

# STIL, the Stockholm Cooperative for Independent Living

STIL, the Stockholm Cooperative for Independent Living, has become a national and international model of user-run personal assistance services based on the [direct payment principle](#). (STIL has its own [homepage in Swedish](#).)

## Background

In order to better understand the work and role of STIL some background information on Swedish social politics is provided here.

## Division of responsibility in the social area

The Swedish social welfare system is administered by the three levels of government: central state, county councils, and local governments. The national government is responsible for issuing laws and regulations and their enforcement. In addition, functions such as social insurance, housing subsidies, labor market measures including vocational rehabilitation and education are administered at this level.

Sweden, as other European countries, has been hit by slow economic growth and austerity programs inflicted on the public sector. Thus, the central government's financial role in social politics is gradually shrinking. At the same time, there are very few guaranteed rights in the area of disability which would protect persons with disabilities from changing political priorities and budget cuts.

The country is divided into 24 county councils which are responsible primarily for health care and related areas such as medical rehabilitation, provision of technical aids to persons with disabilities, and programs for the mentally retarded.

On the third level of government, Sweden is divided into 280 municipalities charged with the provision of housing, social services, public transportation, and schools. Each level of government has taxing authority. Revenue sharing from central government to the county councils and the municipalities for specific programs is being gradually replaced by block grants.

Local governments have a large degree of autonomy in both the extent and the type of services delivered depending on the local tax base and local political priorities. It is for these reasons that the provision of some social services varies widely across the country with severe consequences for the geographical mobility of persons with disabilities.

## National insurance benefits

The backbone of Swedish social policy is the National Social Insurance which covers health insurance, pensions, occupational injury, and unemployment insurance. Swedish citizens and residents are covered regardless of income. Except for a flat fee for some of the services the cost of the National Insurance is borne by national income tax funds. Here a few examples are presented for the extent and type of coverage under the insurance.

Hospital care and out-patient visits including all costs of consultation, diagnosis, prescriptions and treatment such as physical therapy are covered. The user has to pay a fee for each service whose annual total sum is maximized at 2 200 SEK or approximately 270 ECU.

Sick leave allowances correspond to 80 per cent of the income which the beneficiary would have earned, if he or she had not been ill. This amount is taxable and is paid from the second day after notice has been given to the local insurance office.

Pension benefits consist of old age, disability, and widows' and children's pensions. In recognition of the fact that a disability entails higher costs of living a monthly disability allowance is granted to persons with disabilities, the highest amount paid being a taxfree 2000 SEK or 230 ECU.

In connection with the birth of a child, with or without a disability, the parents are paid an allowance to compensate for the temporary loss of income. Both parents together receive the equivalent of a total of 260 days' income which they can share in any way they choose, before or after birth.

Housing expenditures are subsidized by the national insurance scheme for eligible low-income households such as retired people, disabled persons and children with single parents.

## **Assistive devices**

Assistive devices for persons with disabilities are considered an important and cost effective part of the National Health Insurance. The major regional hospitals have a department for technical aids where occupational and physical therapists under the supervision of a rehabilitation M.D. run an exhibition of devices. Clients can try out and take home a wide variety of devices from electric toothbrushes to ceiling hoists, motorized wheelchairs, speech communicators, etc. Devices are dispensed and maintained by the hospital regardless of income. Short-term users may have to pay a fee. Due to budget cuts waiting times for new equipment of several months are not uncommon.

## **Transportation**

Transportation services for the general public including people with disabilities are under the responsibility of local governments. As a result there is a wide variety of solutions of differing quality and costs to consumers. Unlike other countries where disability organizations have demanded equal access as a civil right with the emphasis on accessible public transportation, Swedish municipalities and disability organizations have opted for subsidized taxi cab transportation and segregated paratransit. Persons who cannot transfer from their wheelchair to a car seat are eligible to use the paratransit system which consists of a fleet of specially adapted vans. In Stockholm, for example, the service has to be ordered at least one day in advance. Users have to count in the possibility that other riders may be picked up en route which may extend a trip that ordinarily would last 20 min to a "sight-seeing tour" of 40 min or more.

