procedure which appears neutral but is in practice especially unfair towards people with certain functional impairments when compared with people without such functional impairments. This does not, however, apply to regulations, criteria or procedures whose motives can be justified as being reasonable and the measures are appropriate and necessary to achieve the objective.

5.5.3. Harassment

An employer may not discriminate against a job applicant or employee by harassing him or her. In this Act, harassment implies behaviour in the working life which violates a job applicant's or employees dignity and which is associated with the functional impairment.

6. Financial Support and Economic Conditions

◆ Some will manage with very little assistance whilst others will need far more help from society involving both accommodations as well as daily activities or help in the working life. To cope with their own life situation there are a number of allowances that can be sought from the regional social security office. The size of the remuneration is based on the price base amount which is a figure that shows price development. In 2007 the price base amount is set at SEK 40,300/ 4,272 Euro.

6.1. Activity Allowance

◆ From the age of 19 years a person can apply for activity allowance. The level of this allowance increased successively over the years. At 19 years of age the person receives 2.1% of the price base amount, at the age of 30 it has gone up to 2.4%.

6.2. Sickness Benefit

◆ At the age of 30, activity allowance is replaced by sickness benefit which equals 2.4% of the price base amount which is the equivalent of SEK 96,720/ 10,254 Euro today (dec 2007).

6.3. Disabled Allowance

◆ If a person is afflicted with a functional impairment before the age of 65 years and is in need of extra help or economic support due to the impairment he can, under certain conditions, receive a disabled allowance from the age of 19 years. A requirement is the person with the functional impairment has need of assistance from a second person to cope with his every-day needs, his work, his studies. Disabled allowance is tax-free. A disabled allowance amounts to 36%,

Age	Percentage	Price base amount (SEK 40,300 / 4,272 Euro)
19 years	2,10 %	SEK 84,630 / 8,972 Euro
23 years	2,15 %	SEK 86,645 / 9,186 Euro
29 years	2,35 %	SEK 94,705 / 10,040 Euro

53% or 69% of the price base amount and is paid out depending upon the type of help needed or the size of the extra costs involved which are incurred due to the impairment.

Below are the amounts paid in 2007:

36% SEK 14,508/ 1538 Euro

53% SEK 21,359/ 2264 Euro

69% SEK 27,807/ 2948 Euro

To be entitled to a disabled allowance the persons combined costs, including help services, amount to a minimum of 28.5% of the price base amount, that is to say, SEK 11,486./ 1,218 Euro

6.4. Work Aids

◆ An employer can apply for an allowance to adapt a work place to suit the impaired employee.

Fredrik is still living

in the group housing and working at the cafeteria. He has several friends both at work and at the group housing. Once a year he goes on holiday with the other residents and the personnel. Fredrik also accompanies his parents on a week holiday every year. Fredrik's parents feel secure knowing that Fredrik has the opportunity to live his own life and that he can get all the support he needs without being dependent on them for practical help in managing his every day life now and in the future.

7. Service for Disabled People in Sweden

◆ In Sweden the state takes social responsibility for the citizens. The aim is to give people a certain level of social security and reasonable living conditions. The efforts to create welfare for the people are summed up in Social Welfare Politics. The Social Welfare Service carries out its work in close contact to people.

To create equality and security in all parts of the country there are laws for social care. One of the laws is called The Law on Social Welfare Services. It is a “frame” law, which means that social welfare service must be available in all Swedish municipalities. How a municipality chooses to carry out its social welfare service varies according to its population, age structure, geographical size etc.

The first goals of The Law on Social Welfare Services describe the aims of service, care and treatment within The Social Welfare services. The first paragraph of the law states that people shall have the right to:

- ◆ financial and social security.
- ◆ equal living conditions.
- ◆ take active part in social activities.

The meaning of these goals varies according to what groups they are applied on, e.g. children or elderly people. The first paragraph also contains basic values as:

- ◆ Democracy

- ◆ Solidarity
- ◆ The responsibility of the individual
- ◆ Independence (the right to make your own decisions)
- ◆ Integrity
- ◆ These values shall direct the design of Social Welfare Service in Sweden.

7.1. Processes in Accordance with SOL and LSS

◆ Chapter 4 of the Social Services Act states: If a person cannot himself meet his own needs or have them met by others, he has the right to an allowance to cover his support (maintenance support) and, in general, for his way of life (care, treatment, home-help service, special accommodation for the elderly and functionally impaired etc). The individual, with the aid of this allowance, be guaranteed a reasonable living standard. The allowance will be formulated such as to strengthen the individual's opportunity of leaving an independent life.

