



Presentation of the Organisation and Its Work on Cognitive and Communicative Support

Habiliteringens resurscenter, Stockholm

Presentation of the Organisation and Its Work on Communicative and Cognitive Support

Habiliteringens resurscenter, Stockholm

Editor-in-chief

Claire Davalo

Managing editor

Rupert Hasterok

Author

Fredrik Thurfjell

Edited and designed by

Comparative Research Network e. V.

Picture credits

Habiliteringens resurscenter

© 2022 Habiliteringens resurscenter, Stockholm

Contact address:

Habiliteringens resurscenter

habresurscenter.sls@regionstockholm.se

Olivecronas väg 5, 113 61 Stockholm



Co-funded by the
Erasmus+ Programme
of the European Union



Open Educational Resources

This report has been published within the framework of the project Média +, which has been co-financed by the programme Erasmus+ of the European Union (2019-1-FR01-KA202-063197). The European Commission's support to produce this publication does not constitute an endorsement of its contents, which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Images displayed in this publication are the property of their respective photographers or creators. They may not be reproduced without the permission of the photographer or creator. If you wish to reproduce an image please contact the project coordinator via the address above.

Contents

Sweden's Legislation and Public Policies on Disabilities and the Rights of Persons with Disabilities	1
Habilitering & Hälsa	3
Habiliteringens resurscenter	6
Family-Oriented Work, a Corner Stone of the Organisation	7
Exhibition and Show Room on Cognitive and Communicative Support	8
On Communicative and Cognitive Support	13

Sweden's Legislation and Public Policies on Disabilities and the Rights of Persons with Disabilities

The Act concerning Support and Service to Persons with Certain Functional Disabilities (Lag om stöd och service till vissa funktionshindrade, or LSS) entered into force in 1994. It is a human rights law designed to offer people with extensive disabilities greater opportunities to lead independent lives, and to ensure that they have equal living conditions and enjoy full participation in community life. The law gives people with certain disabilities the right to personal assistance, a form of support that is mostly funded by taxes. The amount of help they receive is determined by the extent of their disabilities. People not covered by it can seek assistance from their local council/municipality under the Social Services Act.

Sweden's disability policy is based on the UN Convention on the Rights of Persons with Disabilities. It takes advantage of the rights and interests that people with disabilities have in society and covers several areas, such as labour market policy and education policy. The aim is to provide equal opportunities for persons with disabilities.

“Design for all” is one of the guiding principles in Sweden's accessibility work. General inaccessibility means that people with functional disabilities do not have the same opportunities as others to participate in community life. The Swedish government is working to overcome this problem in various ways. If society is designed for all, it is also accessible to all.

Overall responsibility for improving accessibility is divided between different levels of government and public agencies:

- The Swedish government and parliament establish guidelines for disability policies, mainly through legislation.
- Government agencies have a national responsibility for specific sectors, including education, health care and employment.
- The county councils are responsible for health and medical care.

- The 290 Swedish municipalities are responsible for education and social services, among other things.

All citizens should feel that laws are reasonable and relevant, that the justice system is there for them and that it is effective and ensures compliance with their legal rights. Accordingly, police authorities must analyse their operations from a disability perspective. For instance, crime victims with disabilities must be able to understand the information they get. Similarly, the Swedish National Courts Administration are tasked with making Swedish courts more accessible.

Habilitering & Hälsa

Mission and organisation

Habilitation & Health changes everyday life for children and adults with disabilities and their relatives in the Stockholm Region. We consist of 30 specialist clinics that provide advice, support and treatment to prevent and reduce the difficulties that a disability entails. As a care business, we have three basic assignments in addition to specialist activities:

- to provide care;
- to supervise students;
- and to contribute research.

We are part of the Stockholm Region and work on behalf of the Health and Medical Care Administration. As a specialist business, we are a complement to the general health-care. Our assignment and who we are to help are described in detail in a care agreement (HSN 2018-1264). Our mission in brief is

- to provide habilitation efforts to children, young people and adults with permanent disabilities;
- to provide habilitation efforts to their relatives;
- to spread knowledge about disabilities and society's support.

Spreading knowledge about disabilities and society's support takes place through, among other activities, open training courses, our websites, a query service and our library specialising in disabilities.

Habilitation & Health's Ressources about Disabilities

Research, reports and best practices are published for a wider audience in our magazine "Funktion I fokus", our newsletter and on our FaceBook page.

Podcasts about living with a disability present personal stories and offer advice from experts.

A query service about society's support in the event of disability.