As far as public transportation is concerned, the underground system in Stockholm, the nation's only one, is fairly accessible to wheelchair users but no attempt has been made to make public busses and commuter trains accessible in Stockholm. All recently purchased low-floor busses in Stockholm, for example, lack lifting platforms or ramps. Wheelchair users without assistance cannot surmount the step of some 30 cm that remains after the bus has

"kneeled" down.

Despite the fact that the lack of accessibility in the public transportation system is a highly discriminatory practice there are presently no legal remedies, since discrimination of persons with disabilities is still not prohibited by law, neither in the Swedish constitution nor in special legislation.

## **Accessibility in the built environment**

Sweden was one of the first countries to adopt accessibility standards for public buildings. The legislation was extended in 1977 and now covers also residential construction both new and, less stringently, existing structures undergoing renovation. All structures erected after 1977 of three floors and more in height must have wheelchair accessible elevators. All kitchens, bathrooms and hallways within apartments must be large enough for wheelchair access. New construction and renovation activity has, however, been low during the 1980's and 1990's the lion's share of the housing stock is still inaccessible. In Stockholm, for example, some 92 per cent of the total housing stock are estimated to be inaccessible to wheelchair users.

While general accessibility in the built environment will come about only slowly, individual adaptation of the homes of persons with disabilities is made possible by local governments housing adaptation grants. These funds are commonly used for kitchen and bathroom remodeling. In some instances installation of elevators in private homes has been funded. The program is applied on the basis of need and eligibility is not means-tested.

## **The keys to Independent Living**

The criterion suggested here for assessing social policy is the degree to which a given policy facilitates or hinders an individual's progress towards Independent Living. Independent Living, by way of a definition, is a philosophy and a movement of people with disabilities who work for equal opportunities, self-respect and self-determination. "Independent Living" does not mean that we do not need anybody, that we want to do everything by ourselves or live in isolation. "Independent Living" means that we want the same control and the same choices in every-day life that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus, work in jobs that are in line with our education and abilities. Most importantly - like everybody else - we need to be in charge of our own lives, think and speak for ourselves.

Accessible housing and appropriate personal assistance services are the two key requirements for de-institutionalization. If one of these two ingredients is not present, persons with extensive disabilities can choose only between living with their parents or move to institutions. These extremely limited and limiting options are incompatible with an ordinary lifestyle, full citizenship and the concept of independent living.

## **Personal assistance: a definition**

Persons with extensive disabilities need assistance by other people in their everyday lives with such activities as getting bathed and dressed or going to the toilet; with shopping, preparing meals, cleaning or doing the laundry; with such responsibilities within the family as doing the practical tasks involved in raising small children or assisting one's aging parents. Assistants help the user at work, about town and on travel. They assist in communicating or in structuring the day, as the case might be. In brief, assistants help with those activities which the user would have done by himself or herself, had it not been for a physical, sensory, mental or intellectual disability.

Just as other persons with less extensive disabilities can compensate their functional limitations by using assistive devices, assistance - if properly organized - can enable us to become fully-functioning citizens. Doing everything by oneself is not always the most efficient

way of achieving one's goals. What counts is to get things done according to one's own needs and wishes.

People who are dependent on others for the most basic needs of life face prejudices. For instance, somebody who is physically dependent on other persons may also be considered emotionally and intellectually dependent. Somebody who cannot pull up his or her pants like a small child, may be treated as a small child in other respects as well. The result is often over-protection and custodial care where other people make the decisions.

It is no surprise then that the Independent Living philosophy is most easily grasped by people who are dependent on assistance in their every-day lives. This is also the reason why the Independent Living Movement emphasizes the importance of the quality of assistance for users who want to achieve maximum independence. In order to provide an operational definition for quality, the Independent Living Movement coined and defined the term "personal assistance":

"Personal" assistance means that users exercise the maximum control over how services are organised and custom-design their services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the individual user decides

- who is to work,
- with which tasks,
- at which times,
- where and how.

Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, "personal assistance", means that the user is the boss.