7.2. Application and Available Assistance

◆ A reception at the social services office is where all applications should be submitted. An application can

be submitted by telephone or in writing. The application should be submitted by the individual but even a member of his family, a district nurse and trustee or similar can make an application. The application should state the actions sought; in accordance with the Social Services Act – SOL – the following are some actions, which can be sought:

- ◆ Home-help service
- ◆ Food delivery
- ◆ Guidance service
- ◆ Safety alarm/telephone service
- ◆ Day activities
- ◆ Relief service
- ◆ Temporary accommodation outside the home
- ◆ Alternative treatment (??)
- ◆ Care accommodation
- ◆ Service apartment

During a home visit or at a care planning meeting, for example at the hospital, the Administrator meets the person who has applied for help and investigates his needs and requirements. At the meeting the Administrator also meets with others including family members or other people important to the investigation. In order to carry out the investigation the Administrator has to ask a number of questions relating to the individual's social situation, for example, how he lives, what sort of social network he has, does he work or what sort of pension does he have. It is also important to know about the person's health situation and how he goes about his daily life.

Together with the application and the investigation the Administrator makes a decision regarding applicable actions. The applicant receives a formal decision. If the application relates to accommodation, the housing part of the investigation will be sent to a placing expert who is responsible for providing accommodation for all those who require a service apartment or care accommodation. An individual can appeal the decision if his application has been turned down. These Right to Allowance actions involve a fee as in most cases a means test must be conducted.

The other legislation involved is the Act concerning Support and Services for Persons with certain Functional Impairments – LSS – that came into force on 1 January 1994. This provides people with severe functional impairments the legal right to, for example, personal assistance and other forms of support and service. The aim of this law is to promote the right to equality of the impaired, improve their ability to live an independent life and to be able to participate in society in the same way as every body else. This legislation should provide the individual with a good way of life.

The Administrators/Needs Assessors in the unit within the social services responsible for care investigate and administrate various applications. They invoke different legislations, the Social Services Act – SOL , the Act concerning

Support and Service for Persons with Certain Functional Impairments – LSS and the Act concerning Compensation for Assistance – LASS.

Those seeking support through LSS must belong to a group with certain functional impairments, they are as follows:

1. an intellectual disability, autism.
2. adults with an acquired brain damage which has resulted in a reduced intellectual function.
3. people with major and permanent physical or mental functional impairments. This does not apply to elderly people with difficulties due to age.

If an individual belongs to one of these groups he can apply for one or more the following:

Personal assistance

If an individual is in need of major help he has the right to personal assistance. The personal assistant can help with those areas that he is unable to manage himself, such as getting dressed, getting undressed, hygiene, eating and communicating. The assistant can also help in other areas such as escort to work, activities, going to the pictures etc.

The assistant shall be a personal support and the individual has the right to decide who shall provide that help and in which when and when it shall be given. The individual can also choose to be the employer or he can go through

the municipality or a private assistance firm.

Guidance service

This is for those who do not have personal assistance but require escort to participate in society, for example, go to the pictures or participate in recreational activities. This service can be adapted to suit personal requirements and interests and is provided when the individual needs it.

Caseworker

This person will help the individual who already has contact with other people but feels the need for assistance with participating in recreational activities or is in need of a friend.

Relief service

This person will provide the family of a functionally impaired child with relaxation and the opportunity to participate in activities that are not suitable for the child. In this case a person will come to the home of the child and relieve the regular guardian. This service is normally applicable to children but can also be used in the case of adults.

Temporary care accommodation centre outside the home

This service allows the child to live a short while at a temporary care accommodation centre to allow the family the opportunity of relaxing but also provides the child with a change of environment and other stimulation.

Even this service is normally reserved for children but temporary accommodation centres are available for adults.

Temporary care of school children over the age of 12

Regular child care services provide supervision after school up to the age of 12 years. But in some cases supervision is needed even after that, from 13 years and as long as the child is in school. This involves supervision before and after the school day and during school holidays.

Appointed family home or accommodation with special services for children and young people

Children, who despite various types of support actions, are unable to live at home with their parents have the right to an appointed family home or accommodation with special services for children and young people. An appointed family home means the child will live with a family other than his own. Accommodation with special services usually involves a number of children living together with support from personnel 24 hours a day.

Accommodation with special services for adults

Adults have the right to their own home which can take various forms. There are different types of service homes and group housing. Group housing is supervised by

personnel who are there to help with the requirements of the residents. This help can take the form of personal care, help with doing the washing, cleaning, shopping, help at mealtimes and recreational activities.

A service home allows the individual to live a more independent life but will access to personnel when the need arises. Communal areas are often available in both types of accommodation which provides the residents with the opportunity of meeting and making social contacts.

Day activities

This action provides meaningful occupation for people with intellectual disabilities, autism and brain damage who do not work or study. The action shall provide stimulation, develop and companionship according to the requirements of the individual. This can take place at a daycentre, the workplace or anywhere else.

There are usually a number of activities, which can be adapted to suit the individual's interests and requirements. Some activities involve factory work whilst others are aimed more at creating, such as painting, sewing or music.

When a person has an illness and as a result is functionally impaired or a child is born with functional impairments, advice and other personal support may be needed. The authority responsible for providing this type of support is the

County Council and people can meet with social workers, psychologists, occupational therapists, speech therapists and more.