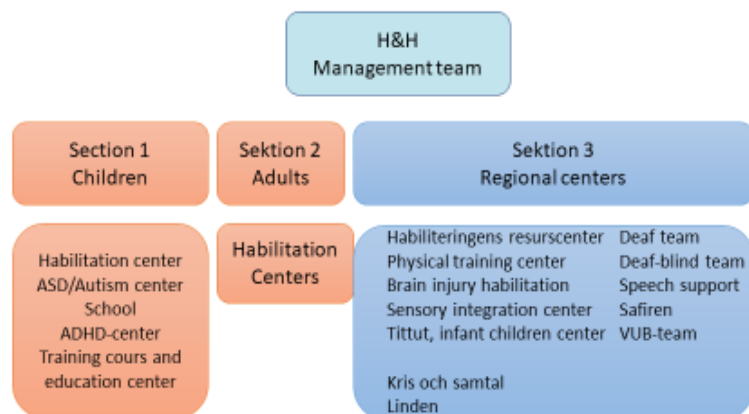
Information on different and multimodal aspects of disability.

Special websites on autism are dedicated to knowledge and support throughout life, to young people with a diagnosis within the autism spectrum and to parents with their own diagnosis.

Courses and educational ressources are presented on our library specialising in disabilities, our display environment for cognitive and communicative support, our catalogue of courses, groups and lectures and through material that can download and ordered.

Habilitation & Health is divided into a management team and three main sections, for children, adults and countywide establishments. It runs 30 specialist clinics in Stockholm County.

Habilitation & Health 2021



The management team consists of an operations manager, section managers, a chief of staff, a communications manager, a habilitation doctor and an R&D manager. It is responsible for central coordination, as well as quality and business development, such as administration, patient safety, e-health, HR and staff training. The staff also includes ex-

Presentation of the Organisation and Its Work on Communicative and Cognitive Support

perts, specialist services and coordinators for habilitation programmes. R&D works on business-related research, supports employees, administers development projects and provides staff training. It also acts in an advisory capacity to management.

Habiliteringens resurscenter

Habiliteringens resurscenter was established in 2019 as part of Habilitering & Hälsa in Stockholm County Council (now Region Stockholm). It came into existence by merging four former independent organisations within Habilitering & Hälsa: Stockholm Centre for Communicative and Cognitive Support (StoCKK), founded in 2012; Forum Funktionshinder, an information and counselling centre on different disabilities and governmental support; Stödenheten, consultative and counseling support to staff; and Internet habilitation, responsible for digital-based education and the treatment for people with neuropsychiatric challenges. The new organisation had been planned for and formed during more than a year through mutual cooperation and profound discussions on its future organisational structure, methods, goals and means. Habiliteringens resurscenter (resource centre) were after the merge commonly located in a single building to develop and promote co-existence and cooperation in common work.

Habiliteringens resurscenter's aims include providing information, counselling and advice on functional disabilities, governmental and social support and on communicative and cognitive support. The centre also offers individually adapted support for persons with communicative and cognitive needs. Another of its important tasks is to provide and arrange for educational activities for families, training courses and internet-based courses designed for patients, parents and relatives, as well as professionals working at Habilitering & Hälsa and staff who meet people with different communicative and cognitive disabilities.

Habiliteringens resurscenter is engaged in partnerships and closely collaborates with associations of deaf persons and parents' associations. Habiliteringens resurscenter has a running cooperation with the deaf-blind professional team of Habilitering & Hälsa organisation, focusing on mutual issues of concern, and development of future handling of matters of common interest. Habiliteringens resurscenter meet people with visual and hearing disabilities, combined with other challenges in physical, cognitive and linguistic ability. Mostly we do not work especially with the visual or hearing impairment, although these matters

are of great importance while dealing with primary matters of concern that we face in meeting people directly or through their network on an advisory function.

Habiliteringens resurscentre is also cooperating with parent and patient organisations, such as The Swedish National Association for People with Intellectual Disability, RBU, The Swedish Association for Disabled Children and Young People, Riksförbundet Attention, an interest organisation for people with neuropsychiatric disabilities (NPF), such as ADHD, autism spectrum disorders (AST), language disorders and Tourette's syndrome.

Habiliteringens resurscenter's staff of 52 persons consists, in addition to its directors and administrators, of occupational therapists, speech and language therapists, psychologists, special education teachers, social workers, technicians, librarians, psychosocial guides (on NPF and multi-functional impairments) and staff providing advice and support on social and community support for children and adults.