It is recognized that users with learning or mental disabilities will need support from third persons with these functions.

Personal assistance enables users to take their rightful place in family, at work and society with all the rights and duties that the general population takes for granted. With personal assistance persons with extensive disabilities need no longer be a burden on their families. Parents, husbands or wives do not need to stay at home and sacrifice their careers. Personal assistance users not only manage on their own, they can also take their share of household and child-rearing. With personal assistance we can attend school and educate ourselves, enter the labour market and become tax-payers. When we fall in love, our partners need not fear that they are about to sign up for a life-long 24 hour job.

Most existing services cannot be called "personal" assistance because they are tied to given physical locations, such as institutions, and not to the individual who needs the service. Thus, the user has to follow the service rather than the other way around. In this way, many disabled persons spend their lives away from their families in institutions, since assistance is provided only in the institution but not in the community.

Most community-based services do not provide "personal" assistance either, because the individual user is not in the position to recruit assistants and has to accept assistance from available staff. Inherent in these solutions is their hierarchical structure with the user at the bottom and the user's dependency on the decisions and rules made by other people. Also, whenever several users share the same staff, freedom of movement and choices are severely limited.

Other limitations exist when assistants do not have proper employment contracts and wages. Under these circumstances users can neither demand quality work, attention and reliability nor can they feel fully in charge.

In the following a brief history and description will be provided of the Swedish local governments' home help services, the founding of STIL and its work culminating in the recent assistance reform.

## **Brief history of Swedish in-home assistance programs**

Swedish in-home assistance programs date back to the beginning of the century when such services were established as small and informal mutual insurance schemes at the neighborhood level or were organized by the incipient labor movement along the lines of trade membership. These schemes were primarily intended to provide temporary relief to the family in case of the mother's illness.

With the the Social Democratic Party's rise to power in the 1930's, local governments took over the programs and expanded them. Now the service was geared more to serve older people in order to free their children from part of the responsibility of caring for their aging parents and to enable them to enter the labor market. The service was probably not meant to support senior citizens with extensive needs who lived by themselves without nearby relatives.

During the next decades both in-home assistance services and institutions for older people increased in number, as the country's growing industrialization with its demand on the labor force's geographical mobility made it increasingly difficult for extended families to exist.

The 1980's have been characterized by a willingness on the part of local governments to experiment with new types of in-home support services which would enable senior citizens to remain in the regular housing stock much longer than it has been possible up to now.

As this very rough outline of the history of Swedish in-home assistance programs shows, the services were intended primarily for older persons whose functional disabilities were not too extensive. Individuals of any age with more severe limitations could not exist outside of institutions without intensive family support. When in the 1950's and 1960's the concepts of normalization and integration began to win ground, the groups that were able to leave hospitals and other institutions (or avoid them) were primarily those individuals who could benefit from advances in medical rehabilitation to such a degree that they were not dependent on assistance in their daily life.

The reasons why Swedish home help schemes were not geared to support independent life styles of individuals with more extensive disabilities can be found in their organization which has not changed materially since the 1930's.

In an international perspective, there have been countries where persons with extensive disabilities had access to consumer-directed services earlier. It was in California, Denmark and England, for example, where ventilator dependent post-polio patients left the hospital wards first. There the first personal assistance schemes were designed specifically for the extensive needs of these former patients. This approach is in recognition of the fact that the more extensive one's need of assistance, the more important it is for the consumer to design his or her own system. In countries without such extensive and consumer-controlled personal assistance programs such as Sweden it took these groups much longer until they could leave hospital wards and nursing homes.

As an aside, the beginning of the Independent Living Movement in the United States can be traced back to 1959 and the introduction of the State In-Home Support Service in California. The service as well as the independent living skills that these ex-patients acquired by hiring, training, and firing their own personal assistants enabled many of them to become community organizers and disability rights advocates. This may be the reason why in the US many prominent disability leaders have been individuals with extensive disabilities. In Sweden, on the other hand, people with extensive disabilities have been in the minority in elected offices and staff positions in their own organizations. One explanation, then, why consumer control in

assistance services has hardly been an issue for Swedish disability advocates might have simply been that they did not need personal assistance themselves.