An application seeking assistance can be made by the individual but a guardian, trustee, custodian or similar can also apply for these actions. Applications are, in this case, also sent to the unit in

the social services office that deals with elderly care and functionally impaired. An Administrator will be in touch to start the investigation to assess the need. Unlike the Social Services Act – SOL – a charge for means testing is not made in this case as all actions under LSS are free of charge. As in the case of SOL, the applicant can appeal against a decision.

An LSS case study

Birgitta Svensson is mother to 23-year-old Kalle and has rung her the social services office to seek action 9.4 in accordance with the Act concerning Support and Service for Persons with Certain Functional Impairments – LSS. Birgitta Svensson is seeking a assistant for her son. Having submitted a written application which has been sent to the LSS group the Administrator contacts Birgitta to book a home visit.

The LSS Administrator visits Kalle and his mother Birgitta in their home. Kalle has an intellectual disability; he has attended a special school followed by upper secondary school for pupils with learning disabilities. When he finished school he started to attend day activities. He is happy there and has learnt to take the bus by himself every day. His day activities are at a carpenter's and his activities at the moment involve screwing together stools. This suits Kalle as he likes doing things with his hands.

But Kalle's parents have, nevertheless, noticed that he has become quieter and more introverted. When Kalle went to school he was happier, had his friends that he also sometimes met at the youth recreation club. Now he goes to his day activities, which he calls "his job" every day and when he comes home he doesn't want to do anything else. In the beginning his parents thought that he might be tired with all the new impressions at work. But now they are becoming worried and are wondering why he has changed.

When they mentioned this to Kalle he couldn't describe what had happened. But they have since noticed that when his siblings meet their friends or their

friends come to the house, Kalle gets moody and sometimes even angry with them. Kalle's parents are wondering if he is jealous. They asked Kalle if he missed his classmates. He did, very much. Kalle's parents hadn't realised that Kalle needed his own friends and not spend all his time with the family on their conditions.

Birgitta is seeking on behalf of Kalle a assistant who can be a friend to him. Kalle tells the LSS Administrator about his interests, if he wants a guy or a girl and even a suitable age for that person.

Kalle says he wants a guy who is about the same age as himself. He would prefer if he was interested in sport as Kalle would very much like to watch the ice hockey and football matches. Maybe even go to town on Saturday and check out the girls, he says. Both the LSS Administrator and Birgitta have noticed how expectant Kalle is and understand how important it is to him to have his own friend that he can do things with in his free time. He has not decided to move away from home just yet but it is important for him to create his own social contacts to become a little more independent of his parents.

The LSS Administrator returns to the social services office and writes a report about Kalle's social situation, health, the actual situation and his needs. The Administrator decides to provide a personal assistant for 16 hours a month. This report is submitted to the placing expert who even recruits caseworkers. A letter informing Kalle of the decision has also been sent to his mother. The LSS Administrator will contact them again when a suitable assistant has been found for him.

8. Working in Different Care Settings

8.1. Ethics and values

◆ A fundamental starting point for all social works is a holistic focus on the needs of the individual. Social services must take a broad view of the individual's situation, problems and resources. It is important understand the individuals situation in relation to the context and environment of which he or she is a part. The necessary interventions must be carried out so that the individual utilises and develops his or hers resources. The general principle of social policy is to safeguard aspect of social work, which is fundamental. The four basic principles are

- ◆ The principle Independence: the individual shall have the right to decide over his/hers life and actions
- ◆ The principle of Goodness: you shall do what is good for others prevent injuries and remove obstacles or harmful elements in everyday life (maximization)
- ◆ The principle of least suffering: you shall strive to avoid harming other people (minimization)
- ◆ The principle of fairness: you shall strive to be fair and just in our actions.

Working with people in need of support in their daily lives means coming close to the aid recipients. It is easy to get emotionally involved and it can be difficult to distance oneself from those

that you care extra for. Our values, i.e. how we look upon things and how we reason, is determined by who we are, our surroundings and society. Values are personal and we are often unaware of them. They determine our actions and how we relate to everything around us. That is precisely why it is important to separate personal values from professional attitudes. In your personal time you are free to act and view matters in your own way. In the workplace however, there is a need to adapt to the organisations and workplace's values and also the unique needs of the aid recipient. All staff that works in different care settings has to follow the basic values stated in the social service act. Everybody also have to sign the secrecy act.

To work as a carer within the disabled welfare sector often involves being part of a team. The place of work can be group housing or the individual's own home. During the day the individual is often away from home participating in various activities, which is when the personnel spend time planning and documenting. Cooperation with other people associated with the individual is also part of the carer's job. This can involve contact with the relatives but also contact with other carers such as physiotherapists and occupational therapists. The exact work tasks are dependent upon the extent of functional impairment of the individual.

A work place can also be a temporary care accommodation centre outside the home. This type of accommodation functions as a relief home for the relatives. There are special temporary care accommodation centres for children and young people. The work tasks involve welfare and care but also making the time at the home enjoyable for the children. This can involve various activities and excursions.