FAMILY-ORIENTED WORK, A CORNER STONE OF THE ORGANISATION

The centre's work focuses in all contacts with children, teenagers and adults on the families and network who meets the person in need of different treatment measures. This means that members of the family: parents, siblings, grandparents, cousins and others, are in the centre of action treatments, ie education training, counselling and other measures to be carried out. The child or person who needs support is referred to the centre either by a speech pathologist, occupational therapist, psychologist or special education teacher at a local habilitation centre, but always on behalf of the family or, on more rare occasions, by the person self. The referral is the result of a direct contact between the therapist and the child during a shorter or longer period of time, often consisting of thorough observation and examination of skills, needs and behavioural factors which are reasons for wanted actions formally expressed in the written referral. It often contains anamnestic details of the persons abilities, skills, challenges and possible ways for future development.

The next step is to arrange a first meeting with the person, their family and often the surrounding network to get to know each other and have their expectations and wanted actions expressed. Through talks, interviews, questioning and answering questions it is possible to reach a higher level of mutual knowledge and understanding of one another. Thus the ground to take steps forward is laid and a plan for further actions and measures

are made. What they consist of is individual and specific from one person to another and are objects for more detailed planning in steps over short and longer periods of time. When the actions are decided it is time to make an agreement of responsibility for each person involved; the child in centre, family members, network, the professionals of the centre and others, such as school staff and care takers. Measures of action can be carried out either at the home of the child or in other suitable places: nursery school, school, day centres or work places. During the intervention all measures are evaluated at certain check points to identify deviations and needs of adjustment so the plan can be implemented. How long this period will last is of individual and related to personal factors and prerequisites among all people involved. Important is to throughout the work uphold an open spirit and climate to raise and discuss questions and uncertainties that occur among all people involved along the road. Doing so will make it possible to reach the desired goal for the child or person in centre of concern.

In addition, the centre arranges training courses for individuals and groups, as well as lectures for persons with a disability and their relatives. The lectures can, for example, deal with society support, problem behavior or empowerment. We also have several web courses, including autism related issues. During spring and summer 2021, only digital courses, groups and web courses were offered.

EXHIBITION AND SHOW ROOM ON COGNITIVE AND COMMUNICATIVE SUPPORT

The exhibition and show room at Habiliteringens resurscenter is a permanent and central part of the organisation and its activities. Once a week it is open to visitors who can attend it for free and with no referral needed. That is, since the pandemic situation emerged in 2020, visitors book a dedicated forty-five-minute visit in the centre and exhibition. Before the pandemic there was a weekly Open House every Wednesday where visitors could arrive without booking a timeslot. Hopefully this can be resumed when the health situation allows so.

The exhibition on cognitive support was originally started as a project called “Klara Mera” (“I can manage!”) via H&H (then the Care Board), the National Board of Health and Welfare and the Assistive Technology Institute in 1997. It was then one of the stimulus grant projects that received funding to increase access to cognitive support and increase

knowledge about the same for people with intellectual disabilities. It was carried out as a project until 1999 and then became part of H & H's services.

Initially, the target group for the project was adults with intellectual disabilities (IF), their relatives and staff. We knew from experience that many with IF were dependent on the knowledge of staff and relatives to gain access to support. It was also known that you can not just talk about cognitive support or show pictures. People with IF need to see and try out things in a concrete way.

In addition, the project also arranged training courses for adults with IF in computer use and software. The courses consisted of five occasions to try in practice, and with image-based manuals. At the last occasion, relatives and staff were invited so that participants could show which programs they had learned and different ways to use a computer.

Thus, we started as early as 1997 with study visits in a “natural environment”, which then became the Basic Course in Cognitive Support (demonstration supplemented with a theory part) and which later became the Open House. As a complement to this, occupational therapists could send requests for individual visits with patients (which later became a referral from various professional groups). Over the years, the target group has been expanded to children, adolescents and adults with various cognitive disabilities and the exhibition has been developed with several rooms and also with technical aids, methodological instructions and picture based low tech material for communicative support. Today, also the public library of Habilitating & Health, specialised in literature about different kinds of disabilities, is situated at our Centre. And frequently visitors to the exhibition and showroom also become borrowers there.

The number of visitors varies over time but the weekly total is around 20-50, some days even up 100. That was before the pandemic situation of today. The total annual number of visitors is between 2,000 and 3,000.

The purpose of the showroom and exhibition is:

- to increase knowledge and the availability of communicative and cognitive support
- for anyone interested in this field. Both individuals with disabilities, their relatives, caretakers and other professionals.

- to show and give good examples of communicative and cognitive support in natural environments and dedicated exhibitions.