### **Description of community-based in-home support services: Administration**

In-home assistance programs are administered by the municipal social service office at the neighborhood level. By way of an example for the organization of the services, the City of Stockholm is divided into 18 social service districts. Each district serves 20 to 30 thousand inhabitants. Each district, in turn, consists of one to two dozen subdistricts. The various social services including home helper services are coordinated by social workers at the district office who dispatch assistants to consumers in their respective subdistricts. In this way social workers who also are supposed to make periodic home visits and assistants gain familiarity with their clientele.

In many local governments, services are provided during regular office hours and only in emergencies after hours or on weekends.

### **Needs assessment**

The need in terms of the number of hours of assistance is assessed by a social worker at the district office of the municipal Social Services Office. The office is also responsible for case finding. In addition, hospital staff and other public and private agencies that might have contact with persons in need of the service commonly refer their clients to the program.

Social workers who are responsible for assessing needs will point out that their directives are to take a person's whole life situation into account including such circumstances as family situation, housing arrangement, and life style. Apart from regional inequalities in the provision of these services, there are indications that even within a given municipality the number of hours granted varies among individuals with the same apparent needs.

According to the Swedish legislation in this area, local governments are the providers of home help services to those who need them in obtaining "a reasonable" quality of life. The interpretation of "reasonable" is the prerogative of the respective local government's social services office and can be appealed by the individual user in the administrative court system.

### **Assistants**

Between 80-90 per cent of the assistants are female, usually middle-aged housewives who choose working hours that suit their families. A minority works full-time despite the labor unions attempts to upgrade the professional standing of the workers. Most workers work regular part-time schedules or on an hourly basis as needed. About fourteen per cent of all home help assistants are relatives who are employed by the city to work for spouses, parents or children who have disabilities. Assistants are paid the lowest municipal wage, presently 75 SEK or 9 ECU an hour.

### **Costs**

The cost of the service to users varies widely among municipalities. In a few communities the service used to be free until recently. In others, fees are charged per hour with a maximum monthly amount. The ceiling is often means-tested and may go up to 3,000 SEK or 360 ECU a month in some cities. In other schemes all users pay the same flat fee regardless of the number of hours of service rendered. In line with the stagnating Swedish economy local government finances are strained with the result that consumers' fees are on the increase throughout the country. The legal limit a local government may charge the individual user is its own break-even cost which has been estimated by some local governments in excess of 230 SEK or 27 ECU per hour.

## **Escort service**

The escort is a municipal employee who is usually already working for the social service office as an attendant and who accompanies and assists the consumer while shopping or pursuing a leisure time activity outside the home. In Stockholm, for example, users of the regular home help service with more extensive functional disabilities are eligible and entitled to 15 hours of service per month for a maximum of three outings at five hours each. The escort service has to be applied for several working days in advance. While the service recognizes an important need, some users criticize the fact that they have no control over who will accompany them on an outing and that there is no room for spontaneous decisions. Some consumers refuse to utilize the program and prefer to make their own arrangements with people they know.

## **Evening and night patrols**

As already noted, in many communities municipal home help service is not available after office hours or on weekends. Thus persons in need of more extensive assistance who could not rely on relatives or could not afford to pay workers out of their own pocket had to move to an institution. During the last decade local governments have begun to remedy this situation by providing "evening patrols" or "night patrols". (The Swedish Independent Living Movement was quick to point out that these para-military terms very aptly describe the nature of the highly hierarchical and bureaucratized municipal services.) The service consists of teams of two municipal employees each who travel by car or taxi from one consumer to the next according to a pre-arranged schedule. The patrol assists with going to bed and preparing for the night.

The program has been criticized by younger consumers who claim that it is inflexible and unreliable, since a delay at one point in the schedule will affect all subsequent users. The common criticism, which applies to most Swedish assistance programs, is that consumers have no control over the staffing of this service and often will not know who will work for them on a given day. Also, instances have been documented in daily newspapers where older persons living by themselves but needing assistance have to go to bed at 5 p.m. every day of the year - even during summer when the sun is up until 10 p.m.