The work is usually according to a schedule, which means that personnel work both days, evening and weekends. At some of the workplaces there are special personnel who work nights and at others duty personnel are also required. This involves the staff sleeping at the workplace and being woken if the need arises.

A carer does not have any medical responsibilities; the duties mainly involve providing welfare and care. A carer can also be asked to administer medication but only after delegation, that means a nurse has given them the responsibility.

The work prospects for persons interested in working within the disability care sector are good. Support and service to individuals with functional impairments is a priority area within society. To work as a carer you need an upper secondary education in health and social care. The salary varies between 1750 – 1900 euro/month depending on your level of education and for how long you been working.

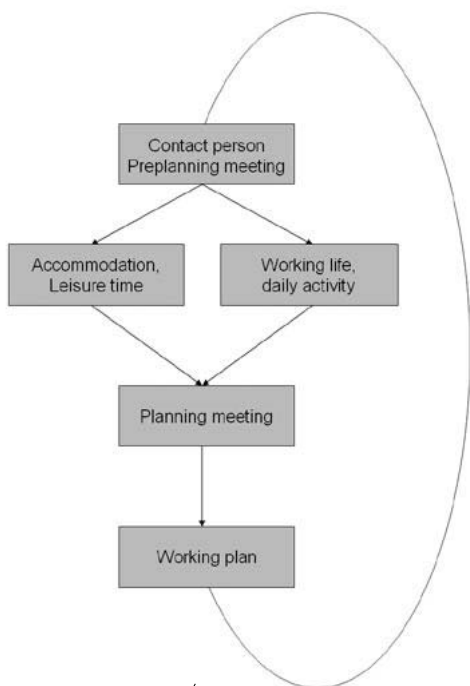
8.2. Working plan

◆ For everyone eligible for support according to LSS/LASS, in their daily activities or in their living situation, a work plan must be drawn up. It should be reviewed on a yearly basis and if needed revised. Before a work plan is drawn up it is important that it is prepared and planned in a series of meetings. In the first meetings the user along with relatives and his or her advocate (if any) meet with a contact person. In the following meetings that contact person meets representatives from the users accommodation, his or her daily activities and the councils social work office. The purpose of the work plan is to set up goals for the user concerning his accommodation, work, activities, health and leisure. The work plan should include a time frame, so that the goals can be evaluated, and an explanation of which party holds responsibility for the specific goals.

The manager at each group housing has the general responsibility to see to it that an individual checklist is established and that there are routines for signing and control of the checklist. The contact person is responsible for ensuring that the checklist corresponds to the individual's needs and that it is reviewed monthly.

For everyone eligible for support according to LSS/LASS, in their daily activities or in their living situation,

a work plan must be drawn up. It should be reviewed on a yearly basis and if needed revised. Before a work plan is drawn up it is important that it is prepared and planned in a series of meetings. In the first meetings the user along with relatives and his or her advocate (if any) meet with a contact person. In the following meetings that contact person meets representatives from the users accommodation, his or her daily activities and the councils social work office. The purpose of the work plan is to set up goals for the user concerning his accommodation, work, activities, health and leisure. The work plan should include a time frame, so that the goals can be evaluated, and an explanation of which party that holds responsibility for the specific goals.



8.3. Work Descriptions

◆ The aim of following work descriptions is to give a picture of how the work is carried out in different care settings and in school. Below is examples of how care for the disabled is provided in Linköping

8.3.1. Group Housing for the Severely Intellectually Disabled at Vallavägen 11

The group housing is located on Vallavägen in Linköping. The building is single storey in pleasant surroundings and houses five people with severe intellectual disabilities. They are four women and one man between the ages of 24-76.

Each resident has his own room which includes a bed and a sofa or similar. There are no kitchen facilities or toilet. They share two bathrooms and a laundry. They also share a kitchen and a combined television room/activity room with a large area in which to move around. The personnel also have a room which they can use to rest in or hold small, planning meetings and also an office. There is a garden surrounding the whole house and an outdoor seating area which is used frequently when weather allows.

Three of the residents share one of the bathrooms with the other two residents sharing a shower room. As they all

use the same laundry their clothes are name-marked before washing.

Every month the residents pay money to the personnel for their food which is then purchased and cooked together. This is usually a light lunch and a more substantial dinner in the evening. Mostly, when all the residents are home they and the personnel spend the time together as it is seldom someone wishes to sit alone in their room. In the evenings dinner is cooked followed by television.

The background of the residents varies. The personnel know a lot about some and very little about others, their previous lives and the childhood. Some come from the parents home, others from a care home or have previously lived with relatives. Their diagnoses include severe intellectual disability, epilepsy, deafness, blindness and/or require wheelchairs.