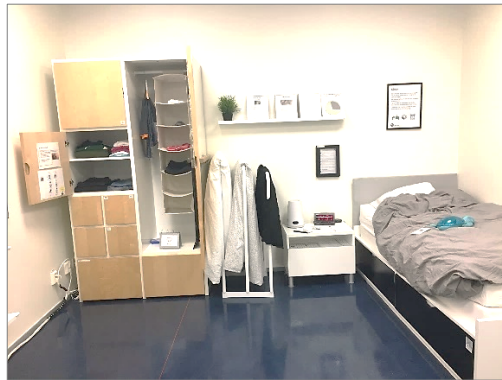
We show products that can be prescribed as cognitive or communicative aids, and others, including commercial products, that can be bought in ordinary shops.

Visitors can also take part of custom adjustments and buy symbol-based support, ie communication boards, schedules for daily or weekly planning, or material that promotes and augments a persons understanding of the concept of time and changing of sequences.

Below are some photographs of the exhibition and the showroom.



Living room



Sleeping room



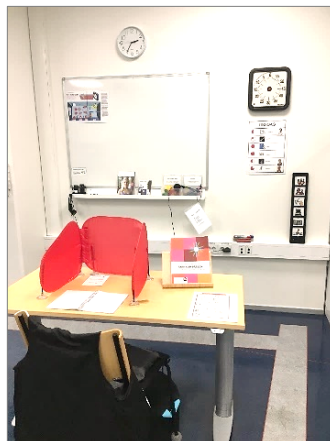
Bathroom



Presentation of the Organisation and Its Work on Communicative and Cognitive Support



Home office



Place for school work



Hall



Kitchen



Adaptations to control an oven



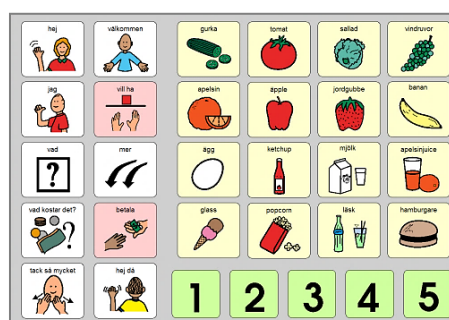
Laundry



AAC exhibition



Symbol-based AAC device



Communication board

måndag	tisdag	onsdag	torsdag	fredag	lördag	söndag

Colour-coded weekly schedule

On our [website](#) there are videos available in several languages from the exhibition centre to watch before and maybe also after a visit.

On Communicative and Cognitive Support

Communicating is a fundamental human right. Not all people can speak, but everyone can communicate in some way. It can be done through speech, writing or through other expressions. In order for a person to be able to express themselves and understand as well as possible, a communicative environment is needed, where the environment adapts to the needs and stimulates interaction and communication. People with communication difficulties may need help both to express themselves, and to understand what others are saying. They need communicative support, which can be a tool or a way for the environment to relate and support communication.

The purpose of communicative support is to create opportunities for the person

- to communicate about anything, anytime, with anyone;
- to understand what is being said and communicated around them;
- to communicate in a socially acceptable way.

You can make it easier for people with communication difficulties by

- making sure the aids the person needs are available;
- using the aids that the persons needs to learn to use;
- using the aids that the person needs to understand;
- customising your speech by, for example, speaking more slowly, using fewer and simpler words and, or, by clarifying what you say through pictures, signs, gestures and similar means;
- by giving extra time – it takes longer to communicate alternatively.

Communicative support can be more than support in situations where you communicate with people nearby. Is it problematic to communicate by phone or electronically? Then you need help with what we can call remote communication, perhaps combined with AAC.

You may also need communicative support in certain situations. For example, if you have difficulties in social situations when communicating with others, if you have a lack of control over your behavior or have difficulty reading from other people. Communicative

support can also be closely related to cognitive support. An image or symbol used to create an understanding of a situation or event can also be used as a kind of "come-on aid" in communication.

What is cognitive support? Cognitive support is something that makes it easier to understand, remember, think, plan and manage time. Cognitive support can be anything from technically advanced devices such as computers, custom computer programs and control methods, to technically simple things such as colored tape and images of various kinds. A cognitive support can also be that a person who is nearby adapts their way of being or their way of working to facilitate and create clarity and structure for the person with cognitive difficulties.

Cognitive support can also involve helping to select information or present information so that the recipient understands and can use it, as well as making information available where and when it is needed.

The purpose of cognitive support is

- to give increased independence and participation in their own lives;
- to make it possible to perform everyday chores on your own, such as cooking, washing or calling;
- to facilitate understanding and control over what is happening in the environment, for example to be able to plan and fit times and to understand information.