## **Fokus or Cluster Housing**

Cluster housing under the name of Fokus housing has been the most widely internationally known Swedish effort for keeping people with extensive need of personal assistance out of institutions. This solution has been in existence in Sweden since the late 1960's. The original 280 Fokus apartments were located in 12 Swedish cities. The common pattern consists of 10-15 special apartments dispersed throughout one large apartment complex of perhaps 50 or more units. In this sense the tenants with disabilities are geographically integrated. Fokus apartments are designed for the accessibility needs of wheelchair users. The units are connected via intercom to a staff on duty 24-hours a day. In the original concept the apartments were mainly intended as a half-way house solution. Individuals with extensive disabilities coming from parental homes or institutions could in these units acquire the skills necessary for a life in regular housing.

In 1973 Swedish local governments were charged with the legal responsibility of providing that type of housing and services. Up to 1985 an additional 720 apartments had been built throughout the country that differ somewhat from the original Fokus concept. Cluster housing is no longer referred to as Fokus but as "boendeservice" which might be translated as "housing with service".

In Stockholm boendeservice apartments are built and operated by municipally owned housing companies within the regular housing stock. The staff based in a large apartment within the apartment complex is under the direction of the home help service of the city's Social Service Office. The cost of the service to the consumer is means-tested. The tenants of the boendeservice units are selected by the city's Social Service Office which also owns the first

lease contract.

Among the shortcomings specific to the cluster housing solution, as cited by residents, is that services are based on the 'house arrest principle', i.e. they are not available outside the apartment, at work, about town or when travelling. Also, for tenants there is the permanent possibility that assistants can be summoned to work for another resident whose momentary needs are considered more pressing. The urgency of tenants' needs is assessed by the staff. Thus, during morning hours the staff can seldom stay during one tenant's entire routine without interruptions (especially, if some workers have called in sick and no substitutes have been found which happens quite often). Such interruptions can cause considerable delays and as a result, residents find it difficult to plan their day. Since staff members are often forced to set priorities in how to allocate their limited time among the residents' competing needs, tenants have developed individual coping strategies. With time many residents have learned to assess the probabilities of receiving assistance for various tasks at a given time of the day and week and to adjust their needs to the staff's schedule. Another response is to try to gain a competitive edge over fellow residents by developing a pleasing, non-offending attitude towards the staff.

The Swedish Independent Living Movement has been most critical of the boendeservice solution claiming that it is an institutional solution and as such represents a formidable obstacle to Independent Living by limiting tenants' choices, geographical and social mobility and their control over their own lives.

A summary critique of these traditional Swedish services would include the following shortcomings: Swedish local governments traditionally have had the monopoly 1) in assessing the needs and supervising the services, 2) in financing the services through local taxes with some revenue sharing from the state government, and 3) in providing the services in kind to the user. This triple monopoly, particularly the production monopoly, critically limits users' choices and creates unnecessary dependencies.

Disabled people as consumers of these public monopoly services have had very little control over which persons are to work for them, at what times and how the tasks are to be carried out. Due to the hierarchical structure and professional orientation of the staff the system cannot respond to the individual user's needs.

## **The history of STIL**

As a student in California in the 1960's and 1970's I had contact with the incipient Independent Living Movement. After moving to Sweden I was puzzled by the following apparent paradox there: On the one hand, persons with disabilities had a relatively high material standard of living. On the other hand, their status in society, opportunities for self-determination and resulting self-respect were low. This discrepancy was most evident among my friends who needed personal assistance but had to rely on either community-based home helpers (whom they referred to as their "home samaritans") or on boendeservice.

In 1984, after organizing the first Scandinavian conference on Independent Living, with Ed Roberts and Judy Heumann representing the American branch of the movement, I gathered a group of disabled persons who needed personal assistance services to found STIL, the Stockholm Cooperative for Independent Living in order to establish our very own services. The group was inspired by the principles of Independent Living: self-determination and "We are the experts!"