This type of operation is called BODA – which stands for accommodation and daily activities. BODA operations came about after a project which was run in Linköping in 1988. There are 4 BODA operations in Linköping. Operations involve cooperation between this group housing and a further group housing operation and day centre, which are in close vicinity. Residents from both the group-housing operations meet at the day centre in the mornings as well as the afternoons where they participate in various activities every day. For

example, some activities are standing on a balance board; play in the ball pool, swimming in the heated pool, hand massage, waterbed, walks and various excursions. This provides a good overall picture and continuity in the operation. The day centre has two employees who work full time, there are also personnel from the group housing on hand if necessary.

The group housing has 6 members of staff during the day and three at night. The night personnel are awake and on duty.

The residents each have their own caseworker, personnel who take responsibility for their economy as well as contacts beyond the group housing, for example family and trustee. The caseworker is also responsible for the cleaning in the resident's room.

A normal working day

The personnel start at 06.45 when the night staffs reports to the day staff. They eat breakfast and plan the day according to the schedule. The personnel look through the various activities the residents have planned, for example, the day centre. All the residents shower every morning and need help with everything, lifting out of bed, showering and getting dressed. They also need help to eat their breakfast.

The day at the day centre begins with assembly at 09.15. During assembly all are welcomed by shaking hands with

each other. A page is taken from the diary and the date and the name of the day is mentioned. They all sing a song and then go to the activity according to the schedule. This is followed by a coffee break and then a new activity before going back home for lunch at 11.30. The day centre begins again at 13.15 and finishes at 15.30.

The personnel and residents that remain home during the day have diverse activities, which, to a certain extent, are governed by a schedule. They take care of everything just as they would in any other home. Shopping is planned and carried out, food cooked and served at regular times, clothes are washed, the home clean and things need filling up. Sometimes a few eat lunch at the day centre but dinner is always eaten together in the group housing, residents and personnel. The evenings are usually spent at home, with the residents choosing to go to bed early, about 19.00 or watching television. At 21.00 the night personnel arrive. The personnel exchange information about the days'

activities and how all the residents are feeling. The evening personnel usually work until 21.00 – 21.30.

The personnel work to a 6-week schedule, which they have decided on themselves. Four work 100% and two work 92%. The three night staffs work to a special night schedule. The group housing also has access to an extra staff member, called a temporary pool, which comprises of a girl who helps out with all the group housing operations and can be called in when to replace a member of staff when required.

To cooperate with so many members of staff during a day is not always easy but functions well on the whole. It is necessary to be attentive and aware, to be flexible and together see the needs of the residents at a particular moment. To communicate with a person who has an intellectual disability demands experience and teamwork with requires various ways of expressing oneself with the surroundings. If a person is unable to speak, cannot show feelings and desires with his body, voice and facial expression, he needs a lot of help from people who knows him well. This works well at this home as the personnel know the residents and can read their signals well.

At the moment the personnel and residents are planning a holiday, this year they will be staying three nights at a hotel in Gränna and are hoping for sun and fun-filled days.



8.3.2. Description of Operations at Boställsgatan 17, Group Housing

The group housing is situated in the area of Lambohov which lies north west of Linköping. It is a one-storey building with 5 complete apartments. There is also a large kitchen, an office, a laundry, a living room and a room for the personnel. The building is surrounded by a garden with fruit trees and some bushes. There is even a vegetable patch where they cultivate a few vegetables and herbs.

There are five residents in the building, 2 women and 3 men aged between 35-47 years. All the residents have some degree of functional impairment and all have different types of behavioural disorder, for example, self-harming behaviour, compulsory or anti-social behaviour. Each has a specially devised treatment programme which is suited to the individual's problems. This programme has been designed by a psychologist who is the administrator for the personnel. Threats and violence against the personnel does occur.

A day with us from the residents perspective

Living with us is a lady which we will call Anna. Anna works at the day centre (DC) where she works with various types of dismantling tasks. She wakes up on her own at exactly 07.00 every weekday. Anna comes out and informs



the personnel that she wants to shower and eat her breakfast. She copes with all the morning routines herself. When she is ready the personnel write in a book describing her mood and if anything special has happened that the personnel at DC should know about. This book Anna takes to DC. Anna is also inclined to put newspapers and other things in her bag to take with her to DC. This bag is checked every morning by the personnel which irritates Anna. The transportation services for the disabled take her to DC. Anna likes her job. She enjoys dismantling things therefore her work suits her! At work she has a lot of friends that she likes talking to. When she comes home the personnel check in her book to see if anything has happened at DC that they should know about. When she gets there she spends about 30 minutes in her apartment to wind down. Anna takes a walk every day. The personnel accompany her and they walk for about 30-45 minutes. This is much appreciated. Anna enjoys jigsaw puzzles. She does this a lot at home. Sometimes she comes out and

drinks coffee with the other residents in the evening. Anna copes with all the evening routines herself but sometimes requires help with brushing her teeth. Sometimes Anna gets moody and can hurt herself by scratching or biting her arms and hands. She has trouble keeping her temper in check if things aren't the way she wants them or thinks they should be. She is very social and pleasant girl who copes with most things herself.