You can make it easier for people with cognitive difficulties by

speaking clearly, concretely and by avoiding parables or complicated word twists;

- showing what you mean by pointing or turning your body;
- using pictures or characters;
- making sure the aids the person needs are available;
- by avoiding disturbing moments and too many other impressions.

ALTERNATIVE AND COMPLEMENTARY COMMUNICATION

Alternative complementary communication (AAC) is the collective name for different communication methods and methods that support communication between people. AAC

helps those who have difficulty communicating to express themselves or understand others, usually both parts.

AAC can be anything from simple pictures or photographs to voice devices and computers with different control modes. The same person usually needs different options and complements depending on the situation and who to talk to. To find the right AAC for a person, you look at the person's conditions and map the needs that exist in the environments the person lives in. In all forms of AAC, the support of the environment is crucial for how communication will work.

Everyone who has such severe communicative disabilities so they can not rely on their natural speech to cope with everyday communicative needs needs some kind of AAC. It is a very heterogeneous group, ie the people show great differences in terms of age, cognitive, communicative and motor abilities. According to research, the group comprises about 1.3 percent of all citizens.

AAC does not hinder the development of speech, but rather increases the opportunity to learn to speak because you get the opportunity to communicate. It is therefore very important that children who need support to develop their communication get access to AAC early. It is also never too late to start with AAC.

Early AAC – close-to-body communication. For people who are at an early communicative level, we in the environment become very important. By being present and responsive, we can ensure that communication and participation are ensured. Natural reactions and body signals are used and interpreted.

TAKK – Sign as AAC. TAKK is one of the most common AAC methods used in Sweden. TAKK is not the same as sign language, but you use TAKK together with spoken language. When you use TAKK, you do not have to worry about gadgets and technology that will work, you use your own hands.

AAC with picture and symbols. Pictures and symbols can make it possible for a person to express themselves and also facilitate the understanding of what others are saying. The pictures and symbols should be supplemented with text, so that everyone around them understands what they mean to the person. When we use image/symbol communication with a person with a communicative disability, it is important that we use so-called

aided language stimulation with the person to enable learning of the communication method and to develop the person's language.

Image-based AAC is available in many different forms:

Situation map is a communication map that is adapted to a specific situation or activity. Such a picture map can be the first contact a person makes with picture communication and can be very positive to use if it is a fun and motivating game or other activity that is pictured!

General communication map is a communication map where the user has his vocabulary on a map.

PODD (Pragmatically Organised Dynamic Displays) is a way of organizing an image-based vocabulary based on communicative and pragmatic functions, that is, based on how one uses language. PODD books have a structure that follows people's linguistic and communicative development and that facilitates the development of more advanced communication. PODD can be used both low- and high-tech, in book form or in a communication computer.

PECS (Picture Exchange Communication System) is an AAC method that aims to train communication for people whose basic problem is that they do not direct their communication to other people. PECS is based on a structured learning and development of request, but the idea is also to develop into more functional communication ways.

SPEAKING AIDS

A talking aid reads out recorded messages or speaks with synthetic speech. Talking aids are available in many designs, ranging from a small button with a message to advanced ones with a large vocabulary. Either you point directly at pictures, symbols, letters or text on the aid, or you control it in an alternative way.

Conversation device where you can record sound, with one or more levels, is a good way to supplement the communication for a person who uses situation maps for their communication. When the person then presses the image/box, the device reads out what you have recorded.

Many AAC solutions can today also be used in a computer, smartphone or tablet. Then you use programs/apps that are dynamic, so you can make customizations with images, text and sound that can be scrolled around with the help of the program's built-in functions.

INDIVIDUALIZED SUPPORT AT THE HABILITATION RESOURCE CENTRE

People with autism, intellectual disability, reduced mobility or acquired brain injury can receive individualized counseling and efforts regarding speech and language, communicative and cognitive support from the Habilitation Resource Centre. There are different ways of get into contact with the centre. Persons in need can either apply by themselves and will then receive advice on or are loaned apps and software for development and learning. Or the centre can assist them through a referral. In order to receive individualised advice or intervention, a referral is required. It can be sent from staff in Habilitation & Health, ie an occupational therapist and speech therapist, or from an occupational therapist or speech therapist in psychiatry, the primary care sector or the municipal LSS health authority.

We work closely with the therapist who refers to us and are happy to see that he is involved in the visit. Often also parents, relatives, staff in school, nursery school, day care and activity centres for adult take part in meetings. The visit at the centre can be for just one occasion or for a longer period of time with several meetings. This is individually formed and based on the needs and wishes of the individuals and their surrounding network.