In 1987 we managed to overcome massive resistance from some political parties, the labor unions, traditional service providers and the established disability organizations and started operations of our cooperative, first as a pilot project, since 1989 on a permanent basis.

During the following years, as a result of our political and media work we managed to spread



our message across the country: "We know best what we need. Those of us who want should get the means to run their own services, with better quality at the same cost." Assistance users in other parts of the country got inspired and started similar cooperatives with training and sometimes loans from STIL.

## **The Personal Assistance Reform of 1994**

In 1994 STIL achieved a major political breakthrough when our solution became the model for a new legal reform. Since January 1994 persons who need more than 20 hours of assistance a week for such essential and basic everyday needs as bathing, dressing, eating or communicating and who are under 65 years are guaranteed the legal right to receive funds directly from the national social insurance.

When this new reform was introduced in Parliament, the Minister of Social Affairs in his speech gave the credit for the reform to STIL. In his words, the new reform follows the model presented by STIL and breathes the spirit of Independent Living. The new law is designed to open the door for self-determination, self-respect and dignity, for full participation and equality for persons with extensive disabilities.

Money received from the national insurance is not means-tested. The amount of the individual user's budget to be used for personal assistance is solely based on the number of hours needed and not on the income of the assistance user or the family. The funds enable users to hire their own personal assistants, join cooperatives or purchase services from the provider of their choice.

The number of eligible persons in 1996 is some 6,200 persons. (The total Swedish population is 8,5 million.) Total costs of the program have exceeded original forecasts by some 900 million SEK or 105 million ECU. Given the government's present austerity program cutbacks have been proposed. Because of the status of the Assistance Reform as a statutory right, budget cuts can only be realized with the consensus of Parliament.

## **The STIL model**

Each cooperative member has his or her personal assistance needs assessed by the local government or, since 1994, by the national social insurance. The need is expressed in number of hours of services a week. The cooperative charges a certain price per hour of services. The local government or the national social insurance pays each member a monthly amount that covers the cost of the numbers of hours that he or she needs. The funds are paid to the individual's subaccount in STIL. Thus, each member has a budget that he/she has to administer. The funds may be used for personal assistance only and have to be accounted for. The budget covers assistants' wages including compensation for unsocial hours, social insurance (no black or grey workers), STIL's administrative costs as well as the user's expenses for accompanying assistants.

STIL is the employer of the personal assistants who work for our members. Each member is the supervisor of his/her own personal assistants. We do not share assistants nor do we have a common assistant pool for emergency. Each member is responsible for recruiting, training, scheduling and supervising his or her own personal assistants. We do not live together in one house, in the same apartment building or even the same city. Each of us lives in his own apartment or house with or without family. We are spread out over the whole county and even other parts of the country and consider our individual housing situation as completely unrelated to our need of personal assistance. (See the reference to accessibility in the regular housing stock above.)

STIL is now an established cooperative company with an annual turnover of 90 million SEK or 10,5 million ECU. We have presently 160 members and are still growing. Each month we send out 700 pay checks to our assistants. In 1996 we will produce over 500,000 hours. This

expanding business is run by disabled people. Our director and over half of the office staff have disabilities. All Board members are personal assistance users.

## Participation and representation

STIL was founded by persons with extensive disabilities and need of personal assistance. Since the goal of the Independent Living movement is self-determination, STIL adopted by-laws and traditions which maximize the input of persons with disabilities, in particular, persons with extensive and often multiple disabilities. According to our bylaws no person without documented need of personal assistance in his or her daily life can become a member with voting rights. Also, the bylaws stipulate that only personal assistance users can serve on the Board. STIL takes pains in making sure that the organization is represented by persons with disabilities in public, in negotiations with politicians and other disability organizations. We also see to it that the majority of positions at the central office is taken by persons with disabilities, preferably personal assistance users. In advertising for new staff, disability is stipulated as a criteria of merit.