A day with us from the personnel perspective

When I arrive here in the mornings I check with personnel to hear how the night has been. Then I look in the diary to see if anything special is happening. We have a computer programme where we write in the daily activities of each of the residents and note their health. Each time a member of staff starts work they check these notes. We have different routines for different days, for example, cleaning or food shopping. Our residents cope with almost all the

morning tasks themselves, we help them by giving instructions so they can manage themselves. Two of our residents are accompanied by personnel to their DC's. When we accompany a resident to the DC we support them by talking to them so that they cope with their work. We often carry out the same or similar tasks. When we come home from DC we write more notes describing the events of the day. It is important that the personnel report to one another on the day's situation and if anything special has happened. The day shift usually ends around 15-16.00. The evening shift personnel check the notes from the morning and look through the day's planning. Almost every evening we accompany the residents to a course, for example, cookery, bowling or drama. For some of these activities we remain and participate. Otherwise we cook and help our residents to cope with their tasks. We make sure they get exercise and the buy the things they need. Our residents cope with most things themselves but need our support to see that things get done. We help most of them with teeth cleaning as they can get a bit careless with that. When they have gone to bed the night personnel fill in the evenings events, they make sure the lights are turned off and the doors to the office and kitchen are locked. We have sleeping duty; this means that we can sleep in a room and the residents can come during the night if they have any worries. It is seldom that we need to get up and help someone in the night. This is a very nice place to work



with nice work colleagues. We all have different areas of responsibility and all the personnel are caseworkers for a resident. This means that we keep an eye out for any incoming post and that they have clothes and anything else they need. I like my job! It's flexible with a lot of responsibility.

Tom Virtanen, 4 April 2007, Boställsgatan 17

8.3.3. Group Housing Aspnäsvägen 120 and Ullnäset Daily Activity Center

Aspnäsvägen is a so-called BoDa unit. BoDa stands for special housing and daily activities as in LSS. The daily activity centre Ullnäset is situated in the vicinity of the housing. The personnel is wholly or partly the same in both units. One of the advantages of this is, according to the personnel, is that it gives the users continuity and security. The goal is for the users to feel relaxed, positive and for the units to be a homely environment where the needs of all individuals are met.

The units have a staff of eight during the day and three during the night. All personnel are scheduled to work at both the housing unit and the daily activity unit. There is a personnel meeting every two weeks.

Living at Aspnäsvägen there are five people with severe intellectual handicaps ranging in age between 29-48 years old. They are all have more than one disability, three of them are in

wheelchairs, epilepsy and probe feeding also occur. The work assignments for the personnel in the housing unit are among other things personal hygiene, laundry, cleaning, cooking, mobilizing the users, contact with next of kin and legal representatives as well as handling the users' finances and shopping.

The daily activity centre Ullnäset is open between nine and four. All users are mobilized according to their abilities. Some of the featured activities are tactile stimulus, pool bathing, listening to tapes, book readings and music, baking, painting, planting flowers, walks and horseback riding. Lunch is prepared and shared together with the users.

One of the advantages, according to the personnel, is the previously discussed continuity and security for the users. The personnel get a much fuller picture of the user than they would get if the units worked in a more traditional fashion, where the users go to a separate daily activity centre with different staff. The personnel feel they



have great influence over the workings of the unit as they get to present wishes for special activities, perhaps with individual users. Another advantage is that the staff gets to know the users in depth and in various situations. The

personnel become more sensitive to the users' body language and are able to interpret subtle nuances. The personnel are involved during the entire day and get a full picture, which creates security and continuity for the users.

8.4. Voluntary Organisations Involved in the Care of People with Intellectual Disability and Functional Impairment

◆ In Sweden there is almost an interest organisation for every type of functional impairment. These associations generally work to protect the rights of the functionally impaired, support research and are even responsible for a large part of the organised recreational activities available.

8.4.1. The Swedish National Association for Persons with Intellectual Disability – FUB

The goal of this association is a society that is available for all and where every person has influence over his own life.

- ◆ Where people with functional deficiencies participate in society and are equal with others, according to the UN standard regulations and Swedish legislation.
- ◆ Where no one is subjected to unfair treatment and discrimination. Legislation which protects and safeguard the rights of the individual are followed.

- ◆ Adaptations to suit the disabled and other support services are provided to ensure the environment in which the individual lives is formed to meet the needs and requirements of the person. FUB does not accept standard solutions.
- ◆ Information and communication designed to allow all to understand and make themselves understood.
- ◆ In solidarity with others our goal of a society for all embrace should our whole world.

FUB together with the Board of Health and Welfare have devised an evaluation tool BUKU, which is a method for evaluating and developing. BUKU stands for Brukarstyrd Utvärdering och Kvalitets Utveckling which means User-steered, Evaluation and Quality Development. This method differs in some respects from other methods insofar as BUKU puts emphasis on the user perspective and immediate benefit through concrete development

proposals. To see that the LSS goals are realised.....

This method comes originally from New Zealand.

8.4.2. The Swedish Federation of Disabled Persons – DHR

The main goal of this federation is to advance the positions in society for people who live with disabilities. The federation's role is to try to inform and create opinion in many different areas. This is called interest politics. Below are just a few of the areas where the federation pursues interest politics: Economic issues, transportation service for the disabled, elderly issues, accessibility in the physical environment, communications, aids etc.

8.4.3. The National Association for Disabled Children and Adolescents – RBU

This is a family organisation offering its members support, companionship and information. RBU pursues and influences politically issues relating to the disabled foremost from a child and family perspective. RBU is represented throughout the country with approximately 13,000 members. The organisation comprises of families with disabled children and young people. The RBU organisation works towards improving the living conditions in society of disabled children and

young people and can provide services such as relief, schooling and aids.

RBU's vision is a fair society and a life of development for children and young people with disabilities.

9. Vocational Education – Curriculum for Nurse Assistants

9.1. The Swedish School System

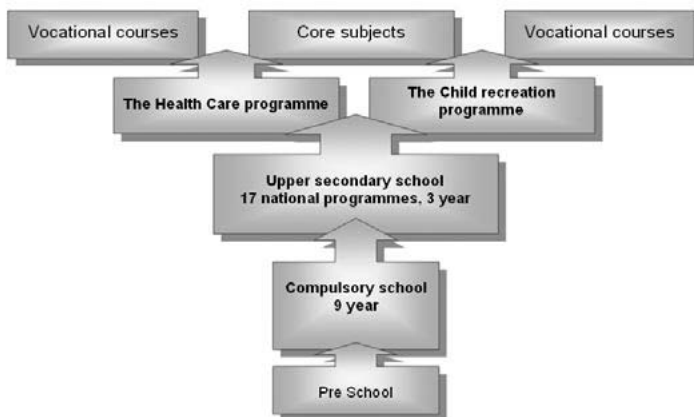
◆ The Swedish public school system comprises compulsory school and various types of voluntary schooling. Compulsory school includes compulsory basic school (for children with impaired sight, hearing or speech), and compulsory school for mentally handicapped. Voluntary schools comprise upper secondary school, municipal adult education and education for mentally handicapped adults.

Tuition in the state school is free. Neither pupils nor their parents usually incur any costs for teaching materials, school meals, health care, school transport, etc.

Curricula, national objectives and guidelines for state schooling in Sweden are defined by parliament (Riksdag) and the government. The national budget includes grants to the municipalities for their various functions.

Upper secondary school

Almost all the pupils attending compulsory basic school continue directly to upper secondary school, and almost all of them complete their upper secondary schooling within three years. Upper secondary school is divided into 17th three-year national programmes, all of which are intended to provide a broad-based education and confer general eligibility for further studies in higher education and confer general eligibility for further studies in higher education. In addition to the national programmes there are also specially designed and individual programmes.



The Health care programme 2500 points



Vocational training is a part of all vocational courses

The Health Care programme is designed to give student's basic vocational training in health care and nursing (somatic and psychiatric), social welfare. By specialisation, students will gain competence corresponding to the requirements needed to work in these areas.

School will aim to give students an education that, on completion, enables them to give service, treatment and care, based on an overall view, and in which the approach used is to release and develop the resources of person in need of care, with respect for their independence, integrity and background.

	Vocational courses 1450 points		Core subjects 750 points	Individual choice 300 points
Year 1	Health and social care		- Swedish - English - Mathematics - Arts education - Physical education and health - Natural science - Religious studies - Civics	
Year 2	Health care	Social care		
Year 3	Individual in-depth courses*			
* Individual in-depth courses <ul style="list-style-type: none"> - Psychiatry - Nursing - Mentally handicapped /disabilities - Care of children and young people - Social Psychiatry - Social care - International co-operation 				

9.2. Aims of the course in intellectual disability/ functional impairment

◆ The course will provide an in-depth knowledge of social welfare as well as providing practical support and service experience to people with intellectual disabilities and other functional impairments. The course will also provide knowledge about factors which affect living conditions and opportunities to develop the individual.

Goals which the students should have achieved after course completion

The student shall:

- ◆ have knowledge of the concept intellectual disability
- ◆ understand and communicate with people who have intellectual disabilities as well as other functional impairments
- ◆ participate in the provision of support and service and welfare to people with intellectual disabilities or other functional impairments



- ◆ participate in planning, reporting and documenting the welfare work
- ◆ have knowledge of how the environment, relatives and carer interact with the individual
- ◆ have knowledge of actual and relevant legislation within this field

9.3 Adult Education

◆ Young persons are entitled to enter upper secondary school up to the age of twenty. After this they can choose between various forms of municipal adult education. This comprises regular adult education (komvux). The komvux programmes comprise both basic adult education corresponding to compulsory basic school and voluntary education corresponding to the courses offer by upper secondary school.

Below is a presentation of the curriculum for adult education at Birgittaskolan in Linköping.