## STIL's peer training and support

STIL's aim is to empower members by providing the practical means for self-determination, independence and integrity in their daily lives. This includes providing role models, sharing experiences, insights and mutual support. We train members to become employers of their personal assistance in the following ways:

Before anyone can become a member of the cooperative he/she has to take a course in which experienced members teach newcomers the necessary skills a supervisor must have. Thus, we train our members so that they, in turn, can train their assistants. Our "boss course" consists of 10 evenings. Passing the course is a prerequisite for becoming a member in the cooperative and for employing one's own personal assistants. The course covers such topics as assessing one's needs, negotiating with government agencies for funds, advertising for assistants, interviewing job applicants, setting up a job contract as well as scheduling, training, supervising and - if necessary - firing assistants. Instructors are members of the cooperative who have long personal experience of employing assistants.

At periodic evening peer support sessions personal assistance users can meet and share information, advice, experiences and insights on topics related to employing personal assistants in one's home, at work and in one's free time. The facilitators are experienced personal assistance users themselves.

Peer support staff who work at the office can be consulted by personal assistance users on any issue that has to do with asserting one's needs in negotiations with government funding agencies, with recruiting and supervising assistants and conflicts that might arise. The peer support staff themselves are experienced personal assistance users.

STIL has contracted skilled and specialized legal experts who will represent individual members in legal disputes with government funding agencies. The member using this service pays a fee of 500 SEK or 60 ECU per case with no additional costs. The remaining costs of the scheme are borne by the cooperative.

Where members due to their multiple disabilities cannot supervise their assistants, STIL is trying to find a "deputy boss" who will support the member and together with him/her act as the assistants' supervisor.

[The video, "Mrs. Schledermann!", is available](#) (with English subtitles in both VHS PAL and VHS NTSC format) which illustrates the various aspects of peer support utilized by STIL.

## STIL's achievements

STIL members by organizing their own personal assistance services customized to their individual needs have improved their position within their own families and in their relationships with their spouses or parents. Instead of being a burden on their significant others, STIL members now have the practical means of not only taking care of themselves regarding their own personal needs. Today we are also able to contribute to the common household by taking over the share of the work which is customary in our culture, social class and age group.

A dozen of STIL's members have started partnerships and have children, an achievement which they often ascribe to the control over their lives that personal assistance allows them and to the role models, mutual advice and support of other personal assistance users whom they met through STIL.

STIL members by learning how to become good employers of their personal assistants gain valuable experience which they can draw upon in their own occupational careers. Also, STIL has been the source of training and jobs for persons with extensive disabilities. Many of these trainees and former employees have found jobs in other areas after they gained job experience and skills at STIL.

Over the years STIL has trained over 600 persons on how to manage the transition from being object of the local government's home help services to becoming good employers of their personal assistants and how to start up similar cooperatives. As a result there are dozens of cooperatives all over the country. Many of these cooperatives have received assistance from STIL in getting started in several ways such as loans, internships at STIL, training through courses and seminars, as well as STIL's training manual.

STIL has helped personal assistance users to start their own cooperatives, patterned after STIL's example, in Germany, Norway, Belgium and the Czech Republic. STIL representatives have been invited to lecture and do training of personal assistance users in several European countries including Germany, Norway, Finland, Belgium, Italy, Austria, the UK, Ireland, the Czech Republic and Hungary. According to STIL's experience in spreading its model the scheme is intuitive and easily grasped by persons with disabilities in other cultures.

Among the many advantages of our scheme are the changes that members are undergoing. There is a strong sense of pride and accomplishment. Instead of limiting ourselves to complaining about the poor quality of the public services, we demonstrated for ourselves and the general public that disabled people are capable of taking their affairs in their own hands. The demonstration of the viability of our vision and our capabilities has gained us respect among politicians and civil servants. We generate good will in the community and contribute to an improved image of disabled people.

Adolf Ratzka, STIL  
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For a more detailed albeit now somewhat outdated description and analysis of traditional Swedish community-based assistance services see Ratzka, Adolf Dieter. 1986. [Independent Living and Attendant Care in Sweden: A Consumer Perspective](#). New York: World Rehabilitation Fund Monograph No. 34. Also available in Japanese.