The Health Care Programme, Adult education

Length of programme:

3 terms. The education is intended to be complemented with a further term covering core subjects. The students have the opportunity of studying individual courses from the programme.

Entrance requirements:

Completion of compulsory school education or equivalent.
Minimum age for adult secondary education (komvux) is 20 years.

General information about the programme

This programme will provide the competence equivalent to the basic professional requirement necessary within health and medical care sector. This means a student can apply for a position as an auxiliary nurse, a psychiatric attendant, personal assistant etc within a municipality, County Council or the private sector. The courses provide the student with the opportunity of conducting in-depth studies in a particular field.

The programme is divided into courses. Certain parts of some of the courses include workplace training (APU) or field studies, in total 15 weeks. During the workplace training periods the student will adopt the work hours of the workplace.

The whole Health Care Programme can be completed within 3 terms or certain courses can be studied individually. It is possible for students to study two terms to achieve a specific competence or individual courses if preferred.

If a student already has work experience from the care sector the knowledge gained can be considered through validation. This means the school will evaluate the knowledge and ability gained through studies, social life and work experience, both formal as well as informal. If a student wishes to study at their own pace this is possible through distance learning.

Future prospects

Today the programme is designed as presented above, but the curriculum will be revised in the coming years..

April 2008, the minister of education presented a reform for all upper secondary education in Sweden, with start 2011. What effect it will have of the health care programme is impossible to say at the moment, but in the proposal you can read that the vocational subject shall have more space in the curriculum. Changes to the programme are not yet known, however opportunity to participate in apprentice training courses may increase.

10. Employment Opportunities

◆ The local authorities are responsible for social services, and the care of people with disabilities. The municipal social services are governed by framework legislation, which specifies the framework and objectives of activities. Each municipality can shape a their own design of the care, as long as the design follows the guidelines in the social service act. In many municipalities there are a buying purchasing process of the care of people with disabilities, the care have shifted over from the society run units to new private providers. Today there are a wide range enterprises working in this field, both small, big, local and nation wide companies alongside with the municipality units.

After finish upper secondary school at Health care programme or Child and Recreation programme, can you either work as assistant nurse, personal assistant, assistant occupational therapist or assistant physiotherapist, at a group dwelling or day centre. If you work as a personal assistant, you assist the person in all type of daily activities he/she needs at home, at school or at work.

Within the coming years the number of people retiring is expected to be large and the municipalities will be recruiting personnel within the disability care sector. In Sweden today there are about 40,000 people working as carers in the disability care sector. A full time job within this sector involves an average workweek of 37-38 hours and an average salary of SEK 18,000 per month (1950 euros).

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A. Appendix

A.1. Work Plan

Accommodation with special service for adults and short time-accommodation for adults as specified in LSS
(Responsible person: Accommodation contact person)

Name of user	Social security number		Plan draw up on date	Plan revised on date
User lives/work at	Existing other work plan? <input type="checkbox"/> Yes <input type="checkbox"/> at the accommodation <input type="checkbox"/> NO <input type="checkbox"/> detailed plan			
Closes kin.	at the work place		Telephone	
Advocate / legal representative			Telephone	
Accommodation contact person			Telephone	
Contact person workplace / daily activities			Telephone	
Special information	Medication? <input type="checkbox"/> Yes <input type="checkbox"/> No	Epilepsy? <input type="checkbox"/> Yes <input type="checkbox"/> No	Special aids? <input type="checkbox"/> Yes <input type="checkbox"/> No	Transportation service? <input type="checkbox"/> Yes <input type="checkbox"/> No
			dental care? <input type="checkbox"/> Yes <input type="checkbox"/> No	Contact person LSS §94? <input type="checkbox"/> Yes <input type="checkbox"/> No but accord
Other details				
Consent (Revised 1 time/year)	As user/legal representative I consent that this work plan is used to plan my work (under condition of confidentiality) in the daily work surrounding the users accommodation and daily activities <input type="checkbox"/> Yes <input type="checkbox"/> No		Consent for Procurement of Education visits (special form) <input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No Signature/ Legal representative User			

ACCOMMODATION			
Goals of effort. How is the effort to be performed? Part goals/ wishes / Participation?			
Who is responsible? Finish date if applicable			
Cooperation		Who is responsible? Finish date if applicable	

WORK ACTIVITIES			
Goals of effort. How is the effort to be performed? Part goals/ wishes / Participation?			
Who is responsible? Finish date if applicable			
Cooperation		Who is responsible? Finish date if applicable	

HEALTH

Goals of effort: How is the effort to be performed? Part goals/ wishes / Participation?

Who is responsible?
Finish date if applicable

LEISURE

Goals of effort: How is the effort to be performed? Part goals/ wishes / Participation?

Who is responsible?
Finish date if applicable

Cooperation

Who is responsible?
Finish date if applicable

Workplan is to be revised (at planning meeting) at least once per year or at need. The work plan is drawn up in two copies, were of one is for the use or legal representative. The original is to be kept in the users personal file

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Care Work with People with Disabilities – Sweden

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